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Impact of seizure-related variables and psychopathology on health-related quality of life in pediatric epilepsy

Aja M. Meyer
University of South Florida

Impact of Seizure-Related Variables and Psychopathology on Health-Related Quality of Life in Pediatric Epilepsy

by

Aja M. Meyer

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Major Professor: Kathy L. Bradley-Klug, Ph.D.
Kathleen Armstrong, Ph.D.
Richard Marshall, Ph.D.
Anthony Onwuegbuzie, Ph.D.

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ABSTRACT

Psychopathology typically is a lasting condition that is persistent from childhood to adulthood. Therefore, it is imperative that children with health conditions and comorbid psychiatric disorders are treated for both conditions as they are likely to have a significant negative impact on children's overall health-related quality of life (HRQL). More specifically, it is important to identify the variables that affect HRQL in children with epilepsy. Research has shown that biomedical variables such as seizure severity and frequency have only moderate relationships with HRQL; therefore, additional factors, such as depression and anxiety, must be identified so that they also may be a focus of treatment.

The purpose of this study was to ascertain the relationship among seizure-related variables, health-related quality of life, and psychopathology (i.e., anxiety and depression) in children with epilepsy (n = 51). The seizure-related variables examined in this study include type of seizure, seizure frequency, and seizure treatment with anti-epileptic drugs (AEDs). Canonical correlation analyses indicated that self-report and parent report of anxiety and depression were most strongly correlated with HRQL. Additionally, seizure frequency and number of anti-epileptic drugs also were correlated with HRQL. It is hoped that results from this study will inform both the medical and

psychosocial treatment children with epilepsy receive. This comprehensive care needs to go beyond simply attempting to control seizures with minimal adverse drug reactions. Results from this study will contribute to the literature underscoring the importance of identifying, diagnosing, and treating children with epilepsy who have comorbid psychopathology so that they have the best possible psychosocial outcomes.

Chapter 1

Introduction

Statement of the Problem

A thorough review of the literature reveals that approximately 10% to 15% of school-aged children in the United States are inflicted with a chronic medical condition (Bethell et al., 2002; Davidoff, 2004; Van Dyck et al., 2002). Of these conditions, epilepsy is one of the most physically and psychosocially debilitating chronic illnesses in children (Devinsky, 2003). Epilepsy is a neurological condition that affects the central nervous system and has various origins, symptoms, courses, and prognoses (Shafer, 2002). Pediatric epilepsy is one of the most common neurological conditions, with a prevalence rate of 3.6 to 5.0 per 1,000 for children, birth to adolescence, in developed countries (Hiemenz, Hynd, & Jimenez, 1999; Ronen, Streiner, & Rosenbaum, 2003). According to the United States Census Bureau, there were 58 million students, kindergarten through 12th grade, enrolled in public schools in 2003. Thus, the above-cited pediatric epilepsy prevalence rates indicate that approximately 290,000 school-aged children in the United States have epilepsy. However, according to Sachs and Barrett (1995), as many as 500,000 children and adolescents in the United States may experience recurrent seizures.

Physical health and mental health are intertwined (Huberty, Austin, & Huster, 2000); therefore, it is important to assess the mental health of individuals who have chronic medical conditions such as epilepsy. Given that depression and anxiety have been

found to be the most prevalent co-morbid psychiatric disorders in adults with epilepsy (Caplan, Siddarth, & Gurbani, 2005), it is crucial for practitioners to ascertain how depression and anxiety manifest in children with epilepsy. This is especially important given recent research findings with adults that indicate depression, through the mechanism of sleep deprivation, can have a direct impact on seizure frequency, increasing the rate of seizures and negatively impacting health-related quality of life (HRQL) (Jackson & Turkington, 2005).

Empirical studies demonstrate a relationship between psychopathology and poor quality of life in children (Bastiaansen, Koot, & Ferdinand, 2005). Furthermore, research has found that children with physical illness have a poorer HRQL (Baker, Spector, McGrath, & Soteriou, 2005). Therefore, the risk for compromised quality of life is confounded in children with physical/medical conditions (e.g., epilepsy) and comorbid psychopathology (Wagner & Smith, 2006). In light of these research findings, there is a need to explore the impact of psychopathology (especially depression and anxiety) on the HRQL of children with epilepsy so that appropriate treatment may be provided early for optimal health outcomes.

Pediatric Epilepsy

Pediatric epilepsy is a neurological condition wherein abrupt changes in how cells in the brain send electrical signals cause seizures in children. Epilepsy is a condition of chronic, recurring seizures. A seizure occurs when there is a sudden discharge or disturbance of the electrochemical firing of neurons in the brain that may cause a change in an individual's sensation, awareness, and/or behavior (DuLac,

MacDonald, & Kelly, 1995). Pediatric epilepsy is a condition that has various origins, symptoms, courses, and prognoses for children (Shafer, 2002).

Numerous factors contribute to the medical and psychosocial difficulties faced by children with epilepsy. For example, the type and frequency of the seizures may be correlated with increased difficulties both medically and psychosocially. Frequency of seizures has been found to be correlated with behavioral problems in children with epilepsy (Austin, Risinger, & Beckett, 1992; Lambert & Robertson, 1999). Furthermore, there are some data to support a relationship between seizure frequency and anxiety, whereby increased levels of stress and anxiety appear to escalate the frequency of seizures (Vazquez & Devinsky, 2003). Finally, the use of antiepileptic drugs (AEDs) may produce negative side effects in children with epilepsy. Mendez, Doss, Taylor, and Salguero (1993) found that the use of multiple AEDs was associated with depression in children with epilepsy. Presently, there is a dearth of research examining the relationship between various seizure-related variables and psychopathology, and the data that have been collected are inconclusive. Therefore, it is imperative that researchers determine the impact of seizure-related variables on psychopathology in children with epilepsy.

Pediatric Epilepsy and Psychopathology

Along with the goal of reducing or eliminating seizures, practitioners also must focus on the individual's psychosocial adjustment to promote the most optimal outcomes for children with epilepsy. Therefore, it is problematic that treatment of pediatric epilepsy has focused primarily on seizure control and treatment adherence while overlooking learning and behavior problems as well as comorbid psychopathology. Because recognition of the relationship between pediatric epilepsy and comorbid psychopathology

is newly emerging in the literature, a comprehensive approach to assessing and treating these children has not yet been established (Caplan et al., 2005). Broadband assessment instruments provide information on an individual's functioning in multiple domains; a number of empirically-based broadband measures of emotional and behavioral symptoms in children may be utilized to assess the presence of psychopathology (e.g., Child Behavior Checklist; Achenbach, 2000; Behavior Assessment System for Children; Reynolds & Kamphaus, 2004).

Pediatric Epilepsy and Health-Related Quality of Life

Quality of life refers to an individual's ability to engage in and enjoy normal life activities (Bastiaansen et al., 2005). More specifically, health-related quality of life (HRQL) represents the functional effects of an illness and its subsequent treatment on a patient, as perceived by the individual (Baker, 2001). Several groups of researchers (Bastiaansen, Koot, Ferdinand, & Verhulst, 2004; Sawyer, Whaites, & Rey, 2002) have conducted studies examining quality of life (QoL) in children with psychiatric disorders. Their findings revealed that children with psychiatric disorders had poor QoL. Moreover, not only were these children's QoL considerably lower than children from the population at large, but their QoL also was poorer than the QoL of physically ill children.

These results suggest that there is a relationship between poor QoL and psychopathology in children (Bastiaansen et al., 2005). In addition, these findings have revealed that not only do children with physical illness have a poorer QoL (as compared with healthy children), but children with psychiatric disorders also have lowered QoL. In light of these findings, it is reasonable to hypothesize that children with a physical illness

such as epilepsy as well as a psychiatric disorder (e.g., anxiety and depression) are at a substantially greater risk for a poor QoL.

Implications for School Psychology

Children with chronic health conditions have increased risk factors for poor academic and psychosocial functioning compared with their healthy peers (Thompson & Gustafson, 1996). A number of researchers (e.g., Aldenkamp, Overweg-Plandsoen, & Arends, 1999; Besag, 1995; Lhatoo & Sander, 2001) have found that children with epilepsy display significant difficulties in learning and behavior compared to healthy children. Furthermore, research has shown that children with chronic neurological conditions such as epilepsy are more likely to experience academic difficulties compared to those whose illness does not have a neurological basis (Howe, Feinstein, & Reiss, 1993). Although it has been hypothesized that academic difficulties may be due to limited intellectual ability, researchers have found that these differences in academic achievement in children with epilepsy are not attributed to limited cognitive functioning (Seidenberg & Berent, 1992; Sturniolo & Galletti, 1994). Unfortunately, the origin of these difficulties still has not been ascertained. It is hypothesized that learning and behavior problems may be due to factors such as seizure-related variables, pharmacological treatment (e.g., AEDs), or environmental factors (e.g., social interactions) that impact children with epilepsy (Bourgeois, 1998).

When children experience learning and behavior problems, it is likely that there will be a direct impact on their academic and behavioral performance at school. Because chronic health conditions such as epilepsy impact a multitude of domains, educational laws have been created to ensure appropriate support for individuals with chronic

conditions in the educational system. One such law that pertains to the education of children and adolescents with disabilities is the Reauthorization of Individuals with Disabilities Education Act (IDEA; United States Department of Education, 2004). Other Health Impaired is a category under IDEA that provides services to students with health conditions such as epilepsy. The reauthorization of IDEA stipulates that educators, including school psychologists, are obligated to provide supports and services to students whose chronic health condition negatively impacts their academic and behavioral functioning. Furthermore, the Rehabilitation Act of 1973 states that children with physical or mental impairments` are eligible to receive reasonable accommodations in school settings under the Section 504 Accommodation Plan. School psychologists could play a role in the development and implementation of these accommodation plans to support the unique needs of students with chronic conditions. An important difference between the IDEA statute and the Section 504 statute is the manner in which disabilities are defined, with Section 504 having a much broader definition and encompassing a greater number of students with disabilities.

Bannon and Ross (1998) found that educators typically have an inadequate understanding of chronic childhood illnesses such as epilepsy. This is problematic given that the initial identification of seizure-related symptoms, such as unusual staring, blinking, and head drops, is commonly made in the school setting (Sachs & Barrett, 1995). Therefore, it is imperative that educators are knowledgeable about the symptoms and the treatment of epilepsy, as well as the impact of the condition on a child's academic, behavioral, and psychosocial functioning. Educators should be aware of

students' specific condition, including their pharmacological and psychological treatment, and potential positive and negative effects of the treatment.

Furthermore, school psychologists, especially those with expertise in pediatric health issues, are in a unique position to act as a liaison among families, educators, and medical staff. As such, school psychologists are able to advocate for students with chronic health conditions to help alleviate psychosocial problems, as well as to improve their medical compliance and enhance their integration into the school setting (Sachs & Barrett, 1995). This can be accomplished by the school psychologist providing psychoeducation about epilepsy to the individual student, classmates and peers, and the entire school staff. Additionally, school psychologists can conduct individual or group therapy sessions to address a variety of difficulties the student with epilepsy may be experiencing. These difficulties may include problem solving deficits, coping deficits, social skills deficits, and/or internalizing (e.g., anxiety and depression) and externalizing (e.g., aggression, rule breaking) behaviors.

Summary

Psychopathology typically is a condition that persists from childhood to adulthood (Hofstra, Van der Ende, & Verhulst, 2000). Therefore, it is imperative that children with health conditions and comorbid psychiatric disorders are treated for both conditions as they are likely to have a significant negative impact on children's overall HRQL. More specifically, it is important to identify the variables that mediate HRQL in children with epilepsy given that researchers have found that the presence of psychopathology also negatively impacts children's HRQL (Bastiaansen et al., 2004; Sawyer et al., 2002). Research has shown that biomedical variables such as seizure severity and frequency

have only moderate relationships with HRQL; therefore, additional factors, such as depression and anxiety, must be identified so that they also may be a focus of treatment (Wagner & Smith, 2006). The awareness of possible mediating factors, such as seizure-related variables and psychopathology, may aid practitioners in the early identification of children with epilepsy who are at-risk for poor HRQL.

Purpose of the Study

The purpose of this study was to ascertain the relationship among seizure-related variables, health-related quality of life, and psychopathology (i.e., anxiety and depression) in children with epilepsy. The seizure-related variables that were examined in this study include type of seizure, seizure frequency, and seizure treatment with anti-epileptic drugs (AEDs). Specifically, type of seizure was classified as either generalized or partial. Seizure frequency was classified into two groups: 0-5 seizures per year or 6-12 seizures per year. Treatment with AEDs was classified as either monotherapy (i.e., treatment with one AED) or polytherapy (i.e., treatment with more than one AED). It was hoped that results from this study would inform both the medical and psychosocial treatment children with epilepsy receive. This comprehensive care needs to go beyond simply trying to control seizures with minimal adverse drug reactions. Seizure frequency and severity is only one important outcome variable. Other factors, such as psychological disorders, also affect children with epilepsy along with their families and close social networks. This study further contributes to the literature underscoring the importance of identifying, diagnosing, and treating children with epilepsy who have comorbid psychopathology so that they have the best possible psychosocial outcomes.

Research Questions

The following research questions were addressed in this study:

Research Question 1. What seizure-related variables (i.e., type of seizure, seizure frequency, and treatment with AEDs) and psychopathology ("at-risk" or "clinically significant" range for anxiety and/or depression) best predict health-related quality of life as reported by children 8 to 11 years of age diagnosed with epilepsy?

Research Question 2. What seizure-related variables (i.e., type of seizure, seizure frequency, and treatment with AEDs) and psychopathology ("at-risk" or "clinically significant" range for anxiety and/or depression) best predict health-related quality of life as reported by parents of children 8 to 11 years of age diagnosed with epilepsy?

Hypotheses

Two research hypotheses were tested in the current study. First, it was hypothesized that children with generalized seizures (as compared with partial seizures), frequent seizures (i.e., 6-12 per year compared with 0-5 per year), who receive polytherapy (i.e., more than one AED compared with monotherapy) and obtain *T* scores of 60 and higher on the depression scale and/or anxiety scale of the BASC (*T* scores of 60 to 69 are in the "at-risk" range and *T* scores above 69 fall in the "clinically significant" range) would obtain a HRQL score in the "highly compromised" (i.e., 5-10) range as reported via parent report. Second, it was hypothesized that children with generalized seizures (as compared with partial seizures), frequent seizures (i.e., 6-12 per year compared with 0-5 per year), who receive polytherapy (i.e., more than one AED compared with monotherapy) and obtain *T* scores of 60 and higher on the depression scale and/or anxiety scale of the BASC (*T* scores of 60 to 69 are in the "at-risk" range and

T scores above 69 fall in the "clinically significant" range) would obtain a HRQL score in the "highly compromised" range (i.e., 5-10) as reported via self-report.

Significance of the Study

This study provides valuable information about the relationship among seizure-related variables, psychopathology, and health-related quality of life in children with epilepsy. These data will allow practitioners, both psychologists and physicians, to assess and treat children with epilepsy by addressing the factors that are correlated with poor health-related quality of life. In addition, this study sheds light on the relationship between health-related quality of life and psychopathology (i.e., depression and anxiety) in children with epilepsy. Because the research clearly supports the importance of addressing comorbid psychopathology in children with epilepsy, it is critical that these children are identified, diagnosed, and treated to enhance their overall development.

Definition of Terms

Antiepileptic Drugs (AEDs). AEDs are a category of drugs that can help control the frequency and severity of seizures; they also are known as anticonvulsants (Kaiser, 2002).

"At-risk" range for anxiety. For the purposes of this manuscript, this phrase refers to children with epilepsy who fall into the "at-risk" range (T-score between 60-69) for anxiety per scores obtained on the child and/or parent version of the Behavioral Assessment Scale for Children, Second Edition (BASC-2, Reynolds & Kamphaus, 2004). *Please note:* Scaled scores in the at-risk range on the BASC-2 are between one and two standard deviations from the mean and may signify developing problems that should be monitored.

"*At-risk" range for depression.* For the purposes of this manuscript, this phrase refers to children with epilepsy who fall into the "at-risk" range (*T* score between 60-69) for depression per scores obtained on the child and/or parent version of the BASC-2 (Reynolds & Kamphaus, 2004).

"*Clinically significant" range for anxiety.* This phrase refers to children with epilepsy who fall into the "clinically significant" range (*T* score between 70-100) for anxiety per scores obtained on the child and/or parent version of the BASC-2 (Reynolds & Kamphaus, 2004). *Please note:* Scaled scores in the clinically significant range on the BASC-2 are two standard deviations or more from the mean and indicate a high level of maladaptive behavior.

"Clinically significant" range for depression. This phrase refers to children with epilepsy who fall into the "clinically significant" range (*T* score between 70-100) for depression per scores obtained on the child and/or parent version of the BASC-2 (Reynolds & Kamphaus, 2004).

Epilepsy. Epilepsy is a chronic neurological condition with abrupt disturbances in the electrochemical firing of neurons in the brain cause seizures. This condition of unprovoked, recurring seizures affects the central nervous system causing change in an individual's sensation, awareness, and/or behavior and has various origins, symptoms, courses, and prognoses (DuLac et al., 1995; Shafer, 2002).

Monotherapy. The term monotherapy refers to the use of one antiepileptic drug (Labiner & Ahern, 2002).

Polytherapy. The term polytherapy refers to the use of more than one type of antiepileptic drug (Labiner & Ahern, 2002).

Psychopathology. Psychopathology refers to the study of the manifestation of behaviors and experiences that may be indicative of mental illness or psychological impairment (Caplan et al., 2005).

Seizure. A seizure is an individual episode in which an abrupt discharge of electrical activity in the brain may cause changes in sensation, behavior, and/or consciousness (DuLac et al., 1995; Ho-Turner & Bennett, 1999).

Health-Related Quality of Life (HRQL). Health-related quality of life represents the functional effects of an illness and its resulting therapy on a patient, as perceived by the individual patient (Baker, 2001).

Chapter 2

Review of the Related Literature

Overview

This chapter provides a review of the literature relevant to this study. Pediatric epilepsy is discussed, including its relevance to school psychology, and the importance of working within an interdisciplinary framework so that the "whole child" is treated and the medical, educational, and psychosocial impact of the disease are addressed. Furthermore, prevalence rates, classification, types of seizures, diagnosis, and potential causes of epilepsy in children are presented. Pharmacological treatment of pediatric epilepsy also is covered, including use of antiepileptic drugs. Next, seizure-related variables that may negatively impact children with epilepsy are discussed. The relationship between pediatric epilepsy and psychopathology (specifically depression and anxiety) and the importance of assessing and treating psychopathology in conjunction with medical/seizure treatment also is delineated. Health-related quality of life (HRQL) is reviewed, including various epilepsy-specific HRQL measures. The chapter ends with a discussion of the importance of assessing both the presence of psychopathology and HRQL when developing and implementing treatment plans for children with epilepsy.

Defining Epilepsy

Epilepsy is a neurological condition that affects the nervous system; it is a condition of recurrent seizures. It is important to differentiate "seizures" from "epilepsy" from the onset of this review. In contrast to epilepsy, a seizure is an individual episode in

which an abrupt discharge of electrical activity in the brain may cause changes in sensation, behavior, and/or consciousness (DuLac et al., 1995; Ho-Turner & Bennett, 1999). Seizure disorders (i.e., epilepsy) are chronic, recurring disturbances in the electrochemical firing of the neurons in the brain (Ho-Turner & Bennett, 1999). Epilepsy is a cluster of disorders that have various origins, symptoms, courses, and prognoses (Shafer, 2002). Seizure disorder and epilepsy are synonymous terms that may be used interchangeably in this document.

Prevalence of Epilepsy in Children

Epilepsy occurs in approximately 5 out of 1,000 children and is considered to be the most prevalent neurological disorder of childhood (Black & Hynd, 1995; Hiemenz et al., 1999; Ronen et al., 2003). Although some seizure disorders self-limit as children mature, it is reported that more than 80% of adults with epilepsy had their first seizure during childhood (Ho-Turner & Bennett, 1999). Incidence and prevalence data are useful in developing hypotheses about the cause of an illness. Furthermore, this information aids in assessing the health care requirements in a population and in determining diagnostic probabilities (Cowan, 2002). When studying epilepsy, however, it is difficult to compare incidence and prevalence rates among various populations because of the lack of homogeneous methods for defining epilepsy (Ho-Turner & Bennett, 1999).

The incidence of epilepsy in children has been estimated from diverse populations using different methods of case definition. For example, when examining recurrent, unprovoked seizures, the annual incidence rates per 100,000 children ranged from a low of 41.0 in Nova Scotia (Camfield, C., Camfield, P., Gordon, Wirrell, & Dooley, 1996) to 82.3 in Northern Sweden (Blom, Heijbel, & Bergfors, 1978). Cowan (2002) reported that

the annual incidence rates across populations are quite similar (i.e., approximately 50-72 per 100,000), particularly when considering the vast differences in methods of obtaining case studies.

Despite the vast differences in both methodology and populations used in determining prevalence rates of childhood epilepsy, the majority of estimates are approximately 4 to 5 per 1,000 children (Eriksson & Koivikko, 1997; Kurtz & Tookey, 1998). Kurtz et al. (1998) found that prevalence rates ranged from 2 to 3 per 1,000 in children up to 7 years of age. However, these researchers found that prevalence rates tend to increase with age, with a rate of approximately 4 to 6 per 1,000 in children 11 to 15 years of age (Kurtz & Tookey, 1998). Furthermore, rates appear to be somewhat higher in males than in females (Eriksson & Koivikko, 1997). Differences in rates related to ethnicity also have been reported in the literature. Murphy, Yeargin-Allsopp, and Decoufle (1995) found slightly higher prevalence rates among African-American children compared to Caucasian children. Furthermore, differences in prevalence rates have been found in developed versus developing countries. For example, Latin America and Africa have been found to have significantly higher prevalence rates (e.g., 10 to 15 per 1,000) compared to developed countries. The higher rate in developing countries may be due to parasitic infections that are common in these countries (Cowan, 2002).

Classification of Seizures

It is difficult to define seizures clinically because there is an infinite variety in the clinical manifestations of seizures. However, the international classification scheme is the most widely accepted and utilized format for clinical classification of epileptic seizure

disorders (Chadwick, 1994). This classification has two major divisions: (a) partial seizures, and (b) generalized seizures.

Partial seizures occur in one or more restricted regions of the brain. These seizures are a secondary effect of a localized physiologic or structural abnormality in the brain such as a tumor, dysplasia, or trauma (Prego-Lopez & Devinsky, 2002). Partial seizures originate locally in the cortex and are typically preceded by an aura (e.g., visual, auditory, or olfactory hallucinations) that reflects the function of the area of the cortex where the seizure takes place. These seizures also may be associated with post-ictal focal disturbances. Furthermore, partial seizures may spread to become generalized with a secondary tonic-clonic seizure (Chadwick, 1994). Partial seizures are further classified as either simple, complex, or secondarily generalized. Simple partial seizures alter behavior but do not impair consciousness, whereas complex partial seizures alter consciousness by impairing awareness, responsiveness, and memory (Prego-Lopez & Devinsky, 2002). Secondarily generalized seizures begin as partial seizures (occurring in one area of the brain) and then quickly spread throughout both hemispheres, becoming generalized seizures.

In contrast to partial seizures, generalized seizures occur bilaterally (i.e., in both hemispheres of the brain) with consciousness lost suddenly; therefore, the patient does not experience an aura (Chadwick, 1994). These seizures are subcategorized into several main types, including generalized tonic clonic, myoclonic, absence, and atonic seizures. These major types of generalized seizures will be defined briefly.

Types of Seizures

Generalized tonic-clonic seizures. These seizures also are called Grand Mal seizures. These are the most common type of generalized seizure that typically begin with a stiffening of the limbs (i.e., tonic phase) followed by a jerking of the limbs and/or face (i.e., clonic phase). Breathing may decrease or stop completely during the tonic phase, but typically returns (although sometimes irregular) during the clonic phase. The presentation of these seizures varies. For example, some individuals may experience only the clonic or only the tonic phase. Furthermore, some may experience a tonic-clonic-tonic seizure pattern (Ho-Turner & Bennett, 1999).

Myoclonic seizures. These seizures present with rapid, brief contractions of muscles that typically occur on both sides of the body; however, they may involve only one limb. Most of the epileptic syndromes that include myoclonic seizures usually begin in childhood. These seizures occur in a variety of epilepsy syndromes that have different characteristics such as juvenile myoclonic epilepsy, Lennox-Gastaut syndrome, and progressive myoclonic epilepsy. Juvenile myoclonic epilepsy and Lennox-Gastaut syndrome will be presented in more detail later in this chapter.

Absence seizures. These seizures also are called petit mal seizures. Individuals who experience absence seizures may experience lapses of awareness that sometimes involve staring episodes that last only a few seconds. Absence seizures are characterized by a brief impairment of consciousness, which usually lasts no more than a few seconds. The individual simply stares vacantly; neither speaking nor appearing to hear what is said. Then, as abruptly as it began, the impairment lifts and the child continues with his or her previous activity. Absence seizures are more common in children than in adults;

however, they are frequently so short-lived that they avoid detection, even when the child is experiencing numerous attacks on a daily basis. Because of the briefness of the episodes, it is all too common for children to experience these seizures for several months or even years before they are diagnosed (Williams et al., 2002). These seizures most frequently develop between 4 and 12 years of age, and very rarely begin after 20 years of age.

Atonic seizures. These seizures also may be referred to as drop attacks, astatic or akinetic seizures. They produce an abrupt loss of muscle tone, which may include the head dropping, a loss of posture, or a sudden collapse. Because they occur abruptly, individuals who experience atonic seizures typically fall with force. Because this type of seizure may result in significant injury to the head and face, protective headgear is sometimes used by both children and adults. Unfortunately, these seizures tend to be resistant to drug therapy.

Electroencephalographic (EEG) results may be used to help differentiate partial and generalized seizures. In patients with partial seizures, inter-ictal (i.e., post seizure) EEG findings typically show localized spikes, and occasionally associated focal slow waves. However, in patients with primarily generalized seizures, EEG findings reveal synchronous, high amplitude, generalized spike-wave discharge (Chadwick, 1994).

Other Classifications of Seizure

Classification by cause of seizure. Causes of epileptic seizures are generally categorized as either genetic, idiopathic (unknown), or cryptogenic (poorly defined). The cause of idiopathic seizures is completely unknown with no evidence of an underlying abnormality. An individual with epilepsy is biologically typical, with the

exception of the occurrence of seizures. Idiopathic seizures are believed to be inherited and are defined by age-related onsets. The cause of cryptogenic seizures is undetermined; however, the cause appears to be related to another neurological or cognitive condition (Ho-Turner & Bennett, 1999). In addition, seizures may be either developmental or acquired, as is the case with symptomatic seizures. Symptomatic seizures also are called reactive or provoked seizures--when in response to an irritation (e.g., fever or trauma to the brain). They have a known cause that may originate from such ailments as trauma, developmental aberrations, metabolic imbalances, or fever (Ho-Turner & Bennett, 1999). Therefore, the cause of this type of seizure may be either developmental or acquired. The various potential causes of epileptic syndromes will be detailed further in a later section of this chapter.

Common Types of Seizures in Children

There are several different types of generalized and partial seizures that are common in childhood. Each of these will be reviewed briefly in this section. The prevalence rates and common symptoms of the various types of seizures will be presented.

Neonatal seizures. Neonatal seizures occur from birth up to approximately one month of age. The occurrence of these seizures is higher in infants with a familial history of epilepsy. Of the infants who experience benign neonatal seizures that are inherited, approximately 14% will develop another childhood epilepsy syndrome (Ho-Turner & Bennett, 1999). However, the majority of infants experience a spontaneous resolution of seizures after two months (Ho-Turner & Bennett, 1999).

Febrile seizures. Febrile seizures are nonepileptic; however, in some cases epilepsy may develop. These seizures occur in approximately 4% of children between 6 months and 5 years of age. These are the most common type of seizures in infancy and are caused by high fever (typically over 102.2 degrees Fahrenheit) (Duchowny & Harvey, 1996). One-half of febrile seizures occur between 12 and 24 months of age, with a peak in occurrence between 18 and 24 months of age. The most important predictor of recurrence of these seizures is age at occurrence of first seizure (Duchowny, 1993). An infant who experiences the first febrile seizure at less than one year of age has approximately a 50% chance of recurrence, with the risk of recurrence decreasing as the child matures (Hulihan, 1997).

Epilepsy has been reported to develop in approximately 1% to 10% of children who have a history of febrile seizures (Duchowny, 1993). Epilepsy is most likely to develop in children who have experienced complex febrile seizures. Duchowny (1993) reported that epilepsy develops in 6% of children with two or more features of complex febrile seizures; however, only 0.9% of children with none of these features develop epilepsy.

Childhood absence epilepsy. This syndrome most often develops between 4 and 8 years of age. Children with this type of epilepsy are typically neurologically normal, and therefore, they are less likely to experience generalized tonic-clonic seizures compared to those who experience other types of absence-seizure disorders (Duchowny, 1993). Currently, there is no consensus regarding the prognosis for individuals with childhood absence epilepsy. However, it is promising that these seizures generally respond favorably to anticonvulsant medications in approximately 80% to 95% of children.

Furthermore, childhood absence seizures typically abate by mid-adolescence (Duchowny, 1993). It is still unclear whether this type of seizure has a genetic component; however, there typically is a family history of seizures in patients who experience childhood absence epilepsy (Duchowny, 1993).

Juvenile myoclonic epilepsy. This type of epilepsy is characterized by brief, rapid jerks of the shoulders and arms. Many patients also have generalized tonic-clonic seizures, and many also suffer absence seizures. Age at onset is typically between 10 and 17 years. Myoclonic seizures may be precipitated by sleep deprivation or alcohol use.

Benign rolandic epilepsy (benign childhood epilepsy with centrotemporal spikes). This type of epilepsy is characterized by focal seizures with sensorimotor symptoms most commonly affecting the face and oropharynx, although at times with secondary generalization to a tonic-clonic seizure. Being the most common epilepsy of childhood, it occurs in children who are otherwise neurologically normal. Seizures may be predominantly or exclusively nocturnal. The characteristic EEG pattern of this disorder can assist in diagnosis in a child who presents with a focal seizure. The same EEG pattern has been found in many first-degree relatives of patients with this disorder, indicating a strong hereditary component (Zupanc, 1996). Virtually all cases of benign rolandic epilepsy remit by mid-adolescence.

Benign occipital epilepsy. Also known as epilepsy with occipital paroxysms, this is a less common type of idiopathic focal epilepsy. These seizures originate in the occipital lobe of the brain and have the potential to generalize to a tonic-clonic seizure. Because approximately 47% of children have a family history of seizure, it is believed that there is a genetic component for these seizures (Duchowny, 1993).

Infantile spasms. Infantile spasm (IS) is a type of seizure observed in an epilepsy syndrome of infancy and early childhood also known as West Syndrome. This syndrome is typically detected early in life (i.e., between 3-6 months of age). Infants with IS commonly present with a sudden bending forward and stiffening of the body, arms, and legs. The spasms tend to occur soon after waking and each spasm typically lasts for 1 to 5 seconds. These spasms occur in clusters, and range from 2 to as many as 100 spasms at a time. Infantile spasms usually remit by 5 years of age, but these spasms are frequently replaced with other types of seizure. Along with the infantile spasms, individuals with West Syndrome also experience hypsarrhythmia (chaotic brain wave patterns) and mental retardation. A close relationship has been detected between IS and Lennox-Gastaut Syndrome, which is an epileptic disorder of later childhood.

Lennox-Gastaut syndrome. This syndrome is a severe condition characterized by mental retardation, multiple seizure types that respond poorly to medication, and often a characteristic EEG pattern with slow spike-and-wave discharges. Many patients are treated with three or more drugs in combination, which may result in medication toxicity. The simplification of anticonvulsant regimens, with reduction in the number of drugs used and the discontinuation of barbiturates, may reduce frequency of seizures and ameliorate behavioral disturbances.

Potential Causes of Childhood Epilepsy

Cowan (2002) reported that approximately 55% to 75% of all epilepsy cases are of unknown cause (i.e., idiopathic), with only 25% to 45% being attributed to specific risk factors. There are a number of factors that appear to contribute to seizure threshold (an individual's propensity to experience a seizure) in childhood epilepsy. Ho-Turner and

Bennett (1999) identified three main factors that affect seizure occurrence: (a) genetic predisposition, (b) seizure threshold, and (c) environmental stressors.

It has long been established that certain types of childhood epilepsy have a genetic or hereditary component (Ho-Turner & Bennett, 1999). A family history of epilepsy appears to increase the risk of developing epilepsy by two to three times (Hauser, Annegers, & Rocca, 1996). The reason is unclear, but the risk of developing epilepsy is greater in the children of mothers with a history of epilepsy than in children of fathers with epilepsy (Annegers et al.). More evidence for a genetic link to the development of epilepsy was found in a study conducted by Kjeldsen, Kyvik, Christensen, & Friis, (2001). The researchers studied 11,900 pairs of Danish twins to ascertain the genetic and environmental factors to the etiology of epilepsy. A concordance rate of .37 for monozygotic twins and .08 for dizygotic twins was found for epilepsy. In summary, the researchers' analyses of the data suggested that approximately 70% to 88% of the proclivity for developing epilepsy may be explained by genetic factors (Cowan, 2002).

Age alone has a significant influence on an individual's susceptibility to developing epilepsy. Newborns typically have a high cortical threshold; therefore, production of a seizure response is quite difficult (Ho-Turner & Bennett, 1999). However, as children mature (e.g., around 2 years of age), they develop a greater susceptibility to certain types of seizures. Therefore, the majority of childhood epilepsy syndromes are first observed around this chronological age. Seizure threshold continues to increase proportionally throughout childhood and adolescence until adult levels are reached (Ho-Turner & Bennett, 1999). Because an infant's brain is continually

developing through adulthood, to understand childhood epilepsy it is important to study the developing brain at various stages. Moreover, there are different implications and manifestations of epilepsy depending on the stage of cortical development (i.e., the age of the child), as well as differences in prognosis and treatment (Ho-Turner & Bennett, 1999).

Environmental stressors that may trigger a seizure episode include such factors as high fever, extreme fatigue or excitement, and metabolism rates (Ho-Turner & Bennett, 1999). Furthermore, metabolic disorders, hypoxia (i.e., insufficient blood oxygen), infectious diseases, and high fevers have been known to produce reactive seizures. Additionally, chemical imbalances, drug or poison ingestion, congenital abnormalities (e.g., aneurysms), or traumatic brain injuries may lead to seizure (Cowan, 2002; DuLac et al., 1995; Heller, Alberto, & Forney, 1996). Overall, in children who survive central nervous system infections, the risk of experiencing subsequent unprovoked seizures is increased substantially (approximately three-fold). Approximately 50% of childhood epilepsy cases go into remission and do not require long-term treatment, whereas around 25% are intractable and have a less predictable outcome (DuLac et al., 1995).

Diagnosis of Epilepsy in Children

Because of the variety of factors involved, it can be difficult to obtain an accurate diagnosis of epilepsy. The child's medical history must be obtained to help determine the cause of the episode. For example, a history of meningitis, encephalitis, head trauma, cancer, or cerebrovascular disease could indicate the origin of the seizure. A review of the child's medications also should be completed because some medications are commonly implicated in seizure. For instance, some antipsychotic drugs (especially

clozapine and phenothiazines), radiocontrast dyes, alkylating agents, and ß-lactam antibiotics are commonly implicated (Prego-Lopez & Devinsky, 2002). Furthermore, general anesthetics, tricyclic antidepressants, newer antidepressants (e.g., selective serotonin reuptake inhibitors [SSRIs], bupropion hydrochloride [Wellbutrin]), ß-blockers, and decongestants also can cause seizure. Conversely, a child's medical history may indicate a condition other than seizure. A history of other neurological disorders in the child or child's family members may aid in differential diagnosis (Prego-Lopez & Devinsky, 2002).

Treatment of Pediatric Epilepsy

Initiating Treatment

Once an individual is diagnosed with epilepsy, a decision must be made regarding treatment. An initial factor in developing a treatment plan is the child's estimated risk of seizure recurrence. Hart and Easton (1986) reported that patients with epilepsy are apt to experience a second seizure within six months after the first episode. A number of researchers have studied the risk of recurrence after the initial seizure. A 5-year recurrence risk of 34% was found by Hauser, Rich, and Annegers (1990), whereas Hopkins, Garman, and Clark (1988) found a 3-year recurrence risk of 52%. The strongest predictors of seizure recurrence are the initial cause of seizure, focal abnormalities, and epileptiform abnormalities found on the EEG (Prego-Lopez & Devinsky, 2002). Seizure recurrence also may be related to type of seizure. For example, after experiencing the first tonic-clonic seizure, depending on additional risk factors, the recurrence rates fluctuate from 15% to 60%. After two tonic-clonic seizures, the risk of experiencing another seizure increases to approximately 85% (Hauser, 1986). Acute symptomatic seizures,

which occur immediately after brain insult, have an increased risk of recurrent seizure (Prego-Lopez & Devinsky, 2002). In addition, family history of seizure disorders, abnormal patterns on an EEG, or a history of neurologic insult increases the risk of recurrence after the first seizure (Hauser, Anderson, & Loewenson, 1982).

Treatment with Medication

A study conducted by the First Seizure Trial Group (1993) investigated 397 patients with seizure disorder. The researchers found that the risk of seizure recurrence in untreated patients was 2.8 times higher than in patients treated with antiepileptic drugs (AEDs). The initial selection of medication to treat seizures is based on a number of factors that include seizure type, EEG results, concomitant medications, and past medical history (Hulihan, 1997).

When prescribing AEDs, it is important to be cognizant of the many side effects that may accompany the AEDs. Some children may experience feelings of sedation, psychomotor slowing, and/or gastrointestinal upset (Prego-Lopez & Devinsky, 2002). In rare cases, AEDs can cause severe side effects such as liver failure, bone marrow failure, and/or pancreatitis (Prego-Lopez & Devinsky, 2002). Furthermore, some AEDs are known to be more likely to induce seizures in patients than other AEDs; therefore, it is imperative that medications are carefully selected for each individual depending on the patient's own unique set of factors. Additionally, several medications have been known to initiate and/or exacerbate seizure episodes. Psychotropic drugs, such as certain antidepressants and major tranquilizers are most commonly indicated, and a majority of tricyclic and nontricyclic antidepressant drugs have been linked with an increase in seizures as well (Hulihan, 1997).

Use of AEDs: Monotherapy versus Polytherapy

For each individual child, it is important to weigh the benefits and risks of pharmacological treatment. The Collaborative Group for Epidemiology of Epilepsy (1986) found that approximately 33% of patients who receive long-term antiepileptic treatment experience adverse reactions. Monotherapy (i.e., use of one antiepileptic drug) is thought to be tolerated better than polytherapy (i.e., use of multiple antiepileptic drugs). However, monotherapy has been reported to cause problems in 20% of patients (Labiner & Ahern, 2002). Very young children appear to have increased susceptibility to adverse medication effects (Ronen et al., 2003), as well as children with other medical problems and those taking concomitant medications. These adverse symptoms often lead to treatment failure; therefore, children should be monitored for compliance and adverse reactions to pharmacotherapy.

Evidence suggests that early identification and diagnosis (soon after the onset of the initial seizure) improves outcomes for these at-risk children (Ronen et al., 2003). Early diagnosis and pharmacotherapy may indeed reduce seizure recurrence as well as decrease the number of antiepileptic drugs needed (i.e., monotherapy rather than polytherapy). Additionally, early diagnosis and treatment is likely to minimize the impact of epilepsy on a child's overall health-related quality of life.

Psychopathology and Epilepsy

It has been well documented in the literature that children with epilepsy are at-risk for psychopathology (McDermott, Mani, & Krishnaswami, 1995; Rodenburg, Stams, Meijer, Aldenkamp, & Dekovic, 2005). A prevalence rate ranging from 21% to 60% for psychopathology in children with epilepsy has been reported--a three to six times higher

risk than that of the general population (Caplan et al., 2004; Devinsky, 2003). An epidemiological study conducted by McDermott, Mani, & Krishnaswami (1995) found that children with epilepsy are at a 4.7 times greater risk for psychopathology compared to children from the general population. This prevalence rate is substantially higher than rates in children with other chronic illnesses (Wagner & Smith, 2006).

Potential Causes of Psychopathology in Pediatric Epilepsy

Relationship between seizure type and psychopathology. There are many factors that contribute to psychosocial difficulties in children with epilepsy, such as features of the actual seizures. The type, location, and frequency of the seizures may have a strong correlation with psychosocial problems. For example, if the seizures are located in the temporal lobes or limbic structures, they may directly affect emotions and coping, because these are crucial areas in the brain that control these emotions. Furthermore, if seizures are located in cortical areas, an individual's cognitive and/or physical functioning may be adversely affected. Therefore, it is critical to diagnose and locate the focus and type of seizure because seizures significantly impact the child, both neurologically and psychosocially (Duchowny, 1993; Ho-Turner & Bennett, 1999).

Relationship between seizure frequency and psychopathology. Seizure frequency is another variable that has been examined by researchers to determine its impact on psychopathology in patients with epilepsy. Several researchers (e.g., Austin et al., 1992; Lambert & Robertson, 1999) found that seizure frequency contributed to behavioral difficulties in children with epilepsy. Although to date there is not a sufficient amount of data to ascertain the relationship between seizure frequency and the presence of anxiety,

there are some data that indicate significant stress and anxiety can escalate the frequency of seizures (Vazquez & Devinsky, 2003).

Relationship between treatment with antiepileptic drugs and psychopathology. Fortunately, antiepileptic drugs often can aid in the management of seizures; unfortunately, seizure control alone does not ameliorate the negative affects of epilepsy on an individual's quality of life. Moreover, there is a plethora of research findings that support the negative side effects of antiepileptic drugs. Researchers who have studied AED treatment in children with epilepsy have found that behavioral side effects are most frequently reported. Several researchers (Fiordelli, Beghi, Bogliun, & Crespi, 1993; Mendez et al., 1993) found that the use of multiple AEDs (i.e., polytherapy) is associated with depression in children with epilepsy. Oguz, Kurul, and Dirik (2002) examined the relationship of epilepsy-related factors to anxiety and depression scores in children and adolescents, 9-18 years of age, diagnosed with epilepsy. Results indicated that children and adolescents who were treated with more than one AED obtained depression and anxiety scores that were significantly higher than the children and adolescents who were treated with one AED.

Currently, the research examining the relationship between seizure-related variables and psychopathology is both limited and inconclusive. Mixed results have been found on the relationship among a number of seizure related variables and their relationship with psychopathology. For example, some researchers have found that epilepsy duration, seizure frequency, and polytherapy are related to psychiatric disturbances (e.g., Cramer, Blum, & Reed, 2003; Oguz et al., 2002), whereas others have not generated significant findings (e.g., Ettinger, Weisbrot, Nolan, Gadow, & Vitale et

al., 1998). Because there is little conclusive evidence in this area, it is important for researchers to determine the impact of specific seizure-related variables on psychopathology so that preventative plans may be put in place for children at-risk of developing psychiatric difficulties and/or poor HRQL.

Neurological Dysfunction and Psychopathology. It has long been hypothesized that neurological dysfunction is the primary cause of psychopathology in children with epilepsy. Researchers have found that children with neurological disorders have elevated levels of psychopathology compared to children with disorders that do not involve the nervous system (Lavigne & Faier-Routman, 1992). This may be due, in part, to the reality that children with epilepsy have the risk associated with chronic illness and the risk associated with a central nervous system disorder, combined. Austin et al. (2002) reported that children with epilepsy have a 2.5 times higher risk for psychopathology than do children whose chronic illnesses do not involve the central nervous system.

Response to epilepsy and psychopathology. An individual's response to seizures has been compared to the concept of learned helplessness because individuals with epilepsy continually experience aversive events (i.e., seizures) over which they have no control (Lambert & Robertson, 1999). The seizure episodes may produce extreme fear and embarrassment in the individual with epilepsy. Moreover, these negative emotions may lead to the development of an external locus of control, which in turn may lead to anxiety and/or depression (Hermann, Seidenberg, & Bell, 2000). It is important to note that underlying psychiatric illness may contribute to a lower quality of life in children with epilepsy.

There are a number of negative emotions that children with epilepsy may experience in relation to their neurological condition. For example, fear and anxiety have been identified frequently in children newly diagnosed with epilepsy (Austin, Smith, Risinger, & McNelis, 1994). Fear and anxiety can present significant emotional burdens on children with epilepsy, and these internal emotions often go unnoticed (Shafer, 2002). Children diagnosed with seizure disorders may have a number of fears related to their epilepsy, including the fear that they will die during a seizure episode, that they will suffer brain damage, and/or they will experience a seizure episode in public. Children and adolescents may fear an overall loss of control. That is, they may fear a loss of control related directly to their medical condition (e.g., over bodily functions during a seizure) as well as a loss of control over their social development and relationships (e.g., losing friends).

Comorbid Disorders: Epilepsy and Internalizing Disorders

Given that epilepsy, anxiety, and depression are all rather common disorders, it is not surprising that for a number of children, these conditions coexist (Jackson & Turkington, 2005). Therefore, it is problematic that few researchers have examined the mechanism of depression and anxiety in epilepsy and even less attention has been focused on the treatment of these comorbid disorders (Jackson & Turkington, 2005).

There is consensus among several researchers who have found mood disorders (e.g., depression) in 12% to 26% of children with epilepsy (Caplan et al., 2005; Oguz et al., 2002; Rodenburg et al., 2005). The reported prevalence of mood disorders varies depending on a multitude of factors, including instruments used for assessment (e.g., self-

report measures, psychiatric interviews), type of informant (e.g., parent, teacher, and child), age range of child, and sample sizes of research studies.

The prevalence of comorbid epilepsy and psychopathology is significant, especially compared to other chronic illnesses. Davies, Heyman, and Goodman (2003) examined the rate of emotional disorders in children with epilepsy, diabetes, and healthy children. Records from the Child Benefit Register (CBR) were used to obtain a representative sample of 10,316 children between 5 and 15 years of age throughout England, Wales, and Scotland. Through data collection from a main caregiver and teacher, 67 children with epilepsy (mean age 10 years 2 months), 47 children with diabetes (mean age 10 years 4 months), and 10,202 controls (mean age 9 years 11 months) were identified.

The researchers derived DSM-IV psychiatric diagnoses from the Development and Well-Being Assessment along with data obtained through clinical interviews. Rates of psychiatric disorder were 37% for epilepsy, 11% for diabetes, and 9% for medically healthy children (i.e., without chronic medical conditions). Furthermore, parents of children with epilepsy reported more emotional and behavioral problems compared to parents of children with diabetes and parents of controls. Regression analyses revealed that epilepsy was independently associated with all behavioral variables, but this association was not found with children with diabetes. Therefore, the researchers concluded that emotional and behavioral problems are frequent in children with epilepsy and that there is a need for effective mental health services for this population (Davies et al., 2003).

Caplan et al. (2005) examined affective disorders, anxiety disorders, and suicidality in children with complex partial seizure disorder and absence epilepsy. Seizure-related, cognitive, linguistic, family history, social competence, and demographic variables and their association with psychopathology also were examined. The study involved 171 epilepsy patients; 100 children with complex partial seizures, 71 with childhood absence seizures, and 93 medically healthy children, all 5 to 16 years of age. Affective and anxiety disorders were present in 33% of children with epilepsy compared to only 6% in the healthy group. Furthermore, 20% of children with epilepsy had suicidal ideation compared to 9% of children in the healthy group. When examining the prevalence broken down by specific disorder, 63% of children had anxiety disorders, and 26% had comorbid affective/anxiety and disruptive disorders. Caplan et al. (2005) noted that only one third of the children who were diagnosed with a psychiatric disorder had previously received psychiatric assessment or treatment. This finding highlights the lack of attention to psychiatric disorders in children with epilepsy. Even more remarkable, results from this study revealed that only one third of children with suicidal ideation received any type of psychiatric care.

Caplan et al. (2005) found that children with epilepsy who also had affective and anxiety disorders obtained significantly higher mean scores on the Child Behavior Checklist (CBCL) internalizing and anxiety/depression factor scores. In addition, children with epilepsy had significantly higher scores on the Child Depression Index (CDI) and the Multidimensional Anxiety Scale for Children (MASC). Furthermore, children with complex partial seizures had significantly higher rates of depression and comorbid depression and anxiety compared to children with absence epilepsy.

Conversely, children with absence epilepsy had significantly higher rates of anxiety disorders as compared to children with complex partial seizures.

In summary, this study was the first to identify a high rate of both affective and anxiety disorders (i.e., 33%) and a high rate of suicidal ideation (i.e., 20%) in children with epilepsy. Caplan and colleagues reported that only 33% of the children with epilepsy identified with affective disorders, anxiety disorders, and/or suicide ideation had received mental health services. Because of this finding, along with the high rates of depression, anxiety, and suicide in adults with epilepsy, and the age-related increase of suicide in adolescence, it is critical that psychopathology is identified and treated early to lessen the negative impact of these conditions on children with epilepsy (Caplan et al., 2005).

Several meta-analyses were conducted by Rodenburg et al. (2005) to examine the types and severity of psychopathology in children diagnosed with epilepsy. These researchers examined which types of psychopathology were most prevalent when children with epilepsy were compared to children with a different chronic illness to ascertain whether psychopathology is generic to chronic illness or specific to epilepsy. Children with epilepsy were compared to four control groups (i.e., normative groups, healthy study controls, children with a chronic illness, and siblings). A multi-informant perspective was utilized, including parent reports, teacher reports, and self-reports. Forty-six studies met inclusion criteria for the meta-analyses. Data were analyzed from a total of 2,434 children with epilepsy, with the average sample size of 65 for children with epilepsy. The mean age of children was 10 years, with a range of 4 to 21 years of age (Rodenburg et al., 2005).

To examine the severity of psychopathology in children with epilepsy, meta-analyses of studies comparing children with epilepsy with children from the general population were conducted. Results from these analyses revealed medium to large effect sizes (i.e., d = .57 to .61) for parent report, teacher report, and self-report. Moreover, large effect sizes were consistently found for differences between children with epilepsy and normative controls for the whole range of psychopathology. Meta-analyses of total behavior problems revealed large effect sizes for parent report and teacher report. Larger effect sizes (i.e., d = .45 versus .23) were found on comparisons between children with epilepsy and normative controls on externalizing problems compared to internalizing problems. Furthermore, meta-analyses of total behavior problems revealed that effect sizes for differences between children with epilepsy and healthy study controls were medium (i.e., .15) for parent report and teacher report (Rodenburg et al., 2005).

These findings confirm that children with epilepsy are at high risk for developing psychopathology. These children appear to be vulnerable to the whole range of psychopathology, including attention problems, thought problems, and social problems, as well as internalizing and externalizing behavior. For parent report, teacher report, and self-report, when comparing children with epilepsy to children from normative groups, effect sizes were larger for internalizing than for externalizing behavior problems. However, effect sizes for externalizing problems were still quite large for parent report and teacher report, indicating that externalizing problems also are frequently present in children with epilepsy. Researchers concluded that their findings indicated that psychopathology in children with epilepsy may be associated partially with generic

factors related to chronic illnesses. Therefore, psychopathology may be partly disease-specific--that is, partly attributed to epilepsy (Rodenburg et al., 2005).

It is well documented that there is often a delay in the diagnosis of internalizing disorders in children (e.g., anxiety and depression) because they lack overt behavioral symptoms that are easy to identify. This problem is the same for children with epilepsy experiencing symptoms of anxiety and/or depression. It is common for internalizing disorders such as depression and anxiety to manifest differently in children compared to adults. That is, children may present with externalizing behaviors, such as irritableness or aggressiveness. Therefore, it is important to administer broadband measures to assess a wide range of behavioral and emotional difficulties in children with epilepsy.

Treating Children with Epilepsy and Comorbid Disorders

Due to the complexities that may arise when treating epilepsy, the best approach for managing pediatric epilepsy is to utilize a disease-based model that distinguishes epilepsy syndromes. Accurate diagnosis is essential to enhance medication selection, determine length of treatment, and to counsel children and family members regarding the overall impact of epilepsy and the likely prognosis. Children who are diagnosed with co-morbid disorders are likely to be prescribed multiple medications for treatment. This is especially problematic for children with epilepsy because there are a number of medications prescribed to treat co-morbid disorders that may exacerbate seizures (Hulihan, 1997). For instance, a number of over-the-counter cold medications may contain epileptogenic compounds that could induce seizure. Furthermore, nonprescription anorectics, as well as several antibiotics, have been linked with seizure episodes in nonepileptic children (Scheuer, 1992). This emphasizes the importance of close

monitoring of the patient and the measurement of drug levels. In most cases, children may safely use a combination of medications to treat multiple disorders (Hulihan, 1997).

The treatment of children with comorbid epilepsy and depression is a challenging undertaking. Research findings indicate that depressive episodes in children and adolescents tend to be quite lengthy, with an average length of 7 to 9 months. In addition, approximately 40% of individuals relapse (i.e., have another depressive episode) within a two-year period (Plioplys, 2003). Therefore, the treatment of comorbid affective disorders requires a long-term commitment by both patient and caregivers. Although medication must be carefully monitored by a physician, antidepressants may be used to treat comorbid depression or anxiety in children and adolescents with epilepsy. According to Plioplys (2003), somatic treatment and psychotherapy are the main psychiatric treatment options for comorbid depression and epilepsy.

It is critical to address comorbid psychiatric disorders in patients with epilepsy because these comorbid disorders present a profound impact on this population (Davies et al., 2003; Devinsky, 2003). The identification, diagnosis, and treatment of comorbid psychopathology can be quite challenging. Research findings have supported a relationship among comorbid psychopathology, poor functional outcomes, and lower quality of life (Devinsky, 2003). However, researchers have only recently begun to focus on this association in adults with epilepsy; this relationship in children with epilepsy has received even less attention (Hermann et al., 2000). Another difficulty in addressing comorbidity in epilepsy is the possibility that the psychopathology may be treatment-related. For example, the psychopathology may be a consequence of treatment with AEDs (Devinsky, 2003).

Another factor that further complicates the treatment of comorbid disorders in epilepsy is that very little is known regarding the pathogenic mechanisms underlying the comorbidity (Devinsky, 2003). Recent research findings have pointed to a possible bidirectional relationship between psychiatric disorders (e.g., depression) and epilepsy; however, further research is sorely needed (Kanner & Palac, 2000). Although suitable treatment strategies are being developed with use of medications that have mood stabilizing effects, the most optimal treatment plans remain unknown (Devinsky, 2003).

Due to primary care providers' lack of clinical expertise in recognizing, diagnosing, and treating both epilepsy and psychopathology (Jackson & Turkington, 2005), collaboration with psychologists and psychiatrists likely would improve pharmacological treatment for these patients. One of the most significant barriers to receiving appropriate and effective treatment for depression may be that primary care physicians and neurologists are reluctant to prescribe antidepressants to their patients. This is because all classes of antidepressants are contraindicated in persons with epilepsy, and when prescribed, must be used with great caution in this population (Jackson & Turkington, 2005). AEDs that effectively control seizures without the adverse effects on behavior and cognition, in combination with psychopharmacological treatment to address comorbid psychopathology, would be an ideal treatment option for children with epilepsy and comorbid psychopathology.

Psychiatric side effects can be linked to all types of AEDs used to treat individual patients with epilepsy. That is, one group of AEDs has sedation effects such as fatigue and cognitive slowing (Ketter, Post, & Theodore, 1999). Another group of AEDs is an activating-type that tend to cause activation, weight loss, and possibly antidepressant

effects. Because of the correlation between use of AEDs and psychopathology, it is critical that knowledge regarding the tolerability of AEDs is increased, possibility through clinical trials and/or patient self-report measures. To diagnosis and treat comorbidity in children with epilepsy accurately and effectively, the administration of AEDs and the potential relationship to psychiatric adverse effects must be considered. It is important to differentiate psychopathology that is independent of treatment of an underlying illness (e.g., epilepsy) and psychopathology that is a consequence of pharmacological treatment of an underlying disorder (Devinsky, 2003).

In conclusion, deciding how to treat seizures can be a very complex task. There are a multitude of factors that can affect patients and their families' decisions regarding treatment. It is imperative that the patient and family understand both the benefits and risks of various treatment options. Depending on past experiences and cultural beliefs, people will have different attitudes and beliefs regarding treatment. It is important to involve the child in his or her own treatment plan as much as possible. When the team (i.e., patient, family members, and practitioners) is able to establish common goals and objectives, it is most likely that the treatment will be successful (Shafer, 2002).

Summary of Psychopathology and Epilepsy

Although often unrecognized and untreated, psychopathology (especially anxiety and depression) is common in children with epilepsy (Plioplys, 2003). It is unfortunate that, to date, the majority of research has focused on psychopathology in adults with epilepsy, and studies with children have been sparse. Children with epilepsy may have different types of risk factors, but these risk factors are equally significant to the risk

factors that adults endure. Just as adults with epilepsy need to adjust to their conditions, children also must adapt to the diagnosis and treatment of epilepsy.

Epilepsy, compounded with a psychiatric comorbidity, further complicates pharmacological and psychosocial treatment planning. The benefits and risks to pharmacological treatment in children should be weighed carefully, and this is especially true when dealing with comorbidities. Further research is needed to develop effective prevention and intervention plans for children with epilepsy and associated psychopathology.

It is imperative that individuals with seizures are carefully screened by clinicians to detect any mood disturbances or other psychopathology (Shafer, 2002). Co-morbid psychopathology in children with epilepsy must be identified and treated with psychotropic medication and psychotherapy as needed. The high prevalence rates for comorbidity in children with epilepsy highlights the need for mental health services in pediatric epilepsy clinics. In 2003, the Epilepsy Foundation of America recommended that the development of evidence-based mental health treatment specifically for children with epilepsy take precedence in the overall management of epilepsy.

Health-Related Quality of Life and Epilepsy

Attention typically has focused on seizure control in patients with epilepsy (Berg et al., 2001). However, research findings are accumulating that shed light on the tremendous psychosocial impact of epilepsy on patients (Devinsky, 2003; Ronen et al., 2003). As the primary goal in health care is the attainment of optimal physical and psychosocial well-being for patients, the impact of chronic illness on psychosocial

functioning should not be overlooked. The cyclical relationship between physical health and mental health must be addressed to promote overall health and well-being.

Epilepsy can have a significant impact on children's overall development, including learning, behavioral, social, and emotional domains. Historically, epilepsy and seizures have been stigmatized (Baker, 2001). This may be due to the fact that self-control and predictability of behavior is expected in our society, and for individuals who experience seizures, this expected behavior is not met. Unfortunately, individuals with epilepsy cannot predict when their next seizure will occur, and this uncertainty can make others around them uneasy. Given that the average adult does not have an adequate understanding of seizure disorders, epilepsy can be a scary condition with which to deal, especially for children. This presents a challenging situation for children diagnosed with epilepsy, especially in the school setting.

Because all children, those with and without epilepsy, have difficulty understanding the disorder, it is crucial that educators inform students about epilepsy, including causes, symptoms, and treatment options. Fear and uncertainty surrounding the condition may lead peers to distance themselves from children with epilepsy. Unfortunately, it is quite common for adults and same-age peers who are uninformed about epilepsy to segregate children with epilepsy from their peers. When children with epilepsy are not permitted to engage in age-appropriate activities with peers, their sense of control and overall quality of life may be significantly restricted (Shafer, 2002). The development of social relationships is of the utmost importance for children; therefore, their exclusion from social activities can severely jeopardize their emotional well-being and sense of self. Quality of life is an especially important health outcome to address in

children with epilepsy because they appear to be at special risk (Austin et al., 1994). Research has shown that epilepsy has a significant negative affect on QOL, with a number of factors identified that may cause poor QOL, such as seizure severity, stigma, fear, and psychiatric problems (Shafer, 2002).

Defining Health-Related Quality of Life (HRQL)

Health-Related Quality of Life (HRQL) represents the functional effects of an illness and its resulting therapy on a patient, as perceived by the individual patient. HRQL may be defined as an individuals' emotional reaction to the illness and their life situation, or by their ability to meet personal needs (Baker, 2001). One of the most comprehensive definitions is provided by Schipper (1990). In the definition, the following five broad domains are covered: physical, occupational, psychological, social, and somatic. When treating children with epilepsy, it is imperative that all areas of functioning are addressed because all of these areas can significantly impact overall functioning. Therefore, an ecological approach to treatment is necessary. One of the chief aims of treating children with epilepsy should be to enable them to feel better and to improve their function in daily activities.

Most clinicians acknowledge that it is critical to incorporate HRQL measures into routine clinical practice to ensure that patients with epilepsy receive the best possible treatment (Ronen et al., 2003). It has been well-established in the literature that chronic medical illnesses, to a certain degree, impact patients' quality of life (Baker, 2001). Additionally, researchers have found that individuals with epilepsy typically experience a more severe decline in their quality of life compared to individuals with other types of chronic illness. This may be due, in part, to the nature of epilepsy; the uncertainty of

when another seizure will occur, how to control the seizures, and when--if ever--they will abate (Baker).

Quality of life in children with chronic conditions is a relatively new area of research (Calaminus, Weinspach, Teske, & Gobel, 2000). However, quality of life data has provided important insight for understanding the impact of a chronic illness on children's psychosocial functioning and development (Noll et al., 1999). To assess HRQL in children with epilepsy, several groups of researchers have investigated various factors that may contribute to a lowered health-related quality of life. Although minimal research has been conducted measuring the relationship between epilepsy and HRQL, the two areas that researchers have studied include seizure-specific variables, and to a lesser extent, psychiatric disorders. The most commonly assessed seizure variables include type of seizure, seizure frequency, seizure severity, and age at onset of seizure (Ronen et al., 2003). However, the relationships between these variables and level of HRQL are only moderate. The following sections will review the literature related to both seizure variables and psychiatric disorders, and their particular influence on HRQL in children with epilepsy.

Measuring HRQL in Children with Epilepsy

Because the chief goal of management of children with epilepsy should be to reduce medical and psychosocial complications as much as possible, it is important that practitioners are aware of the child's perception of her/his quality of life. An efficacious instrument that measures HRQL is necessary to identify areas of functioning that are being negatively impacted so that comprehensive and effective treatment plans can be developed. Research has shown that factors specific to seizures (e.g., frequency and

severity) are merely one pertinent outcome variable (Ronen et al., 2003). Other dimensions, such as social, psychological, and behavioral dimensions also have significant impacts on children with epilepsy and their families.

There have been several HRQL scales specific to epilepsy developed to measure the impact and burden of epilepsy on children (Ronen et al., 2003). However, few researchers have studied the score reliability and validity of these measures. It is important that HRQL scales measure a multitude of factors, including the child's resilience, co-morbid conditions, and societal or cultural variables. The presence of these variables will impact each individual patient to a different degree; however, all have the potential to impact significantly patients' HRQL on a daily basis. Ronen et al. (2003) recommend utilizing children's own perspectives of their HRQL as well as parent reports. Once HRQL measures, both generic and epilepsy-specific, have been determined to be efficacious, they should be used routinely by clinicians in their daily practices (Ronen et al., 2003).

Austin et al. (1994) conducted a study examining quality of life in children with epilepsy and children with asthma. All children who participated in the study were diagnosed with either epilepsy (n = 136) or asthma (n = 134) and were between 8 and 12 years of age. Additional inclusion criteria also required that the children were currently receiving medication for their conditions, had no other chronic physical conditions, and had at least average intellectual functioning. Data were collected from the children, their guardians, and their teachers through a variety of assessment strategies (e.g., interviews, school records, and questionnaires). Participants were compared on four dimensions of

quality of life (physical, psychological, social, and school) to determine the specific areas that are problematic for children with epilepsy.

Data were analyzed via a 2 x 2 between-subjects multivariate analysis of covariance with type of illness as the independent variable and length of time since onset of illness as a covariate. The most significant finding from the study was that children with epilepsy had a more compromised quality of life in the psychological, social, and school domains as compared to the group with asthma, despite a later age of disease onset and fewer illness episodes for the children with epilepsy compared to the children with asthma. Contrarily, children with asthma had a more compromised quality of life in the physical domain (Austin et al., 1994).

Findings revealed that the physical domain had the lowest correlations with the other three domains. Medication side effects also were significantly related to with internalizing and externalizing problems at home, and externalizing problems at school. The difference in quality of life between groups suggests that difficulties in children with epilepsy are not exclusively the result of the chronic condition; poorer HRQL of children with epilepsy is at least somewhat specific to seizure disorders. It is hypothesized that another aspect of the illness is related to poorer quality of life in the psychological, social, and school domains. The researchers hypothesized that whatever caused the epilepsy may also directly affect coping behaviors and school achievement (Austin et al., 1994).

A limitation to this study was that the physical domain was not measured as comprehensively as the psychological, social, and school domains; therefore, future research should investigate additional variables such as illness severity and use of antiepileptic medications. It also is a challenge for future researchers to ascertain a

stronger understanding of the relationship between learning problems and quality of life, such as the sequence of events to determine whether these learning difficulties precede or follow the emergence of psychological and social problems.

These findings suggest that a focus on seizure control will not address the full range of problems that children with epilepsy experience. Furthermore, these results emphasize the need to ascertain the risk and protective factors for developing problems that compromise quality of life. This underscores the need for prevention and intervention programs that ameliorate psychological, social, and school performance problems in children with epilepsy.

Research has revealed that seizure control plays only a minor role in the social adjustment of children; therefore, additional factors are likely contributors. Other researchers also have concluded that although patients with frequent seizures had poorer psychosocial profiles than did those with infrequent or no seizures, important predictors of psychopathology and social dysfunction seemed to exist in the patients with refractory epilepsy that could not be explained by physical or demographic data (Austin et al., 1994).

Health-related quality of life measures. Both generic and condition-specific HRQL scales have been developed to measure quality of life in children. Generic measures such as the Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1996) and Pediatric Quality of Life Questionnaire (PedsQL; Varni, Seid, & Kurtin, 2001) were developed to assess a broad range of HRQL domains in individuals with chronic conditions, irrespective of the specific condition. However, because research has shown that children with epilepsy are more susceptible to a poorer QOL than children with other

chronic illnesses, use of epilepsy-specific scales may be warranted. Furthermore, a generic instrument may lack the sensitivity to detect subtle characteristics of specific conditions in a manner that provides meaningful information to patients and professionals (Ronen et al., 2003).

Disease-specific measures for children have been developed for a number of beneficial reasons. For example, disease-specific measures are specifically designed to assess areas of functioning that are most likely to be affected by a particular illness. Furthermore, they utilize items that are clinically relevant and meaningful for children (Quittner, 1998; Spieth & Harris, 1996). Epilepsy-specific HRQL instruments are developed to assess characteristics of a particular condition. Therefore, these scales are typically more relevant and sensitive to the nuances of epilepsy. However, a drawback to the condition-specific scales is that they address a more restricted range of issues than generic instruments. Another limitation to the utilization of condition-specific instruments is that they often do not have well-documented psychometric properties because they are less widely used than generic measures (Ronen et al., 2003). If researchers determine that the advantages to utilizing disease-specific HRQL instruments outweigh the potential disadvantages, it is important that the psychometric properties (validity, reliability) of these measures are assessed so that psychometrically sound instruments are used to assess HRQL.

Epilepsy-specific HRQL measures for children. Accurately measuring HRQL in children with epilepsy can be challenging. Only recently have researchers focused on studying epilepsy and its impact on HRQL (Ronen et al., 2003). To garner the most useful data when utilizing a HRQL rating scale, it is important to use a measure

developed for children because adult HRQL measures are typically inappropriate for use in children and adolescents (Carpay & Arts, 1996). Different types of information are pertinent depending on the patient's age. For example, scales developed specifically for children focus on social issues and their physical appearance, whereas adult scales focus more on financial issues, career issues, and being self-sufficient. Furthermore, HRQL measures for children must accommodate the changes that occur throughout children's development, whereas these domains are unnecessary for adult patients.

Eiser and Morse (2001) recommend that to assess most accurately children's HRQL, children should rate their own HRQL. Research findings have revealed that children identify more items impacting their HRQL than do their own parents. Furthermore, young children (i.e., seven years of age) appear to be consistent and accurate in their understanding of the items and response options on rating scales, and they have demonstrated very good test-retest score reliability (Eiser & Morse, 2001). These findings support the effectiveness of utilizing self-report measures to assess HRQL in children with epilepsy.

It is essential that epilepsy-specific HRQL scales are developed to focus on problems relevant to children. For example, it would be advantageous if scales could detect subtle changes in the child including evaluation of different therapies. More research must be undertaken to identify accurately attributes of HRQL in children with epilepsy.

One of only two research groups that have addressed this area is Ronen et al. (2003). These researchers used separate focus groups for children with epilepsy, ages 6 to 10 years, and their parents, so that each could discuss their own perceptions of life with

epilepsy. Five dimensions were identified: (a) the experience of epilepsy; (b) life fulfillment and time use; (c) social issues; (d) impact of epilepsy; and (e) attribution. In their follow-up study, 381 children with epilepsy and their parent(s) independently completed a 67 item HRQL questionnaire. Factor analyses revealed five HRQL dimensions that the children considered most important: (a) interpersonal/social impact; (b) areas of worries and concerns; (c) intra-personal/emotional consequences; (d) issues of keeping epilepsy a secret; and (e) quest for normality and resilience. Factor analysis of the parents' reports of their children's HRQL identified only the first four factors. In addition, the parents thought their children were worried as much about the future as about present issues whereas in fact the children worried almost exclusively about present matters. Based on the results of the factor analyses, the questionnaire was reduced to 25 items on both the child form and the parent form without sacrificing the integrity of the questionnaires. Statistics were computed to determine the psychometric properties of the questionnaires. Results showed that the questionnaires were psychometrically robust for parents and children 8 years of age and older. Internal consistency, construct-related validity, and test-retest reliability were found to be adequate. Scores obtained from the matched parent and child were poorly to moderately correlated.

In another study, Arunkumar, Wyllie, Kotagal, Ong, and Gilliam (2000) examined parent and patient-validated content for quality of life assessment in children with epilepsy. The researchers obtained information from both parents of children with epilepsy and the children themselves. A total of 80 parents of children with epilepsy (3 months to 20 years of age) and 48 of the children were asked to share concerns about

living with epilepsy in order of importance. These data were helpful in establishing questionnaires for use with children and parents (Arunkumar et al., 2000).

Gilliam et al. (1997) utilized the parent-proxy generic Child Health Questionnaire (CHQ; Langraf et al., 1996) to assess functioning and quality of life in 33 children before undergoing epilepsy surgery. Significantly poorer scores were found in the domains of emotional impact on parents, time impact on parents, and the general health index. Decreased scores also were found for domains of self-esteem, general behavior, and the physical function index. Results indicated that the intervention did not allow the children who had epilepsy surgery to reach the same levels as healthy controls even though their HRQL scores did increase following surgical treatment. However, a significant limitation to this study was that it failed to assess which HRQL domains improved after surgery, and which, if any, subgroups of patients improved following surgical treatment (Gilliam et al., 1997).

A different group of researchers (Miller, Palermo, & Grewe, 2003) utilized the same parent-proxy CHQ scale to compare 41 children with epilepsy, 4 to 19 years of age, to healthy controls. The majority of the children's seizure disorders were severe, and more than one half of the patients had co-morbid neurological impairments. Results from this study revealed that the presence of co-morbid disorders and the use of multiple AEDs were the strongest predictors for poor HRQL in children with epilepsy. A limitation to this study was that HRQL markers unrelated to epilepsy were not used to compare these scores for children with epilepsy and scores for the healthy controls.

Devinsky, Westbrook, Cramer, Glassman, Perrine, and Camfield (1999) conducted a study to assess the risk factors for lowered HRQL in 197 adolescents, 11 to

17 years of age, with epilepsy. These researchers correlated antiepileptic drug toxicity, socio-demographics, academic and social variables, and health-related variables (including epilepsy), with self-reported HRQL via the Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48; Cramer, Westbrook, Devinsky, Perrine, Glassman, & Camfield, 1999). The variables that were related to lower HRQL included older age, lower socioeconomic status, increased seizure severity, and antiepileptic drug neurotoxicity. Unfortunately, remediable factors that may have been responsible for the lower HRQL in older adolescents and those with a lower socioeconomic status were not identified in this study (Devinsky et al., 1999).

Despite recent achievements in developing HRQL measures, there is a need to improve our understanding of the functional and experiential dimensions associated with complex neurodevelopmental disorders (Ronen, Rosenbaum, & Streiner, 2000). It is difficult to attribute better or poorer quality of life to the nature of epilepsy alone, when so many disparate factors play key roles in people's lives. These factors include, among others, a child's resilience, co-morbid conditions, parental well-being, family factors, attitudes, and societal/cultural variables. Recent studies have shown that clinical symptoms such as seizure frequency and severity, or other biomedical markers, have only moderate correlations with HRQL (Ronen et al.). Furthermore, HRQL may change over time with the development of the child and the family's accommodation to the situation. In addition, we need to learn what truly encompasses comprehensive patient care, define the goals of management, and attempt to evaluate the impact of interventions wherever possible.

Future assessments should include measures where the items originated from children with epilepsy, and allow them to rate their own HRQL. However, parent-proxy report measures may be useful in addition to the child's self-assessment. Even though the ratings of the child and parent may differ, it may be beneficial to obtain ratings from both informants to gain multiple perspectives of the impact of epilepsy (Ronen et al., 2003). The combination of self-report and parent responses may help to understand family dynamics of coping with epilepsy. In addition, these data may help to identify multiple issues that could be addressed through family therapy because a child's chronic illness impacts not only the child, but the entire family. Therefore, future research is needed to assess the advantage of using a multi-informant method for measuring health-related quality of life in children with epilepsy.

Summary

Pediatric epilepsy is a complex neurological condition with a number of possible co-morbid features. Although there is a dearth of research examining comorbid psychopathology in children with epilepsy, it is apparent from the existing literature that there is a significant relationship between psychopathology (i.e., depression, anxiety) and epilepsy in both children and adults. Seizures alone may be difficult to manage as treatment with medication presents numerous challenges. There exists the typical challenge of medical adherence as well as the potential negative side effects that are encountered when using antiepileptic medications. Furthermore, when comorbid disorders are present, treatment difficulties are exacerbated.

The coping process in epilepsy is not linear; it may vary with different life stages and in relation to each patient's unique experiences. When a child is first diagnosed with

epilepsy, the child and family are likely to have a variety of emotions and reactions to the diagnosis. These initial emotions may include fear, anger, and disbelief, and subsequent emotions may involve anxiety and depression (Shafer, 2002). The types and intensity of emotions are likely to change over the course of the illness, depending on factors such as the severity and frequency of seizures and side effects of medications. Because of the multitude of factors that impact the presence of psychopathology and poor health-related quality of life, it is imperative that epilepsy management include early assessment and treatment of seizures as well as psychosocial problems to assist children in successfully coping with their chronic medical condition.

It is imperative that researchers ascertain the risk factors that lead to poor health-related quality of life in children with epilepsy. Knowledge of these factors may help to determine effective treatments to enhance the HRQL of children with epilepsy and their families. Through the attainment of information related to HRQL of children with epilepsy there are many ways that children and their families can be supported. Empirically-validated instruments can aid in the detection, assessment, and follow-up of issues impacting children with epilepsy and their families. It also is important to recognize the need to address opportunities for dissemination, translation of information, and implementation of the obtained research findings into clinical pediatric practice.

To assess the effect of epilepsy on children, the children's own perceptions should be addressed in addition to their families and teachers, and any other significant persons in the child's environment. When a child is coping with a chronic condition, it impacts the child's entire family. Likewise, the child's condition may impact his or her performance at school, both behaviorally and academically. It is imperative that school

faculty and staff (e.g., teachers, psychologists, and administrators) as well as students are aware of the child's condition, including the specific diagnoses, symptoms, and treatment plans. Because children spend a significant amount of their day in school, educators are in the position to recognize symptoms that may indicate internalizing problems (e.g., depression and anxiety) and externalizing problems (e.g., aggression) that may negatively impact their levels of success at school. When children with epilepsy and comorbid psychopathology are identified early, appropriate interventions may be developed and implemented that will help to ameliorate internalizing and externalizing difficulties, as well as academic problems.

It is critical that healthcare and educational professionals recognize the spectrum of issues facing children with epilepsy and become familiar with available resources for these children. The ideal model of care for epilepsy stresses collaboration among patients, families, primary care physicians, epilepsy specialists, mental health professionals, educators, rehabilitation experts, and community resources. Finally, the children diagnosed with epilepsy and their caregivers should be counseled regarding the associated risks and benefit of various treatment options.

Chapter 3

Method

Overview

This chapter presents the methods for the current study in detail. Characteristics of the participants are reviewed, such as inclusion and exclusion criteria, and sampling considerations such as sampling scheme and sample size. Next, all procedures for the study, in a step-by-step fashion, are thoroughly presented. The research design for the study is discussed, as well as the statistical analyses that were conducted to address each research question.

Selection-Eligibility Criteria

The purpose of this study was to determine whether seizure type, seizure frequency, anti-epileptic drug (AED) treatment, anxious symptomatology, and/or depressive symptomatology were correlated with a lowered health-related quality of life in children with epilepsy. A central aim of the study was to identify children with epilepsy who are most at-risk for poor HRQL based on seizure variables and psychopathology. Therefore, children with a variety of types of epilepsy and variability in seizure characteristics were invited to participate in this study.

The inclusion criteria for participation in the current study were (a) a diagnosis of epilepsy confirmed by a pediatric neurologist, (b) chronological age of child between 8 years, 0 months and 11 years, 11 months at the time of the study, (c) pharmacological treatment with AEDs, (d) English proficiency of child and guardian, (e) consent from the

children's parents/guardians, and (f) verbal assent from the children. The age range of 8 to 11 years was chosen because the researcher was interested specifically in elementary-school aged children (i.e., pre-adolescence) diagnosed with epilepsy. Additionally, adolescent participants were not included because this population would introduce unique age-related variables that potentially would confound the findings of the current study. Pharmacological treatment with AEDs was an inclusion criterion because the literature has shown that AEDs, especially use of multiple AEDs, are correlated with lowered health-related quality of life (Devinsky, 2003; First Seizure Trial Group, 1993; Miller et al., 2003). This researcher was interested in examining the impact of AEDs, specifically the number of AEDs prescribed (i.e., monotherapy or polytherapy) on the presence of anxiety and/or depression and health-related quality of life.

Exclusion criteria for participation in this study included children diagnosed with acquired epilepsy (e.g., due to head injury) and those with epilepsy who were not taking any antiepileptic drugs. Furthermore, for purposes of this study, the principal investigator was interested in discovering the distinct impact of pediatric epilepsy on depressive symptoms, anxious symptoms, and HRQL. Because additional medical or psychiatric conditions would likely contribute to depressive symptoms, anxious symptoms, and lowered HRQL, children with additional diagnoses were not included in the current study. Additionally, children who were prescribed psychotropic medications other than anti-depressants and anti-anxiety medication did not meet criteria for the study.

Sampling

Sampling Scheme

A non-random, convenience sampling method was used in this study. That is, the principal investigator attempted to recruit participants for the current study based on their accessibility (e.g., geographic location). This sampling scheme was used because it was the most practical sampling scheme given that epilepsy is a relatively low-incidence condition.

Sample Size

According to Tabachnick and Fidell (2001), the number of variables in a research study, in part, determines the sample size needed to obtain statistically significant results; therefore, when utilizing canonical correlation analyses, a rule of thumb in the social sciences is to have approximately 10 cases for each variable in the study. However, if score reliability is high, then a much lower ratio of cases to variables is adequate. The current study examined the relationship between five independent variables and five dependent variables utilizing a 5% level of statistical significance and a .80 level of statistical power. In view of that, the goal of this study was to obtain data from a minimum of 50 parent-child pairs to have sufficient power to obtain statistically significant findings. The final sample size obtained in this study was 51 child-guardian pairs.

Instruments

Demographics and Seizure Variables Questionnaire (DSV Questionnaire)

A Demographics and Seizure Variables Questionnaire was developed by the principal investigator for parents/guardians to complete to obtain information on their

child diagnosed with epilepsy. This questionnaire was utilized in the study to obtain data on specific variables that were statistically analyzed to determine the impact of seizure-related variables on HRQL, depressive symptoms, and anxious symptoms in children with epilepsy. The specific seizure-related variables (i.e., seizure type, seizure frequency, and use of AEDs) were included because prior research suggested that these variables may negatively impact HRQL in children with epilepsy. Furthermore, demographic data were collected so that descriptive information about the population participating in the study could be ascertained and presented.

The following information was gleaned: (a) age of child, (b) gender of child, (c) race of child, (d) additional diagnoses of child, (e) type of seizure (i.e., generalized or partial), (f) seizure frequency (i.e., 0-5 or 6-12), and (g) treatment with AEDs (i.e., monotherapy or polytherapy). The seizure frequency category ranges of 0-5 and 6-12 were developed based on discussion with a pediatric neurologist. The rationale was that seizures that occurred more often than once per month would be considered uncontrolled (i.e., intractable) seizures and would introduce another subset of patients with epilepsy. The format of this questionnaire consisted of multiple-choice and fill-in-the-blank options. There was a total of 10 items; 4 fill-in-the-blank items and 6 multiple-choice items. After the questionnaire was developed, a pediatric neurologist reviewed the questionnaire to ensure accuracy in the terms used and the wording of the items. The questionnaire took guardians approximately five minutes to complete. The Demographics and Seizure Variables Questionnaire is presented in Appendix A.

Behavior Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004)

The Behavior Assessment System for Children, Second Edition (BASC-2), is a broadband measure that consists of a variety of items and scales that assess internalizing and externalizing domains of behavioral/emotional problems, as well as social and adaptive competencies. The BASC-2 has both clinical and adaptive scales. The clinical scales include: Externalizing Problems (hyperactivity, aggression, and conduct problems), Internalizing Problems (anxiety, depression, and somatization), School Problems, Attention Problems, and Learning Problems. The adaptive scales include: Adaptive Skills (adaptability), Social Skills (leadership), and Study Skills.

The BASC-2 includes a total of six forms: self, parent, and teacher measures for young children (ages 6 through 11), and self, parent, and teacher measures for adolescents (ages 12 through 21). Research has shown that caregivers and teachers are not always aware of the negative effects of an illness on their child, which is evidenced by discrepancies found between child and parent reports (Merrell, 1999). Therefore, both the child self-report form (BASC-SRP-C) and the parent form (BASC-PRS-C) were completed independently.

Moreover, there are significant differences among children with anxiety alone, depression alone, and co-morbid anxiety and depression; therefore, it is imperative to differentiate between anxiety and depression (Brady & Kendall, 1992). Given the co-morbidity of both anxiety and depression in epilepsy, it is necessary to assess anxiety and depression in children with epilepsy to develop effective treatment plans. The BASC-2 provides validity indicators (F, Response Pattern, and Consistency) that make the

interpretation of clinical scale elevations more meaningful. Furthermore, the BASC-2 separates anxiety and depression constructs into two separate scales. There is no item overlap between these two scales, and this allows for a greater opportunity for differential diagnosis (Kamphaus & Frick, 1996). For purposes of the current study, the anxiety and depression scales from the BASC-2 were of most interest.

The BASC-2 produces T-scores, which describe distance from the mean, and percentiles, which describe rarity. The BASC-2 has been normed for a general population as well as clinical populations. Clinical norms are useful when the child's problems are extreme compared to the general population. Therefore, clinical norms help to avoid ceiling effects for children who have significant adaptive and/or behavioral problems. In addition to general norms and clinical norms, the BASC-2 also has gender-based norms. Gender-based norms help identify children whose self-report scores are rare for their age and gender (Reynolds & Kamphaus, 2004).

The BASC-2 generates two interpretive ranges (i.e., at-risk and clinically significant) for composite scales and subscales based on *T* scores obtained using norms. Typically, *T* scores ranging from 60 to 69 on the clinical scales are considered to be in the "at-risk" classification range indicating the potential of developing a problem that requires careful monitoring. *T* scores of 70 and above on the clinical scales are considered to be in the "clinically significant" range. Scale scores in the clinically significant range indicate a high level of maladjustment. The BASC-2 is reported to be a comprehensive and psychometrically sound assessment instrument (Flanagan & Esquivel, 2006).

The Behavior Assessment Scale for Children - Self-Report of Personality (BASC-SRP-C) consists of 152 items and is designed for use with children 8 to 11 years of age to provide insight into children's thoughts and feelings. The BASC-SRP-C takes children approximately 30 minutes to complete. The BASC-SRP-C is written at a first-grade reading level; therefore, children as young as six years of age should be able to complete the measure independently or with minimal assistance. Furthermore, the SRP form contains validity scales to aid in determining the quality of the data collected.

The BASC-SRP-C is a well-developed broadband self-report measure with strong psychometric properties (Merrell, 1999). Analyses conducted with data from the standardization sample revealed that the median internal consistency reliability coefficients of the scale scores were in the low .80 range. Furthermore, the median coefficients for the composite scores were in the mid .90 range, and the test-retest reliability coefficients were in the mid .80 range at one month intervals (Merrell, 1999). In the current sample, the internal consistency reliability coefficient of the scale scores on the BASC-SRP-C Anxiety subscale was 0.72 and the Depression subscale was 0.87.

The Behavior Assessment System for Children – Parent Rating Scale (BASC-PRS-C), is completed by parents or guardians and takes approximately 10-20 minutes to complete. The BASC-PRS consists of 134 to 160 items that measure adaptive and problem behaviors in the home and community setting. Items on the PRS are rated by using a 4-point Likert-type scale ranging from 0 (never) to 3 (almost always). To complete the PRS, a fourth-grade reading level is required. It is reported in the BASC-2 manual that the individual PRS scale and composite scores yield good reliability coefficients (.80), except for the Adaptability, Conduct Problems, Hyperactivity, and

Somatization scales. Fortunately, for purposes of this study, the former scales were not of specific interest. A number of criterion-related and construct-related validity studies indicate that the PRS scores yield adequate validity (e.g., Doyle, Ostrander, Skare, 1997; Kamphaus & Frick, 1996). In the current sample, the internal consistency reliability coefficient of the scale scores on the BASC-PRS-C Anxiety subscale was 0.72 and the Depression subscale was 0.87.

Health-Related Quality of Life Questionnaire (HRQL; Ronen et al., 2003)

The Health-Related Quality of Life questionnaire (HRQL; Ronen et al., 2003) was used to assess the quality of life for children diagnosed with epilepsy. There were two versions of this questionnaire utilized in the current study: a child questionnaire and a parent questionnaire. The child questionnaire was developed for children 6 to 15 years of age. This measure was designed to assess a child's quality of life in multiple domains. The child questionnaire contains five subscales: (a) interpersonal/social, (b) present concerns, (c) intrapersonal/emotional, (d) secrecy, and (e) normality. The parent questionnaire also contains five subscales: (a) interpersonal/social, (b) present concerns, (c) future concerns, (d) intrapersonal/ emotional, and (e) secrecy.

Both the parent form and the child form have 25 items. All items on the questionnaires utilize a 4-point Likert-type scale, ranging from "really true" to "sort of true" for two contrasting statements. An example of an item is, "Some kids with epilepsy feel that other kids treat them differently" but "Other kids with epilepsy feel they are treated the same as everyone else." The individual is instructed to circle the statement that is most like them, and then choose whether the one statement is "really true" or "sort of true" for them. The scores for each subscale range from 5 to 20, with lower scores

indicating more compromised HRQL. Both parent and child HRQL questionnaires are reported by the developer to take approximately five minutes to complete.

The HRQL questionnaire is one of only two disease-specific health-related quality of life scales that uses a self-response questionnaire that has been found to have sound psychometric measures. Furthermore, the HRQL is the only measure that has parallel questionnaires for both the parent/guardian and the child to complete independently. Ronen et al. (2003) assessed the psychometric properties of the HRQL questionnaire. A total of 381 children and 424 parents/guardians participated in the study. All child participants were between 8 and 15 years of age. Results revealed that scores from the HRQL questionnaire yielded good internal consistency, test-retest reliability, and construct-related validity (Ronen et al.). Cronbach's alpha demonstrated adequate internal consistencies (> 0.70) for scores yielded for all scales except the normality subscale in the self-report scale (i.e., 0.63) and the present worries subscale in the parent-proxy scale (i.e., 0.64). In the current sample, the internal consistency reliability coefficient of the five subscale scores on both the HRQL – Child Form and Parent Form were adequate. Cronbach's alpha for scores on the HRQL- Child Form were as follows: Social (0.87), Present (0.90), Emotion (0.91), Secrecy (0.90), and Normalcy (0.91). On the HRQL – Parent Form, the five subscale scores revealed the following score reliability coefficients: Social (0.87), Present (0.88), Future, (0.79), Emotion (0.76), and Secrecy (0.80).

Procedures

Prior to the start of the research study, approval for the proposed study was obtained from the University of South Florida Institutional Review Board to ensure the ethical treatment of all participants. The principal investigator obtained the contact information (e.g., telephone number) of a pediatric neurologist in the west central Florida region. This contact information was obtained by the principal investigator through a psychologist in the same geographical region who was participating on the principal investigator's dissertation committee and had a working relationship with a pediatric neurologist in the region. The pediatric neurologist was contacted via telephone to provide information regarding the goals and objectives of the study. The principal investigator requested permission from the participating pediatric neurologist to hand-deliver packets to his practice to be distributed by the office manager to the parent-child pairs who met all inclusion criteria.

In January 2008, the principal investigator sought and obtained approval from Wayne State University's Institutional Review Board to add a Children's Hospital located in the Midwestern United Sates as a second data collection site. The principal investigator contacted a pediatric neurologist at the Children's Hospital via electronic mail and written letter to provide information regarding the goals and objectives of the study. The principal investigator requested permission from the pediatric neurologist to hand-deliver packets to his clinic within the Children's Hospital to be distributed by the office manager to the parent-child pairs who met all inclusion criteria.

After verbal and/or written consent was obtained from the above-referenced pediatric neurologists, packets (i.e., forms enclosed within a sealable manila envelope)

were generated for parent-child pairs. The packets for the two sites consisted of the same type of information; however, the consent process/requirements of the two sites differed and therefore there was a slight variation in the packets for the two sites. Packets for the site in the Southwestern United States consisted of the following documents: a cover letter and assent form for the child participant (see Appendix B) and a cover letter and consent form for the guardian participant (see Appendix C). Additionally, the packets included each of the following measures: Demographics and Seizure Variables (DSV) questionnaire to be completed by the guardian, Behavior Assessment System for Children – Parent Rating Scale (BASC-PRS; Reynolds & Kamphaus, 2004), Behavior Assessment System for Children – Self Report of Personality, child form (ASC-SRP-C; Reynolds & Kamphaus, 2004), Health-Related Quality of Life (HRQL; Ronen et al., 2004) – parent form (see Appendix D), and Health-Related Quality of Life (HRQL; Ronen et al., 2004) – child form (see Appendix E). The documents included in the packets for the Children's Hospital in the Midwestern United States were the same as stated for the Southeastern United States site with the following exceptions: instead of an assent form (Appendix B) an assent oral script was utilized (see Appendix F), and in lieu of the parental consent form (Appendix C), an information sheet was provided to guardian participants (see Appendix G). The instruments were presented in counter-balanced order; that is, one half of the packets had the BASC-2 rating scale first, followed by the HRQL scale and the other one half were in reverse order.

Two cover letters were developed; one for the child participant and one for the parent/guardian participant. In age-appropriate language, each cover letter reviewed the purpose and goals of the study, and provided detailed instructions regarding how to

complete the questionnaires and rating scales. The instructions emphasized that all forms should be completed independently, and specific guidelines were provided in the parent/guardian cover letter (and information sheet) regarding assisting their child with completing the forms. For example, the parent/guardian could clarify, as needed, any item for which the child requested clarification; however, the parent/guardian should not influence the child's responses. That is, permission was given to read items from the questionnaires out loud to the child if needed; however, the items were to be read verbatim. Both cover letters explained that all data collected would be confidential and would only be used for research purposes. In the event that participants had any questions or concerns regarding the research study, the cover letters provided the principal investigator's contact information (i.e., telephone number and electronic mail address) so that additional information could be provided to participants as requested.

Finally, the cover letters included a description of an incentive for completing and returning all forms in the packet. All parent-child pairs that completed and returned the assent and consent forms, Demographics and Seizure Variables Questionnaire, and rating scales were eligible to receive a $100 Visa gift card through a random drawing that was completed at the end of the data collection period. The cover letter requested that the parent-child pair review the materials in the packet, and if they chose to partake in the study, to sign the consent and assent forms and include them in the packet to be returned to the office manager in the pediatric neurologist's office.

Information was collected from participants in a pediatric neurologist's office in the Southeastern United States and a pediatric neurology clinic housed in a Children's Hospital in the Midwestern United States. When parent-child pairs arrived for their

regularly scheduled appointments with the pediatric neurologists, they were asked by the office manager if they were willing to participate in a research study that required them (parent and child) to take approximately 40 minutes to fill out several forms related to the child's illness. If they consented, they then were given a packet and were asked to read through the materials. The materials instructed the participants to sign the consent and assent forms and to complete the questionnaire and rating scales in the packet prior to their appointment with the pediatric neurologist. The forms were filled out in the reception area while they were waiting to meet with the pediatric neurologist. After materials were completed independently by the parent and child, they were sealed in a manila envelope by the parent, and the office manager collected and held the completed packets at the pediatric neurologist's office until the principal investigator collected the completed packets. After approximately two months of data collection, an adequate number of participants had not be accessed (i.e., less than 30 completed packets); therefore, a pediatric neurologist practicing within a non-profit Children's Hospital was contacted to obtain access to additional participants. The principal investigator was granted access to recruit patients from this neurologist's practice which generated 47 additional participants for the current study.

All data obtained from participants were kept confidential and were accessible only to the principal investigator. All forms in each packet had identification numbers to match parent and child forms/responses in the event that the pair of parent-child forms became separated. The identification numbers were arbitrarily created by the principal investigator. The identification number for each parent-child pair was printed on the individual forms to ensure anonymity; therefore, no identifying information was collected

from participants. That is, in each packet, both guardian and child instruments had the same code number (e.g., 001). Approximately 50 packets were delivered by the principal investigator to the participating pediatric neurologists' clinic. The office managers at each clinic collected the completed packets and made a notation (e.g., asterisk) in the child's private medical file indicating that they returned the completed packet. At the conclusion of the study, the principal investigator provided the neurologists' office managers each with a $100 Visa gift card, and the office managers randomly selected an individual who had participated in the study to receive the gift card. The office manager selected a name from those marked with a notation in their medical file indicating that they had participated in the study. This procedure allowed all participants to remain anonymous, as the neurologists and office managers were the only persons who were privy to the participants' identities and contact information. All completed packets were stored in a locked file cabinet that was accessible only to the principal investigator. Once all data were collected, the principal investigator conducted statistical analyses, interpreted the results, and presented the findings.

For participants at the Southeastern United States site, any child participants obtaining depression and/or anxiety scores in the "at-risk" or "clinically significant" range on the BASC-2 were notified of their increased risk for psychopathology (i.e., depression and/or anxiety). The participants' code numbers and BASC scores in these elevated ranges were disclosed to the neurologist's office manager within 24 hours of scoring the BASC data. In turn, the office manager contacted the guardian participant to relay this information so the guardian could make an informed decision regarding the attainment of appropriate mental health services for their child. Similarly, all participants

recruited from the Midwestern United States site were provided with an outpatient psychotherapy referral form from the Department of Psychiatry and Psychology at the recruitment site (i.e., children's hospital) in the event that they requested outpatient services.

Research Design

The current study utilized an exploratory, non-experimental research design, also known as a correlational research design. This design was used because the principal investigator was interested in determining the statistical association between two or more variables. This study utilized a survey method to collect quantitative data from participants. Survey methods are typically used to gather large amounts of data about a construct when there is little empirical data available (Bordens & Abbott, 1996). The survey method encompassed a multi-informant approach whereby both self-report and parent-report were utilized to obtain data from multiple viewpoints. Specifically, the child with epilepsy and his or her guardian completed the assessment instruments (i.e., rating scales). This multi-informant approach was utilized because research shows that it is advantageous to collect data from multiple sources. Furthermore, in applied research, the multi-informant approach is characteristic of quality research designs (Holmbeck et al., 1998).

Data Analyses

Descriptive Statistics

Once all questionnaires and rating scales were completed by the participants and returned to the researcher, the data were analyzed. Descriptive statistics included the following: mean, median, standard deviation, and skewness and kurtosis of individual

participants' scores across rating scales and questionnaires. In addition, descriptive statistics were computed for the participants' demographic information. No extreme outliers were discovered in the data. The descriptive statistics are illustrated quantitatively in Table 1.

Variables

Independent variables. The independent variables in this study were symptoms of anxiety and depression (as measured by the BASC-2) and seizure-related variables. The seizure-related variables were type of epilepsy, seizure frequency, and use of antiepileptic drugs (i.e., monotherapy or polytherapy).

Dependent variables. The dependent variables in this study comprised health-related quality of life subscale scores, as measured by the Health-Related Quality of Life (HRQL) questionnaire. The five subscale scores for the self-report measures were social, present, emotional, secrecy, and normalcy factors. For the parent report measure, the five subscales consisted of social, present, future, emotional, and secrecy factors. Each individual subscale ranged from 5 to 20, with higher scores indicating better health-related quality of life.

Inferential Statistics

Canonical correlation analysis. Canonical correlation is a procedure that allows researchers to examine the relationship between two sets of variables (Thompson, 1984). The linear correlation between the two sets of latent (i.e., not directly observed; inferred) variables is maximized with a canonical correlation analysis. Sets of variables are combined to produce a predicted value that has the highest correlation with the predicted value of the other (second) set of variables (Thompson, 1984). That is, canonical

correlation analyses allowed this researcher to determine which combination of seizure-related variables and psychopathology variables best correlate with health-related quality of life variables in children with epilepsy.

More than one linear correlation relating two sets of variables may exist, with each correlation representing a different dimension by which the independent set of variables is related to the dependent set. Specifically, the linear correlation relating the two sets of variables is termed a canonical function and the number of canonical functions that can be generated for a given data set is equal to the number of variables in the smaller of the two variable sets. Because there were five independent variables and five dependent variables in the child data set and the parent data set, the number of possible canonical functions in each set was five.

There are several assumptions for canonical correlation analysis. First, there is the assumption of linearity that posits that the correlation coefficient between any two variables is based on a linear relationship, and the canonical correlation is the linear relationship between the variates. It is unlikely that this assumption can ever be truly confirmed; however, canonical correlation analysis is robust to small deviations from this assumption (Thompson, 1984). Nevertheless, a bivariate scatterplot was used to determine if there is curvature in the relationship between each independent variable and dependent variable. If significant curvature was found, then the corresponding variable would have been transformed.

Second, in canonical correlation analysis, it is assumed that there is multivariate normality, which can be assessed, in part, by ensuring that each variable has univariate normality. That is, if univariate distributions are not normal, the multivariate distribution

is not normal; however, if all univariate distributions are normal, it is still possible that the multivariate distribution is not normal. Nevertheless, canonical correlation can accommodate metric variables without the strict assumption of normality (Osborne & Waters, 2002). Third, the assumption of the absence of multicollinearity indicates that there is no redundancy in the independent variables such that a relationship does not exist between them (Osborne & Waters, 2002). Finally, it is important to note that a significant limitation to canonical correlation analyses is that relationships can be determined, but the underlying causal mechanism cannot be ascertained.

Chapter 4

Results

Treatment of the Data

The data were entered into an Excel spreadsheet by the researcher and verified by a colleague (i.e., a clinical psychology graduate student) following the completion of all forms and questionnaires. Each score was entered for every participant on each individual item. Missing data were coded as a blank space in the Excel document while single items with multiple responses were averaged and the mean score was inputted. The researcher and a clinical psychology graduate student checked the data by randomly selecting participants' identification numbers and matching the data in the database to the entrees completed by hand. Additionally, extreme values were checked across each participant for each item to ensure that data were entered correctly. The final sample size of this study was 51 child-guardian pairs; no cases were removed from the analysis due to extreme outliers or incomplete data. Inter-rater agreement was 100%.

Demographics

After all data were transferred from the Excel spreadsheet into an SPSS data editor file, the data were analyzed. Descriptive statistics were computed for participants' demographic information (see Table 1). All demographic information collected in the current study was obtained through parent self-report measures.

Independent Variables

Among the dichotomous variables, gender was coded as "1" for males and "2" for females. Medical insurance was coded as "1" for private insurance and "2" for Medicaid. Regarding seizure type, generalized seizures were coded as "1" and partial seizures were coded as "2." Child participants with 0 to 5 seizures within the last 12 months were coded as "1" and those with 6 to 12 seizures within the last 12 months were coded as "2." Finally, child participants treated with one AED were coded as "1" and those treated with more than one AED were coded as "2." The continuous variable (i.e., age of child) was measured in years and months.

The mean age of the children participants was 9 years 5 months (*SD* = 1 year 8 months). The youngest child participant was 8 years, 0 months of age whereas the oldest child participant was 11 years, 11 months of age. Regarding gender of the child participants, 29 (56.9 %) were identified as male and 22 (43.1 %) identified as female. Twenty-eight (54.9 %) families identified themselves as White, 11 (21.6 %) identified as African American, 4 (7.8 %) identified as Hispanic, and 8 (15.7 %) identified themselves as mixed race.

Information regarding participants' medical insurance was obtained in an effort to infer the socioeconomic status of families participating in the current study. These data were dummy coded; families with private medical insurance were coded as "1" and families with medical insurance through Medicaid were coded as "2." Based on participants self-report, 18 (35.3 %) families had private medical insurance. The remaining 33 (64.7 %) families reported that they had insurance through Medicaid.

Twenty-one (41.2 %) parent participants reported that their child's seizures were generalized seizures, with 30 (58.8 %) parents reporting that their child experienced partial seizures. Regarding seizure frequency, 28 (54.9 %) parent participants indicated that their child experienced between zero and five seizures within the last 12 calendar months. Twenty-three (45.1 %) parent participants reported that their child had experienced between 6 and 12 seizures within the last 12 calendar months. Finally, 34 (66.7 %) parent participants indicated that their child currently was prescribed a single anti-epileptic medication (i.e., monotherapy) compared with 17 (33.3 %) parent participants who indicated that their child was prescribed multiple anti-epileptic medications (i.e., polytherapy).

Table 2 presents descriptive data for child self-report and parent report on BASC-2 and HRQL measures. Means, standard deviations, skewness, and kurtosis are reported for each individual variable. The BASC-2 generates two interpretive ranges (i.e., at-risk and clinically significant) for composite scales and subscales based on *T* scores obtained using norms. Typically, *T* scores ranging from 60 to 69 on the clinical scales are considered to be in the "at-risk" classification range indicating the potential of developing a problem that requires careful monitoring. *T* scores of 70 and above on the clinical scales are considered to be in the "clinically significant" range. Scale scores in the clinically significant range indicate a high level of maladjustment. Scores below 60 are considered to be in the "normal" range and do not indicate maladjustment.

In the current study, child participants' ratings of anxious symptoms (as measured on the BASC-2) had a mean score of 54.9 (*SD* = 8.8), with scores ranging from 37 to 71. Self-report scores on depressive symptoms (as measured by the BASC-2) had a mean

score of 54.7 (*SD* = 9.1) and a range of 38 to 73. Parent-report of anxious symptoms in the child participant (as measured on the BASC-2) had a mean score of 54.9 (*SD* = 8.8), with scores ranging from 37 to 71. Parent-report scores on depressive symptoms (as measured by the BASC-2) had a mean score of 54.7 (*SD* = 9.1) and a range of 38 to 73.

Dependent Variables

The outcome measures for this study were health-related quality of life (HRQL) rated by child self-report and parent-report. Specifically, there were subscale scores for the following five HRQL measures as rated by self report: (a) social concerns, (b), present concerns, (c) emotional concerns, (d) secrecy issues, and (e) normalcy issues. The scores for each subscale range from 5 to 20, with lower scores indicating more compromised HRQL. Descriptive statistics for the HRQL self-report measure were as follows: self-report of social concerns (as measured on the HRQL) had a mean score of 15.2 (*SD* = 3.38) and a range from 8 to 20. Present concerns had a mean score of 16.1 (*SD* = 3.49) and a range from 9 to 20. Emotional concerns had a mean score of 15.4 (*SD* = 3.60) and a range from 8 to 20. Secrecy issues had a mean score of 15.4 (*SD* = 3.34) and a range from 9 to 20. Finally, normalcy issues had a mean score of 15.7 (*SD* = 3.48) and a range from 9 to 20.

The HRQL parent form had five subscales as well, consisting of (a) social, (b) present, (c) future, (d) emotional, and (e) secrecy. Descriptive statistics for the HRQL parent-report measure were as follows: parent-report of social concerns (as measured on the HRQL) had a mean score of 15.3 (*SD* = 3.99) and a range from 6 to 20. Present concerns had a mean score of 15.5 (*SD* = 3.88) and a range from 7 to 20. Future concerns had a mean score of 15.7 (*SD* = 3.66) and a range from 8 to 20. Emotional concerns had a

mean score of 15.3 (*SD* = 3.89) and a range from 7 to 20. Finally, secrecy had a mean score of 15.3 (*SD* = 4.25) and a range from 6 to 20.

Table 1

Descriptive Statistics for Participants (n = 51)

Variable	(%)
Age	
8.0 – 8.11	23.5
9.0 – 9.11	29.4
10.0 – 10.11	25.5
11.0 – 11.11	21.6
Gender	
Male	56.9
Female	43.1
Race	
White (Non-Hispanic)	54.9
African American	21.6
Hispanic/Latino	7.8
Asian American	0.0
Native American	0.0
Mixed-Race/Other	15.7
Medical Insurance	
Private	35.3
Medicaid	64.7
None	0.0
Seizure Type	
Generalized	41.2
Partial	58.8
Number of Seizures	
0 – 5 per year	54.9
6 – 12 per year	45.1
Anti-epileptic Drugs	
Monotherapy	66.7
Polytherapy	33.3

Table 2

Means, Standard Deviations, Skewness, and Kurtosis for Participant Ratings (n = 51)

Variable	*M*	*SD*	Skewness	Kurtosis
Self-Report				
AnxietyCH	54.9	8.78	-0.33	-0.66
DepressionCH	54.7	9.15	0.24	-0.81
SocialCH	15.2	3.38	-0.51	-0.67
PresentCH	16.1	3.49	-0.52	-1.05
EmotionCH	15.4	3.60	-0.21	-1.33
SecrecyCH	15.4	3.34	-0.27	-1.11
NormalcyCH	15.7	3.48	-0.33	-1.05
Parent-Report				
AnxietyPR	54.9	8.33	0.38	-0.87
DepressionPR	57.5	7.16	0.36	0.35
SocialPR	15.3	3.99	-0.56	-0.70
PresentPR	15.5	3.88	-0.51	-0.94
FuturePR	15.7	3.66	-0.53	-0.79
EmotionPR	15.3	3.89	-0.52	-0.98
SecrecyPR	15.3	4.25	-0.47	-1.12

Anxiety and Seizure Type

Anxious symptoms, as measured by the BASC-2 Child Form, had an overall mean of 56.00 (*SD* = 10.58) for children with generalized seizures and 54.13 (*SD* = 7.37) for children with partial seizures. These scores did not indicate a statistically significant difference in anxiety scores based on type of seizure $F(1, 49) = 0.55$, $p = .461$). The effect size for the difference in mean scores between children with generalized and partial seizures was small for self-report ($d = 0.011$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with generalized and partial seizures (*skewness* = -0.42, -0.49; *kurtosis* = -0.88, -0.73, respectively).

Anxiety and Seizure Frequency

Anxious symptoms, as measured by the BASC-2 Child Form, had an overall mean of 51.68 (*SD* = 8.38) for children with seizures 0 to 5 times in the last 12 months and 58.83 (*SD* = 7.72) for children with 6 to 12 seizures within the last year. The effect size for the difference in mean scores between children with more and less seizures was small for self-report ($d = 0.17$). These scores indicated a statistically significant difference between self-report of anxiety and frequency of seizures, with children with more seizures (5-12 within the last year) indicating increased anxiety symptoms, $F(1, 49) = 9.85$, $p < .01$. The skewness and kurtosis values indicated a fairly normal distribution of scores for children with less frequent seizures (i.e., zero to five seizures in last year) and children with more frequent seizures (i.e., 6 to 12 seizures in last year) (*skewness* = -0.27, -0.45; *kurtosis* = -1.03, -0.40, respectively).

Anxiety and Use of AED

Anxious symptoms, as measured by the BASC-2 Child Form, had an overall mean of 52.09 (*SD* = 7.85) for children treated with monotherapy and 60.53 (*SD* = 7.95) for children treated with polytherapy. These scores indicated a statistically significant difference between self-report of anxiety and treatment with AEDs, with polytherapy indicating increased anxiety symptoms, $F(1, 49) = 12.97$, $p < .001$. The effect size for the difference in mean scores between children treated with monotherapy versus polytherapy was small for self-report ($d = 0.210$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with monotherapy and polytherapy (*skewness* = -.32, -1.13; *kurtosis* = -.61, 1.00, respectively).

Defining Characteristics of BASC-2 Anxiety Scale: Parent Report

Anxiety and Seizure Type

Anxious symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 58.10 (*SD* = 9.34) for children with generalized seizures and 52.67 (*SD* = 6.84) for children with partial seizures. These scores indicated a statistically significant difference between parent-report of anxiety and type of seizure, with parents' indicating increased anxiety symptoms for children with generalized seizures, $F(1, 49) = 5.75$, $p < .020$. The effect size for the difference in mean scores between children with generalized and partial seizures was small for parent report ($d = 0.11$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with generalized and partial seizures (*skewness* = -0.05, 0.34; *kurtosis* = -1.43, -0.50, respectively).

Anxiety and Seizure Frequency

Anxious symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 51.07 (*SD* = 6.57) for children with seizures 0 to 5 times in the last 12 months and 59.57 (*SD* = 7.95) for children with 6 to 12 seizures within the previous year. These scores indicated a statistically significant difference between parent report of anxiety and frequency of seizures, with children with more seizures (5-12 within the last year) indicating increased anxiety symptoms, $F(1, 49) = 17.47$, $p < .001$. The effect size for the difference in mean scores between children with more and less seizures was small for parent report ($d = 0.26$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with less frequent seizures (i.e., zero to five seizures in last year) and children with more frequent seizures (i.e., 6 to 12 seizures in last year) (*skewness* = 0.90, -0.28; *kurtosis* = 0.37, -0.58, respectively).

Anxiety and Use of AEDs

Anxious symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 51.85 (*SD* = 7.21) for children treated with monotherapy and 61.00 (*SD* = 7.08) for children treated with polytherapy. These scores indicated a statistically significant difference between parent report of anxiety and treatment with AEDs, with polytherapy indicating increased anxiety symptoms, $F(1, 49) = 18.45$, $p < .001$. The effect size for the difference in mean scores between children with monotherapy versus polytherapy was small for parent report ($d = 0.27$).The skewness and kurtosis values indicated a fairly normal distribution of scores for children with monotherapy and polytherapy (*skewness* = 0.80, -0.16; *kurtosis* = 0.05, -0.85, respectively). See Table 3 for additional data.

Defining Characteristics of BASC-2 Depression Scale: Child Self-Report

Depression and Seizure Type

Depressive symptoms, as measured by the BASC-2 Child Form, had an overall mean of 56.24 (*SD* = 9.71) for children with generalized seizures and 53.63 (*SD* = 8.74) for children with partial seizures. These scores did not indicate a statistically significant difference in depressive symptoms for children with generalized seizures and partial seizures, $F(1, 49) = 1.00$, $p = .322$. The effect size for the difference in mean scores between children with generalized and partial seizures was small for self-report ($d = 0.02$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with generalized and partial seizures (*skewness* = 0.06, 0.35; *kurtosis* = -0.92, -0.59, respectively).

Depression and Seizure Frequency

Depressive symptoms, as measured by the BASC-2 Child Form, had an overall mean of 50.43 (*SD* = 7.71) for children with seizures 0 to 5 times in the last 12 months and 59.91 (*SD* = 8.10) for children with 6 to 12 seizures within the previous year. These scores indicated a statistically significant difference between self-report of depressive symptoms and frequency of seizures, with children with more seizures (5-12 within the last year) indicating increased depressive symptoms, $F(1, 49) = 18.27$, $p < .001$. The effect size for the difference in mean scores between children with more and less seizures was small for self-report ($d = 0.27$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with less frequent seizures (i.e., zero to five seizures in last year) and children with more frequent seizures (i.e., 6 to 12 seizures in last year) (*skewness* = 0.60, -0.09; *kurtosis* = -0.12, -0.77, respectively).

Depression and Use of AEDs

Depressive symptoms, as measured by the BASC-2 Child Form, had an overall mean of 50.82 (*SD* = 7.49) for children treated with monotherapy and 62.47 (*SD* = 7.05) for children treated with polytherapy. These scores indicated a statistically significant difference between self-report of depressive symptomatology and treatment with AEDs, with polytherapy indicating increased depressive symptoms, $F(1, 49) = 28.48$, $p < .001$. The effect size for the difference in mean scores between children with monotherapy versus polytherapy was medium for self-report ($d = 0.37$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with monotherapy and polytherapy (*skewness* = 0.49, -0.08; *kurtosis* = -0.37, -0.90, respectively).

Defining Characteristics of BASC-2 Depression Scale: Parent Report

Depression and Seizure Type

Depressive symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 58.14 (*SD* = 9.26) for children with generalized seizures and 56.97 (*SD* = 5.35) for children with partial seizures. These scores did not indicate a statistically significant difference between parent-report of depressive symptomatology and type of seizure, with parents' indicating increased depressive symptoms for children with generalized seizures, $F(1, 49) = 0.33$, $p < .569$. The effect size for the difference in mean scores between children with generalized and partial seizures was small for parent report ($d = 0.01$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with generalized and partial seizures (*skewness* = 0.06, 0.75; *kurtosis* = -0.68, 1.91, respectively).

Depression and Seizure Frequency

Depressive symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 54.89 (*SD* = 4.78) for children with seizures 0-5 times in the last 12 months and 60.57 (*SD* = 8.36) for children with 6 to 12 seizures within the previous year. These scores indicated a statistically significant difference between parent report of depressive symptomatology and frequency of seizures, with children with more seizures (5-12 within the last year) having increased depressive symptoms, $F(1, 49) = 9.24$, $p < .004$. The effect size for the difference in mean scores between children with more and less seizures was small for parent report ($d = 0.16$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with less frequent seizures (i.e., zero to five seizures in last year) and children with more frequent seizures (i.e., 6 to 12 seizures in last year) (*skewness* = -0.39, -0.21; *kurtosis* = -0.59, 0.01, respectively).

Depression and Use of AEDs

Depressive symptoms, as measured by the BASC-2 Parent Form, had an overall mean of 56.03 (*SD* = 6.27) for children treated with monotherapy and 60.29 (*SD* = 8.13) for children treated with polytherapy. These scores indicate a statistically significant difference between parent report of depressive symptoms and treatment with AEDs, with polytherapy indicating increased depressive symptomatology, $F(1, 49) = 4.29$, $p < .044$. The effect size for the difference in mean scores between children treated with monotherapy versus polytherapy was small for parent report ($d = 0.08$). The skewness and kurtosis values indicated a fairly normal distribution of scores for children with monotherapy and polytherapy (*skewness* = 0.58, -0.25; *kurtosis* = 0.59, 1.04, respectively). See Table 3 below for additional data.

Table 3

Skewness and Kurtosis Coefficients for BASC-2 (n = 51)

	Child Self-Report		*Parent Report*	
	Anxiety Scale	Depression Scale	Anxiety Scale	Depression Scale
Skewness	-0.33	0.24	0.38	0.36
Std. Error of Skewness	0.33	0.33	0.33	0.33
Kurtosis	-0.66	-0.81	-0.87	0.35
Std. Error of Kurtosis	0.66	0.66	0.66	0.66

Understanding Aspects of Health-Related Quality of Life in the Current Study

Of the 51 child-parent participant pairs, scores derived from the Child Self-Report Form of the BASC-2 Anxiety Scale indicated that 68.6% (n = 35) of the child participants fell in the normal range for anxiety (i.e., $T < 60$), 29.4% (n = 15) of the child participants fell in the borderline range for anxiety (i.e., T = 60-69) and 2.0% (n = 1) fell in the clinically significant range (i.e., T = 70 or higher). On the BASC-2 Depression Scale, 68.6% (n = 35) of child participants had scores in the normal range of functioning, 23.6% (n = 12) of child participants had scores in the borderline range (at-risk) for depression, and 7.8% (n = 4) of child participants had self-reported scores in the clinically significant range for depression.

Based on parent report, the BASC-2 Parent Forms revealed that 68.6% (n = 35) of children obtained scores in the normal range for anxiety, 25.5% (n = 13) of children obtained scores in the borderline range, and 5.9% (n = 3) of children obtained scores in

the clinically significant range for anxiety. Regarding depressive symptomatology, parents' ratings indicated that 70.6% (n = 36) of children were in the normal range of functioning, while 23.5% (n = 12) of children were functioning in the at-risk range for depression, and 5.9% (n = 3) of children were functioning in the clinically significant range for depression. This researcher hoped to discover which seizure-related variables and internalizing symptoms were most predictive of health-related quality of life. The following section will address the research questions for this study as presented in Chapter 1.

Research Findings

Question 1. What seizure-related variables (i.e., type of seizure, seizure frequency, and treatment with AEDs) and psychopathology ("at-risk" or "clinically significant" range for anxiety and/or depression) best predict health-related quality of life as reported by children 8 to 11 years of age diagnosed with epilepsy?

To address this research question, a canonical correlation analysis was computed. However, prior to conducting this analysis, the researcher wanted to ascertain the relationship between each independent and dependent variable in the study. Bivariate correlations (i.e., Pearson's correlations) for all of the variables in the analysis are presented in Table 4. Because 45 correlations were of interest in Table 4, the Bonferroni adjustment had to be applied to ensure that the experiment-wise error rate did not exceed its nominal value of 5%. Thus, the adjusted Bonferroni α level of .0011 (i.e., .05/45) was used. According to the Pearson's product moment correlation analysis, scores indicated a moderately strong, positive relationship between ratings of seizure frequency and children's self-report of anxiety (r = .41) and depression (r = .52). All five subscales on

the HRQL measure had negative and moderately strong relationships with seizure frequency (see Table 4). Treatment with AEDs had a moderate, positive relationship with children's ratings of anxiety (r = .46) and a strong, positive relationship with children's ratings of depression (r = .61). Furthermore, strong, negative relationships were found among all five HRQL subscales and treatment with AEDs. Children's ratings of anxiety were moderately correlated with all five subscales of the HRQL measure, with ratings of depression being very strongly correlated with the five HRQL subscales (see Table 4 for list of all correlation coefficients). It is noteworthy that all five subscales from the HRQL measure were strongly correlated with one and another, with correlation coefficients ranging from r = .72 to .83. Given that a correlational relationship was found between ratings of anxiety and depression, it seemed reasonable to proceed with canonical correlation analyses to determine whether a statistically significant relationship existed between the two certain sets of variables.

Table 4

Pearson's Correlations (Child Self-Report)

	Seiz Type	Seiz Freq	AED	Anx CH	Dep CH	Social CH	Pres CH	Emot CH	Secr CH	Norm CH
Seiz Type	1									
Seiz Freq	-.36*	1								
AED	-.42*	.53*	1							
Anx CH	-.11	.41*	.46*	1						
Dep CH	-.14	.52*	.61*	.66*	1					
Social CH	.20	-.58*	-.69*	-.58*	-.78*	1				
Present CH	.12	-.53*	-.59*	-.63*	-.77*	.83*	1			
Emot CH	.18	-.42*	-.59*	-.63*	-.74*	.76*	.80*	1		
Secr CH	.12	-.46*	-.44*	-.51*	-.76*	.72*	.68*	.82*	1	
Norm CH	.07	-.58*	-.52*	-.67*	-.79*	.83*	.82*	.83*	.79*	1

* Statistically significant at the Bonferroni-adjusted level of .0011 (i.e., .05/45).

Statistical Assumptions for Canonical Correlation Analysis

The statistical assumptions presented and discussed in Chapter 3 were assessed (when feasible) to determine if the specific assumptions pertaining to canonical correlation analysis were met. Univariate normality (i.e., skewness and kurtosis) was obtained for all variables examined in this study. However, one cannot assume that multivariate normality (i.e., multivariate skewness and kurtosis) also was obtained.

Canonical Correlation Analysis (Child Report)

Using canonical correlation analysis, a composite of the quality of life subscales that correlate with a composite of seizure-related variable, anxiety, and depression was derived. Two independent canonical correlation analyses were computed; one utilized data derived via self-report, and the other utilized data obtained via parent-report. The first analysis consisted of five independent variables (i.e., seizure type, seizure frequency, AED treatment, anxious symptoms [via self-report], and depressive symptoms [via self-report]) and five HRQL dependent variables—all of which were derived from child self-report (i.e., social, present, emotion, secrecy, and normalcy). Table 5 presents information about the first canonical function (the only function that was statistically significant). This first function had a canonical correlation coefficient of .94, which indicates that the most variance is attributed to this first pair of linear combinations (statistically significant at $p < .001$). The second function, which had a canonical correlation coefficient of .55, had far less variance associated with it and therefore was not statistically significant using Bartlett's approximate chi-square test ($X^2 = 14.51$, df = 16, $p = .561$).

The standardized function coefficients for the first canonical function also are presented in Table 5. These standardized coefficients indicate the relative contribution of each independent variable to the variance of its respective within-set canonical variable. An examination of the standardized function coefficients revealed that of the five independent variables (i.e., seizure type, seizure frequency, AED treatment, anxious symptoms, and depressive symptoms), only depression (as rated by child participants) made a significant contribution to the dependent variables composite (i.e., social, present, emotion, secrecy, and normalcy).

Additionally, the structure coefficients are presented in Table 5 to provide more information about the relationships across pairs of canonical variates. Structure coefficients are the correlations between a given variable and the scores on the canonical composite (i.e., latent variable) in the set to which the variable belongs. Thus, structure coefficients indicate the degree of relationship of a given variable in the set with the canonical composite for the variable set (Thompson, 1984). Structure coefficients greater than $\pm$0.30 were considered to be practically significant (Hair, Anderson, Tatham, & Black, 1998). The structure coefficients revealed that four of the five independent variables (i.e., seizure frequency, AED treatment, anxious symptoms, and depressive symptoms) made important contributions to the first canonical variate. The size of the structure coefficient indicated that all four of these independent variables made very large contributions, with depression making the largest contribution. With regard to the dependent set, all five variables made large contributions, social making the largest contribution, followed closely by present.

Finally, the cross loadings for the first canonical function are presented in Table 5. The cross loadings are the most stable coefficients for reliable interpretation because they are the product of each variable's canonical loading and the canonical correlation coefficient. Therefore, the cross loadings allow the most accurate/confident interpretation of relationships between independent and dependent variables in each canonical function (Hair et al., 1998). Data generated from the cross loadings indicate that depression contributes the most to the relationship with the dependent variable composite. Additionally, seizure frequency, AED treatment, and anxiety, respectively, make significant contributions on the first canonical function for the set of dependent variables. With respect to the dependent variables set, all five variables made an important contribution to the composite set, with social and present making the most significant contribution, followed closely by normalcy, secrecy, and emotion, respectively.

Table 5

Canonical Correlations (Child Self-Report) for First Canonical Function

Variable	Can *r*	Wilks □	X^2	Df	*P*	Std. Coeff	Struct Coeff	Cross Ldgs
1	.937	.077	80.84	25	.0001			
Independent Variables:								
Seize Type						.11	-.25	-.24
Seize Freq						.24	.84	.79
AED						.16	.76	.72
Anx CH						.02	.75	.71
Dep CH						.70	.98	.92
Dependent Variables:								
Soc CH						-.42	-.97	-.91
Pres CH						-.36	-.95	-.89
Emot CH						.01	-.85	-.80
Secr CH						-.16	-.88	-.83
Norm CH						-.13	-.92	-.86

Can *r* = canonical r
Std. Coeff = standardized function coefficient
Struct Coeff = structure coefficient
Cross Ldgs = cross-loadings

Question 2. What seizure-related variables (i.e., type of seizure, seizure frequency, and treatment with AEDs) and psychopathology ("at-risk" or "clinically significant" range for anxiety and/or depression) best predict health-related quality of life as reported by parents of children 8 to 11 years of age diagnosed with epilepsy?

This research question was addressed by computing a second canonical correlation analysis with data obtained via parent report. Prior to conducting this analysis, bivariate correlations (i.e., Pearson's correlations) were computed for all of the variables in the analysis. These results are presented in Table 6. As previously indicated, because 45 correlations were of interest in Table 4, the Bonferroni adjustment had to be applied to ensure that the experiment-wise error rate did not exceed its nominal value of 5%. Thus, the adjusted Bonferroni α level of .0011 (i.e., .05/45) was used. According to the Pearson's product moment correlation analysis, scores indicated a moderately strong, negative relationship between ratings of seizure type and parent report of anxiety (r =.32). Seizure frequency had a moderately strong, positive relationship with anxiety (r = .51) and depression (r = .40). Additionally, treatment with AEDs had a moderately strong, positive relationship with anxiety (r = .52) and a small correlation with depression (r = .28; significant at the .05 alpha level). Parents' ratings of anxiety were highly correlated with all five subscales of the HRQL measure, with correlations ranging from -0.74 to -0.78. Parent ratings of depression also were highly correlated with the five subscales of the HRQL measure, ranging from -0.58 for social concerns to -0.74 for secrecy issues.

Seizure type had a small, positive correlation with four of the five subscales on the HRQL measure (i.e., social, future, emotion, and secrecy). Seizure frequency had

moderately strong, negative correlations with all five subscales on the HRQL measure. Finally, treatment with AEDs had strong, negative correlations with all five HRQL subscales (see Table 6). It is noteworthy that all five subscales from the HRQL measure were strongly correlated with one and another, with correlation coefficients ranging from r = .83 to .93. Given that a correlational relationship was found among ratings of seizure-related variables, psychopathology, and HRQL, it seemed reasonable to proceed with canonical correlation analyses to determine whether a statistically significant relationship existed among certain sets of variables.

Table 6

Pearson's Correlations (Parent-Report)

	Seiz Type	Seiz Freq	AED	Anx PR	Dep PR	Social PR	Pres PR	Fut PR	Emot PR	Secr PR
Seiz Type	1									
Seiz Freq	-.36*	1								
AED	-.42*	.53*	1							
Anx PR	-.32*	.53*	.52*	1						
Dep PR	-.08	.40*	.28*	.51*	1					
Social PR	.30*	-.53*	-.39*	-.78*	-.58*	1				
Pres PR	.26*	-.60*	-.46*	-.76*	-.73*	.87*	1			
Fut PR	.33*	-.60*	-.53*	-.78*	-.67*	.90*	.93*	1		
Emot PR	.31*	-.53*	-.39*	-.77*	-.69*	.83*	.90*	.88*	1	
Secr PR	.32*	-.52*	-.42*	-.74*	-.74*	.87*	.91*	.91*	.92*	1

* Statistically significant at the Bonferroni-adjusted level of .0011 (i.e., .05/45).

Canonical Correlation Analysis (Parent Report)

Using canonical correlation analysis, a composite of the quality of life subscales that correlate with a composite of seizure-related variables, anxiety, and depression was derived. The second (parent) analysis consisted of five independent variables (i.e., seizure type, seizure frequency, AED treatment, anxious symptoms [via parent report], depressive symptoms [via parent report]) and five HRQL dependent variables; all of which were derived from parent report (i.e., social, present, future, emotion, and secrecy). Table 7 presents information about the first canonical function (the only function that was statistically significant). This first function had a canonical correlation coefficient of .927, which indicated that the most variance was attributed to this first pair of linear combinations (statistically significant at $p < .001$). The second function had a correlation coefficient of .533 had far less variance associated with it and therefore was not statistically significant using Bartlett's approximate chi-square test ($X^2 = 20.26$, df = 16, p = .209).

The standardized function coefficients also are presented in Table 7. The standardized coefficients indicate the relative contribution of each independent variable to the variance of its respective within-set canonical variable. The data suggest that depression ($r = .43$) as rated by parent participants contributes the most to the relationship with the first canonical variable, followed by seizure frequency ($r = .36$) and anxiety ($r = .31$). With respect to the dependent variables set, present and emotion made moderate contributions to the composite set.

Additionally, the structure coefficients are presented in Table 7 to provide more information about the relationships across pairs of canonical variates. Structure

coefficients are the correlations between a given variable and the scores on the canonical composite (i.e., latent variable) in the set to which the variable belongs. Thus, structure coefficients indicate the degree of relationship of a given variable in the set with the canonical composite for the variable set (Thompson, 1984). Structure coefficients greater than ±0.30 were considered to be practically significant (Hair et al., 1998). An examination of the structure coefficients revealed that all five independent variables made significant contributions to the dependent variables composite–with seizure frequency and anxiety making the largest contributions. The structure coefficients revealed that all five independent variables made significant contributions to the first canonical variate—with seizure frequency and anxious symptoms making the largest contributions, and seizure type making the smallest contribution. With regard to the dependent set, all five variables made very large contributions, with present making the largest contribution, followed closely by emotion, future, secrecy, and social, respectively.

Finally, the cross loadings are presented in Table 7. An examination of the cross loadings revealed that seizure frequency (r = .79), anxiety (r = .78), and depression (r = .74) made large contributions to the dependent variables composite, with AED treatment making a moderate contribution to the composite (r = .60). The fifth independent variable, seizure type, made the smallest (although still statistically significant) contribution to the composite (r = -.44). With respect to the dependent variables set, all five variables made significant contributions to the composite set, with present concerns making the largest contribution, followed closely by future, emotion, secrecy, and social, respectively.

Summary of Canonical Correlation Analyses

Results of the canonical correlation analysis examining data derived via child report revealed that four out of five independent variables assessed (i.e., seizure frequency, AED treatment, anxiety, and depression) were significantly correlated with the five HRQL subscales. Specifically, depressive symptomatology provided the largest contribution on the first canonical function for the set of dependent variables. Data derived via parent report indicated that all five independent variables made significant contributions to the dependent variables composite, with seizure frequency, anxiety, and depression making the largest contributions, followed by a moderate contribution of the independent variable, AED treatment, and a relatively smaller contribution of the independent variable, seizure type. The implications of these findings are presented and discussed in the following chapter.

Table 7

Canonical Correlations (Parent-Report) for First Canonical Function

Variable	Can *r*	Wilks □	X^2	Df	*P*	Std. Coeff	Struct Coeff	Cr Ld
1	.927	.074	81.90	25	.0001			
Independent Variables:								
Seize Type						-.10	-.47	-.44
Seize Freq						.36	.85	.79
AED						.07	.65	.60
Anx PR						.31	.84	.78
Dep PR						.43	.80	.74
Dependent Variables:								
Soc PR						.04	-.87	-.81
Pres PR						-.35	-.98	-.91
Future PR						-.26	-.96	-.89
Emot PR						-.33	-.96	-.89
Secrecy PR						-.13	-.96	-.89

Chapter 5

Discussion

Summary of Study

The present study was conducted to explore which seizure-related variables and/or psychopathology variables were most significantly correlated with health-related quality of life (HRQL) in children with epilepsy. This study was novel in nature because it was one of only several studies to explore the relationship of anxiety and depression on HRQL in children with epilepsy. Findings suggested that anxiety and depression were statistically significantly correlated with HRQL for both self-report and parent report measures. Moreover, several seizure-related variables were found to correlate with the social and present concerns subscales on HRQL. That is, on self-report measures, both seizure frequency and number of antiepileptic drugs (AEDs) were correlated with HRQL. For parent report measures, seizure type, frequency, and number of AEDs were correlated with HRQL. However, it is important to note that although statistical significance was found, it is questionable whether these findings were clinically significant. That is, the majority of scores generated from child- and parent-ratings fell in the sub-clinical range of functioning for anxiety and depression as measured on the BASC-2. This chapter summarizes the results from Chapter 4, discusses implications of the results, examines limitations, and suggests directions for future research.

Relationship between Seizure-Related Variables and Health-Related Quality of Life

Seizure Frequency and Health-Related Quality of Life

Seizure frequency, as rated by both child- and parent-report, was found to be correlated with all five subscales on the HRQL measure. These findings indicate that children who have more frequent seizures (between 6 and 12 per year) are more likely to experience a lowered HRQL, especially associated with present concerns (i.e., current worries) and social concerns. The social subscale of the HRQL assesses interpersonal issues such as children's interactions with peers, their perceptions of friendships, and experiences of bullying behavior.

The reduced HRQL scores could be related, in part, to the social stigma of epilepsy that has been well documented in the literature (Baker, 2001). The social stigma associated with epilepsy and seizures may stem from the unpredictability of behavior evident in individuals who experience seizures. Although the effect of race on health-related quality of life (HRQL) was not a focus of the current research, a significant percentage of minority children and parents participated in this study, and the potential impact of race on HRQL should not be overlooked. In fact, Nei Wu et al. (2008) found that ethnic minority groups may face a double stigma (i.e., minority status and neurological condition) or a triple stigma (with the addition of mental health concerns). Minority groups may be more impacted by social concerns and/or negative social interactions; therefore, these groups may be less likely to seek mental health services. Given that epilepsy has historically been stigmatized, it is not surprising that adding psychopathology/mental health difficulties exacerbate the perceived stigma for

individuals who experience seizures. This may be an important variable to examine in future research studies that assess HRQL in the pediatric epilepsy population.

Health-related locus of control (HLC) is defined as the degree to which individuals' believe that their health is controlled by internal or external factors (Lau, 1982). In other words, HLC measures the degree to which an individual believes that his/her health is or is not determined by his/her own behavior. HLC may play a significant factor in children's present concerns regarding their epilepsy condition. For example, an individual with epilepsy typically has a poor sense of an internal locus of control and a strong awareness of an external locus of control (Asadi-Pooya, Schilling, & Glosser et al., 2007). This is especially true for individuals with epilepsy because of the unpredictability of when their seizures will occur. This unpredictability may lead individuals with epilepsy to experience an increase in feelings of helplessness and hopelessness, both with their cognitive and behavioral functioning.

Given the lack of control over their seizure occurrence and the subsequent externally-based locus of control, children with epilepsy would benefit from increasing their self-efficacy as well as self-reliance in an attempt to decrease their dependence on others (e.g., parents, clinicians) as experts. One method to increase the self-efficacy of children with epilepsy would be to educate children about their condition. Children should be knowledgeable about their medical condition, including the symptoms, treatment options, and likely prognosis related to their seizure disorder. Education should be used as a first line of defense to increase children's understanding of their condition. Additionally, as is developmentally-appropriate, children should play an active role in

their medical care because their involvement will likely lead to increased feelings of empowerment.

Treatment with AEDs and Health-Related Quality of Life

Results from the current study also supported previous findings that number of AEDs and HRQL are correlated (Cushner-Weinstein et al., 2008; Herranz, Armijo, & Artega, 1988). To analyze the relationship between child depression and anti-epileptic drug treatment, Cushner-Weinstein and colleagues found a significant correlation between rates of depression (specifically, interpersonal problems) and polytherapy. Furthermore, these researchers found that children on polytherapy had scores indicating significant difficulties with interpersonal relationships, feelings of ineffectiveness, and negative self-esteem compared to scores of children on monotherapy. The current findings substantiate the relationship between number of AEDs and HRQL, indicating that increased numbers of AEDs are correlated with poorer quality of life. These findings highlight the importance of prescribing the least number of AEDs possible that successfully control seizure activity.

Seizure Type and Health-Related Quality of Life

Type of seizure was found to be correlated with HRQL based on the parent ratings of children with seizure disorders, whereas children's self-report on the HRQL subscales did not reveal a significant relationship with seizure type. It is important to note, however, that the correlation between parent ratings of HRQL and seizure type was small. Differing perceptions of parents and children is the most likely explanation for this finding. That is, the perceptions, concerns, and worries of parents are likely quite disparate from those of children (Eiser & Morse, 2001). Previous research has revealed

mixed findings regarding the effect of seizure type on the quality of life of individuals with epilepsy, with some researchers finding a significant correlation between type of seizure and HRQL (e.g., Baker, Gagnon, & McNulty, 1998) and other researchers failing to find a significant relationship (e.g., Jacoby, Baker, Steen, Potts, & Chadwick, 1996). Given the inconsistent findings regarding the relationship between these two variables, future researchers should attempt to ascertain the effect of seizure type on the health-related quality of life of children with epilepsy.

Relationship between Psychopathology, Seizure-related Variables, and HRQL

Findings from the current study indicate that a statistically significant relationship exists among anxious symptomatology, seizure frequency, and HRQL (both parent and self-reported). It has been presumed that individuals' level of anxiety would be directly related to the number of seizures they experience, with a positive correlation between seizure frequency and anxiety. Therefore, it was expected that individuals with more frequent seizures would report increased anxious symptomatology, and those with both frequent seizures and increased anxiety would, in turn, be correlated with a lowered health-related quality of life. However, researchers are now hypothesizing that it may not be the actual number of seizures that predicts level of anxiety; instead, it may be the individual's *perceived* level of control that is correlated with anxiety (Pedroso de Souza & Salgado, 2006). That is, researchers have found that it is the *perception* with which individuals regard their seizure disorder that dictates their quality of life; this perception has a larger impact on HRQL than seizure-related variables such as type of seizure, seizure frequency, age of onset, and disease duration (Meador, 1993).

Depression, as rated by self- and parent-report, was found to be significantly correlated with lowered HRQL in the current study. This result was not surprising given the previous research that revealed increased rates of depression in the adult literature (Robertson & Trimble, 1983). It is important for clinicians to recognize that children may manifest symptoms of depression differently than adults. For example, children tend to present with disruptive behaviors and/or irritability (Carlson & Cantwell, 1980; Ettinger et al., 1998). These symptoms may not be readily identified as symptoms of depression, making the identification of depression in children rather challenging. This reality highlights the need for practitioners to inquire directly about and assess specific depressive symptomatology.

Previous studies have found large percentages of adult patients with both unrecognized and untreated psychopathology; namely depression (Boylan et al., 2004; O'Donoghue et al., 1999). The few studies examining rates of depression in children with epilepsy reveal similar results (Ettinger et al., 1998). Given that the current study, along with previous studies, indicate that depression has a significant negative effect on health-related quality of life in individuals with epilepsy, it is important to consider patients' psychosocial functioning in addition to the standard seizure-related variables in order to provide comprehensive care to this population.

Limitations of the Study

Internal and External Validity

It is important to establish internal and external validity in a well-designed and effectively implemented study. However, the results of the current study have several possible threats to both internal and external validity. One possible threat to internal

validity of the findings is instrumentation (Onwuegbuzie, 2003); that is, because the instruments for this study are designed to obtain information from participants via self-report, the researcher will not be able to ascertain with complete confidence the accuracy of the data collected. In addition, given that the data being requested are sensitive in nature (and have potential negative connotations), there is an increased likelihood that participants would minimize psychopathological symptomatology. Furthermore, there exists the possibility of a threat to construct-related validity (Onwuegbuzie, 2003) because items on the questionnaire and/or rating scales may be unclear or confusing to some participants. However, the score reliability of each scale and subscale on each measure has been previously validated.

Differential selection of participants, also known as selection bias, may be a threat to the internal validity of the findings. That is, there may be a notable distinction between participants who completed and returned the questionnaires and rating scales and those who did not complete and return these forms (Best & Kahn, 2003). In addition, there may be a threat to historical validity, such that external events may impact the participants' responses (Best & Kahn, 2003).

Several potential threats to external validity of the results of this study exist as well. One possible threat to external validity is population validity (Best & Kahn, 2003), whereby results are generalized to populations that are not included in the study, such as children with medical conditions other than epilepsy or children with co-morbid medical conditions. Another threat to external validity is ecological validity. This refers to the extent to which findings can be generalized across settings, conditions, and contexts (Onwuegbuzie, 2003). To control for the threat to ecological validity, the results of this

study will not be generalized to children diagnosed with epilepsy who do not also meet all inclusion criteria from this study. Temporal validity also may be a threat to external validity in this study. This refers to the extent that results from a study are applicable across time. Therefore, it is important to consider the function of time during the period of data collection for the study (Onwuegbuzie, 2003).

Sample Size

The sample size was minimally acceptable, and the principal investigator would have preferred to obtain a larger number of participants. However, the researcher had a rather small pool from which to draw the sample given the specific inclusion and exclusion criterion. Thus, with the small sample size, the ideal statistical procedures were not carried out because statistical significance may not have been ascertained. Given the smaller sample size obtained in this study, results should be interpreted with some caution as a larger sample size may have generated disparate results.

It also is important to note the potential positive effects of medication on ratings of anxiety and depression. Research findings have revealed that anti-epileptic drugs (AEDs) used to manage seizures may have an effect on mood, with AEDs improving mood in children and adults with epilepsy (Messenheimer, 2002; Uvebrant & Bauzien. 1994). Therefore, given that all participants in this research study used AEDs to manage seizures and AEDs may improve mood, these results may partially explain why the majority of self- and parent-reporters rated their levels of anxiety and depression in the sub-clinical range of functioning (i.e., 68.6% to 70.6% of the sample received scores in the normal range).

Contributions of the Study

Although there is a dearth of research in the area of pediatric epilepsy and psychopathology, the research that has been conducted has documented a statistically significant relationship between epilepsy and psychopathology, specifically depression and anxiety (Caplan, Siddarth, & Gurbani, 2005). The current study contributes to the sparse literature in this area of pediatric research, by providing valuable information about the relationship among seizure-related variables, anxiety, depression, and health-related quality of life in children diagnosed with epilepsy.

It has been well established in the literature that health-related problems negatively impact children's academic performance; therefore, the importance of addressing chronic health needs of children in schools is apparent (e.g., Power, Shapiro, & DuPaul, 2003). School psychologists are in the position to make large contributions to the health promotion of children in schools and ensure that both educational and health needs are appropriately addressed and successfully met. School psychologists should facilitate the coordination of educational, health, and mental health services for children with medical conditions (Power & Blom-Hoffman, 2004). Additionally, school psychologists should play a role in the provision of additional supports and services provided through IDEA and/or a Section 504 Accommodation Plan.

Results from this study will hopefully highlight the importance of identifying, diagnosing, and treating children with epilepsy who have co-morbid psychopathology and poor health-related quality of life so that they may have the best possible educational and psychosocial outcomes. The Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) views pediatric health care through the view of a biopsychosocial

lens. That is, children and their families function in a multitude of complex systems, and when a child is affected with a chronic health condition the normal course of development is interrupted. The PPHM has three levels of prevention and intervention: universal, targeted, and clinical/treatment. The universal level represents the largest group of children and families entering the health care system in which children and families are distressed yet remain resilient. At the universal level it is assumed that the individuals are functioning normally and have adequate coping strategies; therefore, at this level general information and support is provided. A smaller number of children and families require support and services at the second (Targeted) level. At this level, children and families are experiencing acute distress and risk factors are identified; therefore, support and services tailored to the family's specific needs are provided and distress is closely monitored. The third level (Clinical/Treatment) is reserved for children and families who are at-risk for persistent distress and for whom significant risk factors are identified. At this level, anxiety, depression, and other psychosocial difficulties may become apparent; therefore, these children and families receive the most intensive support and treatment.

Given that other three-tiered models have been effectively introduced and implemented in the public school system (e.g., Response to Intervention), the PPPHM also could be successfully implemented in the school setting with psychologists and other mental health specialists playing important roles in the provision of services to students and their families. An effectual start may be to incorporate training for both psychologists and physicians regarding epilepsy and co-morbid psychopathology and its impact on HRQL. Physicians must work collaboratively with psychologists to address the medical

aspects and the psychosocial aspects of seizure disorders in children. Additionally, the importance of early, routine screenings to assess anxious and depressive symptomatology in children with seizure disorders should be emphasized. This effort could involve the combination of didactic training as well as supervisors and chief residents modeling best practices with the use of routine, early screenings for anxiety, depression, and health-related quality of life for all children diagnosed with epilepsy. Additionally, it is imperative that information regarding the medical and psychosocial aspects of epilepsy is communicated to parents so that they are well-informed, empowered, and able to advocate most effectively for their children.

While interventions historically have focused on the medical management of seizure disorders, findings from this study underscore the importance of treating anxiety and depression in children with epilepsy. Additionally, it is the hope of this researcher that children with epilepsy and their families will be informed of available preventative and early intervention services to address both the medical and psychosocial aspects of epilepsy. To provide a high quality level of care, practitioners need to incorporate prevention and intervention services that address children's psychosocial functioning rather than focusing solely on the medical management of their seizures. These services may help enable children to lead a life with minimal psychosocial difficulties stemming from epilepsy and improve their overall quality of life.

Future Research

Previous researchers have discovered that behavioral problems in children with epilepsy is a better predictor of parental depression than is the severity of the children's seizure condition (Shore, Austin, Huster, & Dunn, 2001). In light of these findings,

important data would be gleaned by investigating rates of depression in the parents of children with epilepsy as well as parental coping skills. It would be advantageous for future researchers to glean information regarding the relationship between parental psychosocial functioning and the overall functioning of their children.

Another important area that has not been explored by researchers is what strategies children with epilepsy use to define their personal and social reality and how to implement strategies that would increase their sense of personal control (Attarian, Vahle, & Carter, Hykes, & Gilliam 2003). That is, children with epilepsy would benefit from psychosocial interventions that would empower them and provide them with a stronger sense of support from their communities. Future studies must address the mechanisms that lead children to feel unsupported by their peers and community as well as what strategies could be implemented to build social support. Psychologists in education and medical settings are in the ideal position to provide both psycho-education and psychosocial support to children with epilepsy within the various systems in which they function.

Additionally, invaluable information could be gleaned regarding resilient factors that may protect children with epilepsy from psychopathology such as anxiety and depression. Future studies would benefit from examining resiliency in children and families inflicted with epilepsy to determine what factors help children become resilient. Moreover, information about resiliency in children with epilepsy could be incorporated in early intervention services to decrease the probability that children with epilepsy will develop co-morbid psychopathology and lowered health-related quality of life.

It is hoped that this study has laid the groundwork for subsequent studies to explore further the role of psychopathology (especially anxiety and depression) on health-related quality of life in children with epilepsy. A future research path that would greatly augment the current research in this area would be to utilize a mixed methods research design, incorporating both quantitative and qualitative components. Furthermore, it may be beneficial to complete a qualitative research study prior to a quantitative study design with children diagnosed with seizure disorders. The above-mentioned research components would enable researchers to understand better how children with epilepsy conceptualize internalizing disorders such as anxiety and depression. Although researchers have developed measures to assess HRQL for specific pediatric populations, children may conceptualize HRQL differently. Therefore, studies that include qualitative components such as focus groups may be better aligned with children's own perceptions. Additionally, it is important that future researchers explore the relationship between parents' and children's ratings of psychopathology and HRQL. Adding a qualitative component, such as focus groups, would provide invaluable information about the similarities and differences between parent and child perceptions of epilepsy and its impact on psychosocial functioning and overall quality of life.

Furthermore, future researchers may want to investigate additional variables that were not examined in this study. For example, it may be advantageous to determine which factors contribute to increased perceived control in children with epilepsy. It is critical to examine outcome variables in addition to health-related quality of life because it is likely that seizure disorders (especially with co-morbid anxiety and depression) have a broad impact on children's functioning. For example, it would be beneficial to

understand the relationship between psychopathology and academic performance in children with seizures. This study could be replicated with additional variables to assess the relationship among psychopathology, academic functioning, and HRQL. These data would allow for more comprehensive interventions to alleviate negative emotions, cognitions, and behaviors as well as address variables that impact the educational success of children with epilepsy.

Future researchers also may benefit from including a larger age range of participants, perhaps including adolescents to examine risk and resilience factors specific to an adolescent population. The inclusion of older children/adolescents also may provide greater insight regarding the effect of seizure-related variables and psychopathology on HRQL as younger children are likely less introspective and may have more difficulty identifying anxious and depressive symptomatology and the effect on their HRQL. Finally, another relationship that should be teased out is the correlation between the socio-economic status of families and the presence of psychopathology and/or lowered health-related quality of life in children with epilepsy. Determining the relationship between SES and children's psychosocial functioning may provide valuable information for the development of interventions and support services for children with epilepsy.

Final Thoughts

Psychopathology and poor health-related quality of life is a significant concern for children with epilepsy and their families. Given that children who manifest symptoms of anxiety and depression have significantly lowered HRQL, it is apparent that psychopathology has implications for the mental health of children with epilepsy. This study was one of only several to examine internalizing disorders and HRQL in children

with epilepsy. It was hypothesized that significant correlations would be found between specific seizure-related variables, anxiety, depression, and the outcome variable (HRQL). It is imperative that clinicians and researchers alike utilize existing research findings to develop prevention and intervention programs for children at greatest risk for poor HRQL.

The overall quality of life of children with epilepsy should be a primary focus of their treatment. It is hoped that findings generated from this study serve to be an impetus to developing interventions that will improve their quality of life. Given the importance of early identification and intervention for children with co-morbid epilepsy and psychopathology, it is critical that professionals who are in the position to identify these children obtain the knowledge and resources necessary to provide children with the supports and services needed as early as possible after seizure diagnosis. Practitioners working with children and families impacted by epilepsy have the privileged opportunity to identify and ameliorate the numerous challenges this population endures.

Although research findings reveal that as many as 33% of children with epilepsy have co-morbid psychopathology (Caplan et al., 2005), it is also evident in the literature that the majority of children with psychopathology do not receive appropriate mental health services. If the relationship among seizure-related variables, internalizing disorders, and health-related quality of life is ascertained, then children with epilepsy who are at-risk for poorest HRQL may be identified early and receive mental health services as appropriate. It is quite clear that changes in treatment must occur so that children with epilepsy may receive adequate medical and psychological services.

References

Achenback, T. M. (2000). Child Behavior Checklist. *In: Encyclopedia of psychology*, *Vol. 2.* Kazdin, Alan E.; Washington, DC, US: American Psychological Association, 69-70.

Aldenkamp, A. P., Overweg-Plandsoen, W. C., & Arends, J. (1999). An open, nonrandomized clinical comparative study evaluating the effect of epilepsy on learning. *Journal of Child Neurology, 14,* 795-800.

Annegers, J. F., Hauser, W. A., & Elveback, L. R. (1979). Remission of seizures and relapse in patients with epilepsy. *Epilepsia, 20,* 729-737.

Arunkumar, G., Wyllie, E., Kotagal, P., Ong, H. T., & Gilliam, F. (2000) Parent and patient-validated content for pediatric epilepsy quality-of-life assessment. *Epilepsia, 41,* 1474-1484.

Asadi-Pooya, A. A., Schilling, C. A., Glosser, D., Tracy, J. I., & Sperling, M. R. (2007). Health locus of control in patients with epilepsy and its relationship to anxiety, depression, and seizure control. *Epilepsy & Behavior, 11,* 347-350.

Attarian, H., Vahle, V., Carter, J., Hykes, E., & Gilliam, F. (2003). Relationship of depression & intractability of seizures. *Epilepsy & Behavior, 4,* 298-301.

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

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

Austin, J. K., Smith, M. S., Risinger, M. W., & McNelis, A. M. (1994). Childhood epilepsy and asthma: Comparison of qualitFy of life. *Epilepsia, 35,* 608-615.

Baker, G. A. (2001). Assessment of quality of life in people with epilepsy: Some practical implications. *Epilepsia, 42*(3), 66-69.

Baker, G. A., Gagnon, D., & McNulty, P. (1998). The relationship between seizure frequency, seizure type and quality of life: Findings from three European countries. *Epilepsy Research, 30,* 231-240.

Baker, G. A., Spector, S., McGrath, Y., & Soteriou, H. (2005). Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior, 6*, 556-562.

Bannon, M. J., & Ross, E. M. (1998). Administration of medicines in school: Who is responsible? *British Medical Journal, 316,* 1591-1593.

Bastiaansen, D., Koot, H. M., & Ferdinand, R. F. (2005). Psychopathology in children: Improvement of quality of life without psychiatric symptom reduction? *European Child & Adolescent Psychiatry, 14,* 364-370.

Bastiaansen, D., Koot, H. M., Ferdinand, R. F., & Verhulst, F. C. (2004). Quality of life in children with psychiatric disorders: Self-, parent, and clinician report. *Journal of the American Academy of Child & Adolescent Psychiatry, 43,* 221-230.

Berg, A. T., Shinnar, S., Levy, S. R., Testa, F. M., Smith-Rapaport, S., Beckerman, B., & Ebrahimi, N. (2001). Defining early seizure outcomes in pediatric epilepsy: The good, the bad and the in-between. *Epilepsy Research, 43*, 75–84.

Besag, F. M. (1995). Myoclonus and infantile spasms. In M. M. Robertson & V. Eapen (Ed.), *Movement and allied disorders in childhood* (pp. 149-175). Oxford, England: John Wiley & Sons.

Best, J. W., & Kahn, J. V. (2003). *Research in education*. Boston: Pearson Education.

Bethell, C. D., Read, D., Stein, R., Blumberg, S. J., Wells, N., & Newacheck, P. W. (2002). Identifying children with special health needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics, 2,* 38–48.

Black, K. C., & Hynd, G. W. (1995). Epilepsy in the school aged child: Cognitive-behavioral characteristics and effects on academic performance. *School Psychology Quarterly*, *10,* 345-358.

Blom, S., Heijbel, J., & Bergfors, P. G. (1978). Incidence of epilepsy in children: A follow-up study three years after the first seizure. *Epilepsia*, *19,* 343-350.

Bordens, K. S., & Abbott, B. B. (1996). *Research design and methods: A process approach* (3rd ed.). Mountain View, CA: Mayfield.

Bourgeois, B. F. (1998). Temporal lobe epilepsy in infants and children. *Brain & Development, 20,* 135-141.

Boylan, L. S., Flint, L. A., Labovitz, D. L., Jackson, S. C., Starnter, K., & Devinksy, O. (2004). Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. *Neurology, 62,* 258-261.

Brady, E. U., & Kendall, P. C. (1992). Comorbidity of anxiety and depression in children and adolescents. *Psychological Bulletin, 111,* 244-255.

Calaminus, G., Weinspach, S., Teske, C., & Gobel, U. (2000). Quality of life in children and adolescents with cancer. First results of an evaluation of 49 patients with the PEDQOL questionnaire. *Klinische Padiatrie, 212*, 211–215.

Camfield, C. S., Camfield, P. R., Gordon, K., Wirrell, E., & Dooley, J. M. (1996). Incidence of epilepsy in childhood and adolescence: A population-based study in Nova Scotia from 1977 to 1985. *Epilepsia, 37,* 19–23.

Caplan, R., Siddarth, P., & Gurbani, S. (2005). Depression and Anxiety Disorders in Pediatric Epilepsy. *Epilepsia, 46,* 720-730.

Caplan, R., Siddarth, P., Gurbani, S., Ott, D., Sankar, R., & Shields, W. D. (2004). Psychopathology and Pediatric Complex Partial Seizures: Seizure-related, Cognitive, and Linguistic Variables. *Epilepsia, 45,* 1273-1281.

Carlson, G., & Cantwell, D. (1980). Unmasking masked depression in children and adolescents. *American Journal of Psychiatry, 137,* 445-449.

Carpay, H. A., & Arts, W. F. (1996). Outcome assessment in epilepsy: Available rating scales for adults and methodological issues pertaining to the development of scales for childhood epilepsy. *Epilepsy Research, 24,* 127-136.

Chadwick, D. (1994). Epilepsy. *Journal of Neurology, Neurosurgery & Psychiatry*, *57,* 264-277.

Collaborative Group for Epidemiology of Epilepsy. (1986). Adverse reactions to antiepileptic drugs: A multi-center survey of clinical practice. *Epilepsia, 27,* 323-330.

Cowan, L. D. (2002). The epidemiology of the epilepsies in children. *Mental Retardation and Developmental Disabilities Research Reviews, 8,* 171–181.

Cramer, J. A., Blum, D., & Reed, M. (2003). The influence of comorbid depression on seizure severity. The Epilepsy Impact Project Group; *Epilepsia, 44,* 1578-1584.

Cramer, J. A., Westbrook, L. E., Devinsky, O., Perrine, K., Glassman, M. B., & Camfield, C. (1999). Development of the Quality of Life in Epilepsy Inventory for Adolescents: The QOLIE-AD-48, Epilepsia, 40 1114-1121.

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

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

Davidoff, A. J. (2004). Identifying children with special health care needs in the National Health Interview Survey: A new resource for policy analysis. *Health Services Research, 39,* 53-72.

Devinsky, O. (2003). Psychiatric comorbidity in patients with epilepsy: Implications for diagnosis and treatment. *Epilepsy & Behavior, 4*, S2-S10.

Devinsky, O., Westbrook, L., Cramer, J., Glassman, M., Perrine, K., & Camfield, C. (1999). Risk factors for poor health-related quality of life in adolescents with epilepsy. *Epilepsia*, *40,* 1715-1720.

Doyle, A., Ostrander, R., & Skare, S. (1997). Convergent and criterion-related validity of the Behavior Assessment System for Children-Parent Rating Scale. *Journal of Clinical Child Psychology, 26,* 276-284.

Duchowny, M. (1993). Febrile seizures in childhood. In E. Wyllie (Ed.) The treatment of epilepsy: Principles and practice. (pp. 647-653). Philadelphia: Lea & Febiger.

Duchowny, M., & Harvey, A. S. (1996). Pediatric epilepsy syndromes: An update and critical review. *Epilepsia,* 37(S1), S26-40.

DuLac, O., MacDonald, R. L., & Kelly, K. M. (1995). *Age-specific antiepileptic drug treatment and development of age-specific antiepileptic drugs. Brain development and epilepsy.* New York: Oxford University.

Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 10,* 347-357.

Eriksson, K. J., & Koivikko, M. J. (1997). Status epilepticus in children: Aetiology, treatment, and outcome. *Developmental Medicine & Child Neurology, 39,* 652-658.

Ettinger, A. B., Weisbrot, D. M., Nolan, E. E., Gadow, K. D., Vitale, S. A., Andriola, M. R., & Lenn, N. J. (1998). Symptoms of depression and anxiety in pediatric epilepsy patients. *Epilepsia, 39,* 595-599.

Fiordelli, E., Beghi, E., Bogliun, G., & Crespi, V. (1993). Epilepsy and psychiatric disturbance. A cross-sectional study. *The British Journal of Psychiatry, 163,* 446-50.

First Seizure Trial Group. (1993). Randomized clinical trial on the efficacy of antiepileptic drugs in reducing the risk of relapse after a first unprovoked tonic-clonic seizure. *Neurology, 43,* 478-483.

Flanagan, R., & Esquivel, G. B. (2006). Empirical and clinical methods in the assessment of personality and psychopathology: An integrative approach for training. *Psychology in the Schools, 43,* 513-526.

Gilliam, F., Wyllie, E., Kashden, J., Faught, E., Kotagal, P. et al. (1997). Epilepsy surgery outcome: Comprehensive assessment in children. *Neurology, 48*, 1368-1374.

Hair, J. F., Anderson, R. E., Tatham, R. L., & Black, W. C. (1998). *Multivariate Data Analysis, 5th edition.* Prentice Hall, Inc.

Hart, R. G., & Easton, J. D. (1986). Seizure recurrence after a first, unprovoked seizure. *Archives of Neurology*, *43,* 1289-1290.

Hauser, W. A. (1986). Should people be treated after a first seizure? *Archives of Neurology*, *43,* 1287-1288.

Hauser, W. A., Annegers, J. F., Rocca, W. A. (1996). Descriptive epidemiology of epilepsy: contributions of population-based studies from Rochester, Minnesota. *Mayo Clinic Proceedings, 71,* 576-586.

Hauser, W. A., Anderson, V. E., Loewenson, R. B., et al. (1982). Seizure recurrence after a first unprovoked seizure. *New England Journal of Medicine*, *307,* 522-528.

Hauser, W. A., Rich, S. S., Annegers, J. F., et al. (1990). Seizure recurrence after a 1st unprovoked seizure: An extended follow-up. *Neurology*, *40,* 1163-1170.

Heller, K. W., Alberto, P. A., & Forney, P. E. (1996). *Understanding physical, sensory, and health impairments: Characteristics and educational implications.* Belmont, CA, US: Thomson Brooks/Cole Publishing Co.

Hermann, B. P., Seidenberg, M., & Bell, B. (2000). Psychiatric comorbidity in chronic epilepsy: Identification, consequences, and treatment of major depression. *Epilepsia*, 41(Sl), S31–41.

Herranz, J. L., Armijo, J. A., & Artega, R. (1988). Clinical side effects of Phenobarbital, pirimidone phenytoin, carbamazepine and valproate during montherapy in children. *Epilepsia, 29,* 794-804.

Hiemenz, J. R., Hynd, G. W., & Jimenez, M. (1999). Seizure disorders. In R. T. Brown (Ed.), *Cognitive aspects of chronic illness in children* (pp. 238-261). New York: Guilford.

Hofstra, M. B., Van der Ende, J., & Verhulst, F. C. (2000). Continuity and change of psychopathology from childhood into adulthood: A 14-year follow-up study. *Journal of the American Academy of Child & Adolescent Psychiatry, 39,* 850-858.

Holmbeck, G. N., Belvedere, M. C., Christiansen, M., Czerwinski, A. M., Hommeyer, J. S., et al. (1998). Assessment of adherence with multiple informants in pre-adolescents with spina bifida: Initial development of a multidimensional, multitask parent-report questionnaire. *Journal of Personality Assessment, 70,* 427–440.

Hopkins, A., Garman, A., & Clark, C. (1988). The first seizure in adult life: Value of clinical features, electroencephalography, and computerized topographic scanning in prediction of seizure recurrence. *The Lancet*, 1(8588), 721-726.

Ho-Turner, M., & Bennett, T. L. (1999). Seizure disorders. In S. Goldstein & C. R. Reynolds (Eds.), *Handbook of neurodevelopmental and genetic disorders* (pp. 499-524) New York: Guilford Press.

Howe, G. W., Feinstein, C., & Reiss, D. (1993). Adolescent adjustment to chronic physical disorders: I. Comparing neurological and non-neurological conditions. *Journal of Child Psychology and Psychiatry, 34,* 1153-1171.

Huberty, T. J., Austin, J. K., & Huster, G. A. (2000). Relations of change in condition severity and school self-concept to change in achievement-related behavior in children with asthma or epilepsy. *Journal of School Psychology, 38,* 259-276.

Hulihan, J. F. (1997). Seizures in special populations: Children, the elderly, and patients with coexistent medical illness. *Postgraduate Medicine, 102,* 165-168, 171-172, 175-176.

Jackson, M. J., & Turkington, D. (2005). Depression and anxiety in epilepsy. *Journal of Neurology, Neurosurgery and Psychiatry, 76,* 45-47.

Jacoby, A., Baker, G., Steen, N., Potts, P., & Chadwick, D. (1996). The clinical course of epilepsy and its psychosocial correlates: Findings from a UK community study. *Epilepsia, 37,* 148-161.

Kaiser, S., Selai, C. E., & Trimble, M. R. (2002). Long-term follow-up of topiramate and lamotrigine: A perspective on quality of life. *Seizure, 11,* 356-360.

Kamphaus, R. W., & Frick, P. J. (1996). *Clinical assessment of child and adolescent personality and behavior.* Needham Heights, MA, US: Allyn & Bacon.

Kanner, A. M., & Palac, S. (2000). Depression in epilepsy: A common but often unrecognized cormorbid malady. *Epilepsy & Behavior, 1,* 37-51.

Kazak, A. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice and collaboration in pediatric family systems medicine. *Families, Systems and Health, 24,* 381-395.

Ketter, T. A., Post, R. M., & Theodore, W. H. (1999). Positive and negative psychiatric effects of antiepileptic drugs in patients with seizure disorders. *Neurology, 53,* S53-S67.

Kjeldsen, M. J., Kyvik, K. O., Christensen, K., & Friis, M. L. (2001). Genetic and environmental influence in the etiology of epilepsy: A population-based study of 11,900 Danish twin pairs. *Epilepsy Research, 44,* 167-178.

Kurtz, Z., & Tookey, R. (1998). Epilepsy in young: 23 year follow up of the British National Child Development Study. *British Medical Journal, 316,* 339-342.

Labiner, D. M., & Ahern, G. L. (2002). Neurologic consultation for seizures: When, why, and how to pursue. *Postgraduate Medicine, 111,* 53-64.

Lambert, M. V., & Robertson, M. M. (1999). Depression in epilepsy: Etiology, phenomenology and treatment. *Epilepsia, 40,* S21–S47.

Landgraf, N.J., Abetz, L., & Ware, J.E. (1996). The child health questionnaire (CHQ): A user's manual. *Boston, The Health Institute, New England Medical Center*.

Lavigne, J. V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17,* 133–157.

Lhatoo, S. D., & Sander, J. W. (2001). The epidemiology of epilepsy and learning disability. *Epilepsia, 42,* 6-9.

McDermott, S., Mani, S., & Krishnaswami, S. (1995). A population-based analysis of specific behavior problems associated with childhood seizures. *Journal of Epilepsy, 8,* 110-118.

Meador, K. J. (1993). Research use of the new quality of life of epilepsy inventory. *Epilepsia, 34,* S34-38.

Mendez, M. F., Doss, R. C., Taylor, J. L., & Salguero, P. (1993). Depression in epilepsy. Relationship to seizures and anticonvulsant therapy. *Journal of Nervous and Mental Disease, 181,* 444-447.

Merrell, K. W. (1999). *Behavioral, social, and emotional assessment of children and adolescents.* Mahwah, NJ: Erlbaum.

Messenheimer, J. (2002). Efficacy and safety of lamotrigine in pediatric patients. *Journal of Child Neurology, 17,* 2S34-2S42.

Miller, V., Palermo, T. M., & Grewe, S. D. (2003). Quality of life in pediatric epilepsy: Demographic and disease-related predictors and comparison with healthy controls. *Epilepsy & Behavior, 4,* 36-42.

Murphy, C. C., Yeargin-Allsopp, M., & Decoufle, P. (1995). The administrative prevalence of mental retardation in 10-year-old children in metropolitan Atlanta, 1985 through 1987. *American Journal of Public Health, 85,* 319-323.

Nei Wu, K., Lieber, E., Siddarth, P., Smith, K., Sankar, R., & Caplan, R. (2008). Dealing with epilepsy: Parents speak up. *Epilepsy & Behavior, 13,* 131-138.

Noll, R. B., Gartstein, M. A., Vannatta, K., Correll, J., Bukowski, W. M., & Davies, W. H. (1999). Social, emotional, and behavioral functioning of children with cancer. *Pediatrics, 103*, 71–78.

Oguz, A., Kurul, S., & Dirik, E. (2002). Relationship of epilepsy-related factors to anxiety and depression scores in epileptic children. *Journal of Child Neurology, 17,* 37-40.

Onwuegbuzie, A. J. (2003). Expanding the framework of internal and external validity in quantitative research. *Research in the Schools, 10*(1), 71-90.

Osborne, J. W., & Waters, E. (2002). Four assumptions of multiple regression that researchers should always test. *Practical Assessment, Research & Evaluation*, 8(2). Retrieved March 20, 2007, from http://PAREonline.net/getvn.asp?v=8&n=2.

Plioplys, S. (2003). Depression in children and adolescents with epilepsy. *Epilepsy & Behavior, 4*, S39-45.

Power, T. J., & Blom-Hoffman, J. (2004). The school as a venue for managing and preventing health problems: Opportunities and challenges. *Handbook of pediatric psychology in school settings.* R. T. Brown (eds.). Mahwah, NJ: Lawrence Erlbaum Publishers.

Prego-Lopez, M., & Devinsky, O. (2002). Evaluation of a first seizure: Is it epilepsy? *Postgraduate Medicine*, *111*(1), 34-36, 43-48.

Quittner, A. L. (1998). Measurement of quality of life in cystic fibrosis. *Current Opinion in Pulmonary Medicine, 4,* 326-331.

Reynolds, C. R. & Kamphaus, R. W. (2004). *Behavior Assessment System for Children,* (2nd ed.), Circle Pines, MN: AGS Publishing,

Robertson, M. M., & Trimble, M. R. (1983). Depressive illness in patients with epilepsy: A review. *Epilepsia, 22,* 515-524.

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

Ronen, G. M., Rosenbaum, P., & Streiner, D. L. (2000). Outcome measures in pediatric neurology: Why do we need them? *Journal of Child Neurology, 15,* 775-780.

Ronen, G. M., Streiner, D. L., & Rosenbaum, P. (2003). Health-related quality of life in childhood epilepsy: Moving beyond seizure control with minimal adverse effects. *Health Quality of Life Outcomes, 1*, 36-46.

Sachs, H., & Barrett, R. P. (1995). Seizure disorders: A review for school psychologists. *School Psychology Review, 24,* 131-145.

Sawyer, M. G., Whaites, L., & Rey, J. M. (2002). Health-related quality of life of children and adolescents with mental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 41,* 530-537.

Scheuer, M. L. (1992). Medical patients with epilepsy. In S. R. Resor& H. Kutt (Eds.), *The medical treatment of epilepsy* (pp. 557-572). New York: Dekker.

Schipper, H. (1990). Quality of life: Principles of the clinical paradigm. *Journal of Psychosocial Oncology, 8,* 171-185.

Seidenberg, M., & Berent, S. (1992). Childhood epilepsy and the role of psychology. *American Psychologist, 47,* 1130-1133.

Shafer, P. O. (2002). Improving the quality of life in epilepsy: Nonmedical issues too often overlooked. *Postgraduate Medicine*, *111*(1). Retrieved March 20, 2007, from http://www.postgradmed.com/issues/2002/01_02/shafer.htm.

Shore, C. P., Austin, J. K., Huster, G. A., & Dunn, D. W. (2001). Identifying risk factors for maternal depression in families of adolescents with epilepsy. *Journal for Specialists in Pediatric Nursing, 7,* 71-80.

Spieth, L. E., & Harris, C. V. (1996). Assessment of health-related quality of life in children and adolescents: An integrative review. *Journal of Pediatric Psychology, 21,* 175-193.

Sturniolo, M. G., & Galletti, F. (1994). Counseling children and parents about epilepsy. *Patient Education and Counseling, 55,* 422-425.

Tabachnick, B. G., & Fidell, L. S. (2001). *Using multivariate statistics* (4th ed.), Needham Heights, MA: Allyn & Bacon.

Thompson, B. (1984). *Canonical correlation analysis: Uses and interpretations.* Newbury Park, CA, Sage. (ERIC Document Reproduction Service No. ED199269).

Thompson, R. J., & Gustafson, K. E. (1996). *Psychological adjustment. In adaptation to chronic childhood illness*. Washington, DC, US: American Psychological Association, pp. 57-86.

Uvebrant, P. & Bauzien, P. R. (1994). Intractable epilepsy in children. The efficacy of lamotrigine treatment, including non-seizure-related benefits. *Neuropediatrics*, 25, 284–289.

Van Dyck, P. C., McPherson, M., Strickland, B. B., Nesseler, K., Blumberg, S. J., Cynamon, M. L., & Newacheck, P. W. (2002). The national survey of children with special health care needs. *Ambulatory Pediatrics, 2,* 29–37.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL-super(TM) 4.0: Reliability and validity of the Pediatric Quality of Life Inventory-super(TM) Version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care, 39,* 800-812.

Vazquez, B., & Devinsky, O. (2003). Epilepsy and anxiety. *Epilepsy & Behavior, 4,* S20-S25.

Wagner, J. L., & Smith, G. (2006). Psychosocial intervention in pediatric epilepsy: A critique of the literature. *Epilepsy & Behavior, 8,* 39–49.

Williams, J., Sharp, G.B., DelosReyes, E., Bates, S., Phillips, T., et al. (2002). Symptom differences in children with absence seizures versus inattention. *Epilepsy & Behavior, 3,* 245-248.

Zupanc, M. L. (1996). Update on epilepsy in pediatric patients. *Mayo Clinic Proceedings*, *71,* 899-916.

Appendices

Appendix A: Demographics and Seizure Variables Questionnaire

Demographics and Seizure-Related Variables Questionnaire

Please read the items below and circle or write-in **one** response for each item. If you have any questions about this form, please ask for assistance.

(1) ***My child's age is:*** _____

(2) ***My child's gender is:*** Male Female

(3) ***My child's race/ethnic identity is:*** African American/Black Hispanic/Latino

Asian American Native American

Caucasian/White Mixed-Race or Other

(4) ***Type of medical insurance:*** Private Medicaid None

(5a) ***Does your child have any medical/physical diagnoses <u>in addition</u> to epilepsy?***
(for example: cystic fibrosis, diabetes, asthma)

Yes No

(5b) ***If you answered yes to (5a), please provide the diagnosis:*** _____

(6a) ***Does your child have any emotional/behavioral diagnoses?*** *(for example: attention deficit-hyperactivity disorder, autism, depression)*

Yes No

(6b) ***If you answered yes to (6a), please provide the diagnosis:*** _____

(7) ***Please circle the type of seizure your child experiences:***

Generalized seizures Partial seizures

(8) ***Number of seizures in the past <u>12 months</u>:***

0-5 per year 6-12 per year

(9) ***Please list all medications your child has been taking for the past 3 months:***

_____

_____

_____

Appendix B: Child Cover Letter and Assent Form

Hello!

You and your parent are being asked to take part in a research study by filling out several surveys. I am trying to find out what types of things impact the quality of life of children with epilepsy.

- ✓ Why You Should Take Part in the Study: I want to learn more about what things impact the lives of kids with epilepsy. Any information you give will be confidential: that means it is private. Also, you and your parent will be entered into a drawing to win a $100 gift card!

- ✓ Filling Out the Surveys: These surveys will ask about your thoughts, behaviors, and attitudes about different things. I expect it will take you about 30 minutes to fill out the surveys.

- ✓ Confidentiality (Privacy) of Your Responses: I do not expect that there will be more than minimal risk to you for taking part in this research study. The information you provide will be kept confidential (private, secret). Your surveys will have a code number to protect the privacy of your responses.

- ✓ Please Note: Your involvement in this study is voluntary: you get to decide if you want to fill out the surveys. By signing this form, you are agreeing to take part in this research. If you choose not to participate, or if you want to stop participating at any time, you will not be punished in any way. You are free to stop participating in this study at any time.

- ✓ What We'll Do With Your Responses: I will use the information from this study to let others know what sort of things impact the lives of kids with epilepsy. The results of this study may be published; however, your responses will be combined with responses from other people. The published results will not include your name or any other information that would in any way identify you.

- ✓ Questions? If you have any questions about this research study, you may contact me (Ms. Aja Meyer) at (813) 810-2526. If you have questions about your rights as a person who is taking part in a research study, you may contact a member of the Division of Research Compliance of the University of South Florida at 813-974-5638 or the Department of Health and Human Services.

Thank you for taking the time to take part in this study.

Sincerely,

Aja Meyer, M.A.
Doctoral Candidate
Psychological and Social Foundations
University of South Florida

Assent to Take Part in this Research Study

I freely give my permission to take part in this study. I understand that this is research. I have received a copy of this letter and assent form for my records.

_____	_____	_____
Signature of child taking part in the study	Printed name of child	Date

Statement of Person Obtaining Informed Assent

I certify that participants have been provided with an informed assent form that has been approved by the University of South Florida's Institutional Review Board and that explains the nature, demands, risks, and benefits involved in participating in this study. I further certify that a phone number has been provided in the event of additional questions.

_____	_____	_____
Signature of person obtaining assent	Printed name of person obtaining assent	Date

Investigator Statement:

I certify that participants have been provided with an informed consent form that has been approved by the University of South Florida's Institutional Review Board and that explains the nature, demands, risks, and benefits involved in participating in this study. I further certify that a phone number has been provided in the event of additional questions.

_____	_____	_____
Signature of Investigator	Printed Name of Investigator	Date

Appendix C: Parent Cover Letter and Consent Form

Dear Parent or Guardian:

This letter provides information about a research study that will be conducted at Dr. Fernandez's office by Aja M. Meyer, M.A., a doctoral candidate from the University of South Florida. Please carefully read through this information and sign the bottom of the form.

Purpose of study: The purpose of the study is to determine which factors are correlated with quality of life in children with epilepsy so they may receive appropriate supports and services to improve their physical and psychosocial well-being. This study is part of my dissertation research entitled, "Impact of Seizure-Related Variables and Psychopathology on Health-Related Quality of Life in Pediatric Epilepsy." Information from this study will inform educators and psychologists about the relationship between seizure variables and internalizing disorders (i.e., anxiety and depression) and the health-related quality of life of children with epilepsy.

What participation requires: If you and your child agree to take part in this study, you both will be requested to complete several forms. You will be asked to complete a short questionnaire requesting basic information about your child's medical condition, a rating scale that assesses your child's behavioral and emotional symptoms, and a rating scale that measures your child's health-related quality of life. These forms should take approximately 40 minutes to complete. Your child will be asked to complete the child version of the two rating scales. It should take your child about 30 minutes to complete these scales. Please note that all forms should be completed independently. However, if your child asks for help with some items from the forms, you may assist them, but you should not provide the responses for them.

Risks and benefits: There are no direct risks or benefits to you or your child for participating in this study; however, by participating you will provide valuable information about the factors that impact the quality of life of children with epilepsy. If the researcher should find that your child is at-risk for depression or anxiety (based on scores obtained on the BASC-2 questionnaire), Dr. Fernandez will be informed that code number participant "XXX" is in the at-risk range for depression and/or anxiety. Dr. Fernandez will match the participant with the code number on the consent form and may refer the patient for further evaluation. **Compensation**: Each child/guardian pair who participates in this study will be included in a drawing to win a $100 gift card.

Confidentiality: There are federal laws that say I must keep your study records private. Your records will be kept private by not asking for information that could identify you or your child. However, certain people may need to see your study records, and they must keep your records completely confidential. The only people who are allowed to view your records are the research team members, the University of South Florida Institutional Review Board staff, and government agencies who make sure that your rights and safety are being protected. I may publish what I learn from this study; however, nothing will be published that would let people know who you are.

Voluntary Participation: You and your child's participation in this study is completely voluntary. Your decision to take part in this study will not affect your current or future relationship with Dr. Fernandez. If at any time you have questions or concerns regarding this study, please contact the principal investigator (Aja M. Meyer) at 813-810-2526 or ameyer@mail.usf.edu. If you have questions or concerns about you or your child's rights as research subjects, you may contact the Institutional Review Board at the University of South Florida at 813-974-5638 or the Department of Health and Human Services. You may retain this letter for your personal records, if desired.

Aja M. Meyer, M.A.
Psychological and Social Foundations
University of South Florida

Consent for Child to Take Part in this Research Study

I give consent for myself and my child to participate in this study.

_____	_____	_____
Signature of Participant	Printed Name of Participant	Date

I do **NOT** give consent for myself and/or my child to participate in this study.

_____	_____	_____
Signature of Participant	Printed Name of Participant	Date

Investigator Statement:

I certify that participants have been provided with an informed consent form that has been approved by the University of South Florida's Institutional Review Board and that explains the nature, demands, risks, and benefits involved in participating in this study. I further certify that a phone number has been provided in the event of additional questions.

_____	_____	_____
Signature of Investigator	Printed Name of Investigator	Date

Appendix D: Health-Related Quality of Life: Parent Questionnaire

○○○ - ○○○
Centre Code Child's Reference No.

HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH EPILEPSY: WHAT CONSTELLATION OF FACTORS IS IMPORTANT?

HEALTH-RELATED QUALITY OF LIFE: PARENT QUESTIONNAIRE

This form is to be completed by the parent.

The next set of questions has been developed specifically to ask parents about your judgements about the 'quality of life' of your child with epilepsy. This measure was developed with hundreds of parents like you, so the ideas in it will probably seem familiar!

Date: _____
month/day/year

INSTRUCTIONS

To answer the following questions, there are three steps you need to remember...

(1) Decide which of 2 sentences is most like you.

Some kids say the sky is blue	BUT	Other kids say the sky is green

(2) Circle it!

Some kids say the sky is blue	BUT	Other kids say the sky is green

(3) Then choose whether that sentence is REALLY TRUE or SORT OF TRUE and check it off!

Some kids say the sky is blue		BUT	Other kids say the sky is green	
Really true ✓	Sort of true ○		Really true ○	Sort of true ○

Canadian Quality of Life Instrument in Childhood Epilepsy – Parent Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

Remember, for each box...

Circle this side ONLY.....OR.....Circle this side ONLY


For example...

Some kids have one nose on their face.		BUT	Other kids have three noses on their face!	
Really true ☑	Sort of true ❍		Sort of true ❍	Really true ❍

Now you try...

1. Some kids with epilepsy say kids won't play with them.		BUT	Other kids with epilepsy say other kids always play with them.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

2. Some kids with epilepsy think they are not as good at things as other kids.		BUT	Other kids with epilepsy think they are just as good at things as other kids are.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

3. Some kids with epilepsy don't have many friends.		BUT	Other kids with epilepsy have lots of friends.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

4. Some kids with epilepsy feel that other kids treat them differently.		BUT	Other kids with epilepsy feel they are treated the same as everyone else.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

5. Some kids with epilepsy feel they are being picked on.		BUT	Other kids with epilepsy don't feel they get picked on.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Parent Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No

6. Some kids with epilepsy have to think about their epilepsy before doing things.		BUT	Other kids with epilepsy don't think about their epilepsy before doing things.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

7. Some kids with epilepsy think their parents are worried that they will hurt themselves.		BUT	Other kids with epilepsy don't think that their parents are worried about them	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

8. Some kids with epilepsy may not be able to go away to camp or similar places.		BUT	Other kids with epilepsy can go away to camp or similar places if they want to.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

9. Some kids with epilepsy worry about what might happen to them if they forget to take their medicine.		BUT	Other kids with epilepsy are not worried about what might happen if they forget to take their medicine.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

10. Some kids with epilepsy worry about getting hurt during a seizure.		BUT	Other kids with epilepsy are not worried about getting hurt during a seizure.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

11. Some kids with epilepsy feel scared about the future.		BUT	Other kids with epilepsy do not feel scared about the future.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

12. Some kids with epilepsy worry they won't be able to drive a car.		BUT	Other kids with epilepsy think that they will be able to drive a car.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Parent Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

13. Some kids with epilepsy don't know if they will be able to work at what they want to do.		BUT	Other kids with epilepsy feel that they will be able to work at what they want to do.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

14. Some kids with epilepsy don't know how they will manage when they are teenagers.		BUT	Other kids with epilepsy think they will manage fine when they are teenagers.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

15. Some kids with epilepsy are afraid that people will not treat them well when they are grown up.		BUT	Other kids with epilepsy feel that people will treat them well when they grow up.	
Really true ❍1	Sort of true 2❍		Sort of true ❍3	Really true 4❍

16. Some kids with epilepsy get upset easily.		BUT	Other kids with epilepsy do not get upset easily.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

17. Some kids with epilepsy have trouble paying attention at school.		BUT	Other kids with epilepsy can concentrate well at school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

18. Some kids with epilepsy get angry easily.		BUT	Other kids with epilepsy do not get angry easily.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

19. Some kids with epilepsy have trouble remembering things that they learn at school.		BUT	Other kids with epilepsy can easily remember things that they learn in school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

20. Some kids think their epilepsy will never go away.		BUT	Other kids think their epilepsy will go away.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

21. Some kids feel okay telling people about their epilepsy.		BUT	Other kids are nervous telling people about their epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

22. Some kids are afraid that their friends will find out they have epilepsy.		BUT	Other kids don't mind if their friends find out they have epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

23. Some kids feel embarrassed to have epilepsy.		BUT	Other kids are not embarrassed to have epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

24. Some kids feel safe with their friends if they have a seizure.		BUT	Other kids don't feel safe with their friends if they have a seizure.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

25. Some kids live are afraid that no one will know what to do if they have a seizure away from home.		BUT	Other kids don't worry that nobody will know what to do if they have a seizure away from home.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Parent Health-Related Quality of Life Questionnaire

○○○ - ○○○
Centre Code Child's Reference No.

HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH EPILEPSY: WHAT CONSTELLATION OF FACTORS IS IMPORTANT?

HEALTH-RELATED QUALITY OF LIFE: CHILD QUESTIONNAIRE

This form is to be completed by the child

Child's Reference #: _____
Your site ID #: _____
Date: _____
month/day/year

INSTRUCTIONS

To answer the following questions, there are three steps you need to remember…

(1) Decide which of 2 sentences is most like you.

Some kids say the sky is blue BUT Other kids say the sky is green

(2) Circle it!

Some kids say the sky is blue BUT Other kids say the sky is green

(3) Then choose whether the one the sentence is REALLY TRUE or SORT OF TRUE and check it off!

Some kids say the sky is blue		BUT	Other kids say the sky is green	
Really true ☑	Sort of true ○		Really true ○	Sort of true ○

Canadian Quality of Life Instrument in Childhood Epilepsy – Child Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

Remember, for each box...

Circle this side.....OR.....Circle this side


For example...

Some kids have one nose on their face.		BUT	Other kids have three noses on their face!	
Really true ✓	Sort of true ❍		Sort of true ❍	Really true ❍

Now you try...

1. Some kids with epilepsy say kids won't play with them.		BUT	Other kids with epilepsy say other kids always play with them.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

2. Some kids with epilepsy think they are not as good at things as other kids.		BUT	Other kids with epilepsy think they are just as good at things as other kids are.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

3. Some kids with epilepsy don't have many friends.		BUT	Other kids with epilepsy have lots of friends.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

4. Some kids with epilepsy feel that other kids treat them differently.		BUT	Other kids with epilepsy feel they are treated the same as everyone else.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

5. Some kids with epilepsy feel they are being picked on.		BUT	Other kids with epilepsy don't feel they get picked on.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Child Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

6. Some kids with epilepsy have to think about their epilepsy before doing things.		BUT	Other kids with epilepsy don't think about their epilepsy before doing things.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

7. Some kids with epilepsy think their parents are worried that they will hurt themselves.		BUT	Other kids with epilepsy don't think that their parents are worried about them	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true 4❍

8. Some kids with epilepsy may not be able to go away to camp or similar places.		BUT	Other kids with epilepsy can go away to camp or similar places if they want to.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

9. Some kids with epilepsy worry about what might happen to them if they forget to take their medicine.		BUT	Other kids with epilepsy are not worried about what might happen if they forget to take their medicine.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

10. Some kids with epilepsy worry about getting hurt during a seizure.		BUT	Other kids with epilepsy are not worried about getting hurt during a seizure.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

11. Some kids with epilepsy get upset easily.		BUT	Other kids with epilepsy do not get upset easily.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

12. Some kids with epilepsy have trouble paying attention at school.		BUT	Other kids with epilepsy can concentrate well at school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Child Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

13. Some kids with epilepsy get angry easily.		BUT	Other kids with epilepsy do not get angry easily.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

14. Some kids with epilepsy have trouble remembering things that they learn at school.		BUT	Other kids with epilepsy can easily remember things that they learn in school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

15. Some kids with epilepsy think they will have to take seizure medicine for the rest of their life.		BUT	Other kids with epilepsy can soon stop taking medicine for their seizures.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

16. Some kids feel okay telling people about their epilepsy.		BUT	Other kids are nervous telling people about their epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

17. Some kids are afraid that their friends will find out they have epilepsy.		BUT	Other kids don't mind if their friends find out they have epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

18. Some kids with epilepsy feel safe away from home.		BUT	Other kids with epilepsy don't feel safe away from home.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

19. Some kids feel embarrassed to have epilepsy.		BUT	Other kids are not embarrassed to have epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

Canadian Quality of Life Instrument in Childhood Epilepsy – Child Health-Related Quality of Life Questionnaire

❍❍❍ - ❍❍❍
Centre Code Child's Reference No.

20. Some kids with epilepsy feel their friends are a bit afraid of them.		BUT	Other kids with epilepsy feel their friends are not afraid of them.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true 4❍

21. Some kids with epilepsy are treated the same as their brothers and sisters.		BUT	Other kids with epilepsy are treated differently than their brothers and sisters.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

22. Some kids live a normal life even though they have seizures.		BUT	Other kids can't live a normal life because of their seizures.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

23. Some kids with epilepsy feel their teachers treat them the same as other kids at school.		BUT	Other kids with epilepsy feel that their teachers treat them differently from other kids at school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

24. Some kids do not let their epilepsy slow them down.		BUT	Other kids get slowed down by their epilepsy.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

25. Some kids with epilepsy feel comfortable at school.		BUT	Other kids with epilepsy feel nervous at school.	
Really true ❍1	Sort of true ❍2		Sort of true ❍3	Really true ❍4

About the Author

Aja M. Meyer graduated with honors from the University of Florida in 2000 with a Bachelor's of Arts Degree in Psychology. She earned her Ph.D. in School Psychology from the University of South Florida in 2008, specializing in pediatric health issues. Aja completed her pre-doctoral internship at the Children's Hospital of Michigan and currently is completing a post-doctoral fellowship at Akron Children's Hospital. Aja specializes in working with children who have neurological impairments and plans to pursue a career within a pediatric medical setting.

During her graduate studies, Aja gained experience working in school and medical settings with children and adolescents. She received advanced training at the Early Steps Clinic through the University of South Florida's School of Medicine and at the Silver Child Development Center. Aja also conducted research in the areas of autism spectrum disorders and epilepsy and has presented her findings at state and national conferences.