# ACADEMIC ACHIEVEMENT IN CHILDREN WITH NEW-ONSET SEIZURES OR ASTHMA

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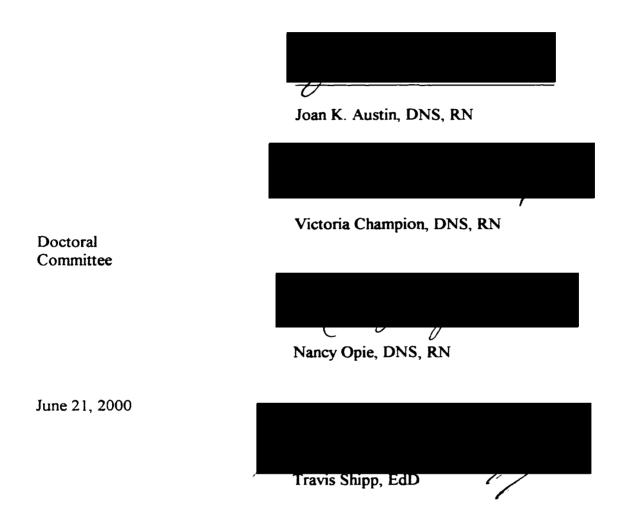
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A.M.M.

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#### **ABSTRACT**

# Angela M. McNelis

# Academic Achievement in Children with New-Onset Seizures or Asthma

It has long been recognized that children with epilepsy have more learning difficulties in school than either children without seizures or children with other chronic disorders, such as asthma. Problems such as repeating a grade, receiving special services, and scoring poorly on standardized achievement tests are over-represented in children with epilepsy. Factors that lead to problems with academic underachievement are not well understood.

Primary purposes of the study were to examine change in academic achievement over a 12-month period and to identify factors related to achievement in children with new-onset seizures. A secondary purpose was to examine differences in academic achievement between children with new-onset seizures and those with new-onset asthma. Baseline data were collected within 6 weeks of children (8 to 14 years) having a first seizure or being placed on daily asthma medications. Data collected during the baseline interview provided information from the year prior to the onset of the health condition. The 12-month data collection provided information for the period of baseline to one year after the condition onset.

V

Results at baseline indicated that children with seizures had lower math scores than children with asthma. Moreover, in both samples girls had higher reading and total battery scores than boys. At 12 months, there were no differences in achievement between the seizure and asthma samples, nor were there differences between girls and boys. In general, over the 12 months there was a decline in academic achievement for all children, however, children with seizures did not show more of a decline than children with asthma. Across samples, girls declined in reading, language, math, and total battery, and boys declined in language and total battery. Factors associated with higher academic achievement at 12 months in children with seizures were higher socioeconomic status, better child adaptive functioning at school, and higher parent and teacher expectations for the child's academic achievement.

Findings suggest that clinical assessments for children with seizures should include both psychosocial and illness components. Future prospective longitudinal research should be conducted to explore factors that lead to changes in academic achievement, including the role of gender and illness condition variables.

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#### CHAPTER 1

#### THE NATURE OF THE STUDY

#### Introduction

It has long been recognized that children with epilepsy have more learning difficulties in school than either children without seizures or children with other chronic disorders, such as asthma (Austin, Huberty, Huster, & Dunn, 1998; Austin, Huberty, Huster, & Dunn, 1999; Green & Hartlage, 1971; Holdsworth & Whitmore, 1974b; Mitchell, Lee, Chavez, & Guzman, 1991; Rodin, Shapiro, & Lennox, 1977; Rutter, Graham, & Yule, 1970). Problems with academic achievement, such as repeating a grade, receiving special services, and scoring poorly on standardized achievement tests, are over-represented in children with epilepsy (Fowler, Johnson, & Atkinson, 1985; Thompson & Gustafson, 1996). Approximately one-third receive some form of special education support (Aldenkamp, 1983) and about half have some schooling difficulties (Besag, 1995).

In a classic study, Holdsworth and Whitmore (1974b) found that over 68% of children with epilepsy were below average to seriously behind in their subject performance as measured by standardized tests or school examinations. In a longitudinal study, the educational advancement of children with epilepsy examined over a 5-year period stayed significantly lower than a healthy control

group, despite a marked improvement in their seizure condition (Suurmeijer, 1991). Feeman and Hagen (1990) found in a cross-sectional study that children with a seizure disorder scored lower on reading and mathematics than both their healthy siblings and a healthy control group. Similarly, Bain (1986) found that children with a seizure disorder performed less well than their healthy siblings on general intelligence tests and academic fundamentals. In a large epidemiological study, Rutter and colleagues (1970) found that children with epilepsy had reading underachievement, with an average of approximately 12 months delay. Two cross-sectional studies found that arithmetic was the academic area most negatively affected (Aldenkamp, 1987; Green & Hartlage, 1971). In general, past studies indicate that the academic performance of children with epilepsy is poorer than what would be expected for their intellectual ability (Seidenberg & Berent, 1992), however, reasons for the academic underachievement are not well delineated.

#### Problem Area

There is evidence of great variability in patterns of achievement and progress among children with epilepsy. It is not known why some children do better than others and if variations in achievement are influenced by family characteristics, child characteristics, and specific illness characteristics. Although previous research has found poor academic achievement in many children with epilepsy, factors that lead to problems with academic underachievement in this

population are not well understood. In most studies, a cross-sectional approach has been used to assess the level of achievement in a chronic sample. The change in achievement over time using a longitudinal approach to assess academic achievement in children with seizure disorders is an area of investigation that has received relatively little attention, but is needed to accurately examine academic progress. Moreover, no studies have systematically examined the natural history of academic achievement over time in children with new-onset seizures.

Past research in other areas has identified family and child factors associated with academic achievement in children and adolescents, however, these factors have not been studied in children with new-onset seizures. In addition, most studies have not investigated both illness and psychosocial factors in a comprehensive model. Seizure condition and psychosocial factors may interact and need to be examined simultaneously. Thus, there is a gap in the literature describing family and child factors in combination with illness-related factors and their relationship with academic achievement in children with new-onset seizures. The relationship of these factors with child academic achievement merits investigation so that effective interventions can be developed to enhance scholastic success in a population of children at risk for underachievement.

# Purpose

The primary purpose of the study was to identify factors related to academic achievement in children with new-onset seizures and to examine change in achievement over time. A secondary purpose was to examine differences in academic achievement between children with new-onset seizures and those with new-onset asthma. A sample of children newly diagnosed with asthma with a similar age distribution to the seizure sample served as a comparison group. An asthma comparison group was selected because like seizures, asthma is an episodic, chronic condition characterized by onset in early childhood; is characterized by unpredictable episodes; and is treated primarily by pharmacological agents. Furthermore, unless children are having either a seizure or asthma symptoms, there is no outwardly visible sign of disability. The groups differ, however, in that seizures are a neurological condition involving the brain; asthma is not considered a neurological disorder. This difference is important because studies have consistently shown that children with conditions involving neurological impairment are at greater risk for adjustment problems than children with non-neurological conditions (Breslau, 1985; Graham & Rutter, 1970; Hoare, 1984; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Matthews, Barabas, & Ferrari, 1982; Seidel, Chadwick, & Rutter, 1975; Yule & Rutter, 1970). Moreover, children with asthma are one of the chronic condition groups that

perform well academically (Guerin, 1979; Rutter, Tizard, & Whitmore, 1970). By comparing the groups with new-onset seizures and new-onset asthma, factors specific to a seizure condition can be separated from the general effects of recent onset of a chronic condition.

#### Theoretical Framework

A theoretical framework was proposed that focused on family and child characteristics, and parent, child and teacher response variables as predictors of academic achievement. The Double ABCX Model of Family Adjustment was used as a source theory to guide the selection of family factors for the proposed study (McCubbin & Patterson, 1983). This model identifies factors that influence family adaptation to a stressor, such as seizures in a child, and is used to increase understanding of how families approach and manage life's hardships. The major concepts in McCubbin and Patterson's (1983) Double ABCX Model are family demands (stressors), family resources, family definition of the stressor, family coping, and family adaptation. The model proposes that family pile-up of stressors or demands interact with family adaptive resources and family definition of the stressor to produce coping behaviors that, in turn, influence adaptation.

The rationale for using the Double ABCX Model as a source theory stems from the importance and influence of the family on child adaptation. McCubbin and Patterson (1983) suggest that the model is useful for describing the outcome

of family adaptation, including the individual family member. In the extended model developed for this study, child academic achievement was conceptualized as one aspect of child adaptation. Although the major concepts from the Double ABCX Model are retained in the extended model, the primary outcome was individual child academic achievement. A review of the academic achievement literature led to the inclusion of three additional concepts (parent and teacher expectations for child academic achievement and child school self-concept) in the model (Figure 1). The focus on psychosocial factors is important in nursing because these are areas where nursing interventions can be made, whereas illness-related factors are often not amenable to change.

# **Conceptual Definitions**

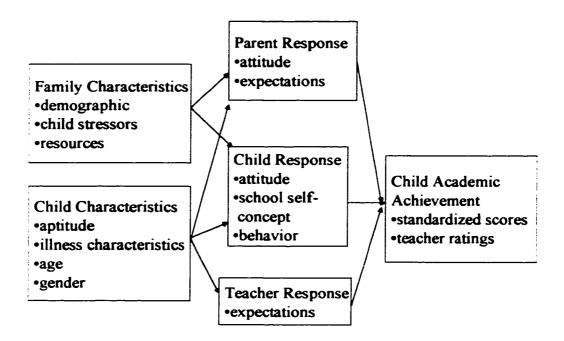
#### Family Characteristics

<u>Demographic characteristics</u>. Demographic characteristics represent the family's socioeconomic status (SES) and level of parent education.

<u>Child stressors</u>. Child stressors constitute the normative changes or negative events experienced by the child (McCubbin & Patterson, 1983).

Family resources. Family resources are the assets available to the family to help deal with stressors and strains, including previously existing resources and those gained or strengthened during a crisis situation (McCubbin & Patterson,

Figure 1. Model of Academic Achievement in Children with Seizures



1983). Families having a larger repertoire of resources will manage and adapt to stressful situations more effectively than families with fewer resources.

# **Child Characteristics**

Aptitude. Aptitude represents the child's intellectual ability to succeed academically as measured on standardized tests.

<u>Illness characteristics</u>. Illness characteristics include frequency of episodes and medications. For the seizure group, seizure type and severity also are included.

Age. The child's chronological age in years and months.

Gender. The child's sex: male or female.

# Parent Response

Parent attitudes. Parent attitudes are the positive or negative evaluations parents associate with seizures in their child. Attitudes predispose a person to respond and are thought to be acquired through personal experience and social learning (Austin, 1998).

<u>Parent expectations</u>. Parent expectations are the beliefs that parents hold for their child's ability to have academic success in school.

# Child Response

Child attitude. Attitude is the overall evaluation of the child's positive and negative feelings associated with the illness (seizures or asthma). If the child's perceptions about the illness are primarily negative, the attitude can contribute to

the stressors on the child and family. Conversely, if their perceptions about the illness are relatively positive, the attitude can serve as a resource to help the child and family adapt.

School self-concept. Self-concept is defined as self-attitudes reflecting a description and an evaluation of one's own behavior and attributes. It is a relatively stable set of attitudes that focuses on conscious self-perceptions, rather than inferring how children feel about themselves from their behavior or the attributions of others (Piers, 1984). As conceptualized in this study, self-concept can be used interchangeably with self-esteem and self-regard.

Child behavior. Behavior is the adaptive competencies and behavior problems of the child (Achenbach, 1991a).

# Teacher Response

<u>Teacher expectations</u>. Expectations are the beliefs that the teacher holds for the child's ability to have academic success in school.

#### Child Academic Achievement

<u>Child academic achievement</u>. Achievement is conceptually defined as the academic success obtained by the child.

# Relationships Among Components of Model

The theoretical model asserts that family and child characteristics at the onset of the illness condition influence the adaptation process (parent, child, and

teacher response) which, in turn, influence the adaptation outcome of the child's academic achievement. In the model, family and child characteristics directly influence parent, child and teacher responses and are related to each other as well as to the child outcome of academic achievement.

# Research Design

Baseline data were collected within 6 weeks of a child having a first seizure or being placed on daily asthma medications. Data collected during the baseline interview were retrospective, providing information from the year prior to the onset of the health condition. The 12-month data provided information for the period of baseline to one year after the seizure or asthma onset. The sample for the study was 109 children with new-onset seizures and 46 children with new-onset asthma and their mothers. At baseline, the children's teachers were contacted and asked to complete questionnaires about the child's behavior and academic achievements during the 2-month period prior to condition onset. At 12 months after the condition, the children's teachers were contacted and asked to complete questionnaires about the child's behavior and academic achievements during the past two months.

# **Research Questions and Hypotheses**

The following research questions and hypotheses were developed for the study.

Question 1. Are there differences between the groups of children with seizures and those with asthma in academic achievement at baseline?

Hypothesis 1. There will be no differences between the groups in academic achievement at baseline.

Question 2. Are there differences between the groups of children with seizures and those with asthma in academic achievement at 12 months?

Hypothesis 1. Children with seizures will have poorer academic achievement outcomes than children with asthma at 12 months.

Question 3. Are there differences in change in academic achievement over time between children with seizures and those with asthma?

Hypothesis 1. Children with seizures will have more negative change in academic achievement outcomes from baseline to 12 months than children with asthma.

Question 4. How much variance do variables of family characteristics (demographics, child stressors, family resources), child characteristics (aptitude, illness characteristics, age, gender), parent response (attitude, expectations for achievement), child response (attitude, school self-concept, behavior), and teacher response (expectations for achievement), account for in child academic achievement (test scores of Reading,

Language, Math, and Total Battery, and Teacher Rating of Performance) at 12 months for the seizure sample?

Hypothesis 1. Family characteristics of higher SES, greater number of years of parent education, lower child stressors, and higher family resources, will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 2. Child characteristics of higher aptitude and less severe seizure conditions will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 3. Parental response of more positive attitudes and higher expectations for their child's achievement will be significantly related to higher academic achievement in children with seizures at 12 months

Hypothesis 4. Child response of more positive attitude, more positive school self-concept, more adaptive competencies, and fewer (internalizing and externalizing) behavior problems will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 5. Teacher response of higher expectations for the child's academic achievement will be significantly related to higher academic achievement in children with seizures at 12 months.

# Significance for Nursing

This study broadens the research base on achievement in children with chronic illness by investigating predictors of change in academic achievement, an area that has rarely been investigated. Identifying factors associated with underachievement will enable nurses to focus on problematic areas. This information can be used to create interventions aimed at reducing psychosocial morbidity in children at risk. In past studies, approximately 40% of the children with seizures have been found to have some difficulties in school, including repeating a grade and scoring poorly on standardized achievement tests. Nurses can work with families and children to optimize success in school by intervening to reduce the negative effects of the seizure disorder and by acting as children's advocates in securing appropriate resources necessary to meet their educational needs. Additionally, nurses can provide information and support to the families and school professionals, and assist them in developing educational plans that will increase opportunities for success in school. Nurses are in an exceptional position to develop interventions that will assist families and children with seizure disorders to maximize positive adaptation and minimize negative adaptation to the situation.

#### **CHAPTER 2**

#### **REVIEW OF THE LITERATURE**

#### Introduction

The purpose of this chapter is to present a critical review of the research literature on academic achievement in children with new-onset seizures. The chapter is organized to provide an understanding of the concepts outlined in the theoretical framework. Following a brief description of each of the illness conditions (epilepsy and asthma), literature concerning child characteristics in relation to academic achievement, and parent, child, and teacher response in relation to child academic achievement are reviewed.

A literature search was conducted using the Medline, CINAHL, Psychlit, and ERIC databases to obtain publications. Dissertation Abstracts International also was searched for relevant publications. Although the focus of the literature searches was for the past five years, all significant literature in these areas was reviewed.

# Seizures and Epilepsy

A seizure involves the paroxysmal and disorderly depolarization of neurons and the spread of the neuronal discharge through the brain tissue. These neuronal discharges disturb the normal functioning of the nervous system. The disturbance may result in alterations of sensation, movement, or cognitive function. A seizure

can involve a temporary loss of consciousness or temporary changes in behavior, depending on the area of the brain involved (Hauser, 1994). Epilepsy is defined as repeated, unprovoked seizures. The annual incidence of epilepsy among children under 9 years of age is between 71.9 and 85.8 per 100,000 individuals, with higher rates among boys than girls. The prevalence of active epilepsy among children is between 4.3 and 9.3 per 1000, making epilepsy one of the most common neurological disorders of childhood (Hauser & Hesdorffer, 1990). Approximately 150,000 children are evaluated for a new-onset seizure condition each year (Hauser, 1994).

Seizure types are classified according to their point of origin and are categorized as either generalized or partial. Generalized seizures involve both hemispheres of the brain from the onset. Generalized seizures may involve only a loss of consciousness, as in absence seizures, or may involve motor control, as in tonic-clonic seizures (Hauser, 1994; Penry, 1986). Partial seizures are limited to a specific portion of the brain with clinical manifestations ranging from disorders of sensation or thought to convulsive movements of a part of the body.

Consciousness is impaired in complex partial seizures, but in simple partial seizures consciousness is never impaired (Penry, 1986). Seizures also are classified by syndrome as a mechanism for incorporating other signs and symptoms related to the seizure condition. These other signs and symptoms include etiology,

anatomical correlates, precipitating factors, age at onset, diurnal or circadian cycling, severity, chronicity, and prognosis.

The goal of pharmacological treatment of seizures is to decrease the severity and frequency of abnormal neuronal activity. Antiepileptic medications either block the initiation of electrical discharges from a hyperirritable focus or prevent the spread of abnormal electrical discharges to adjacent brain areas. The success rate of complete seizure control is approximately 50% and improvement is attained in about 25% of patients (Winkelman, 1999).

#### Asthma

Asthma is a reversible obstructive lung disease that is caused by an increased or excessive reaction of the airways to different stimuli, including infections, allergies, irritating gases, and particles in the air. Asthma is a chronic condition with acute exacerbations and is the most common chronic illness among children. Breathing problems are usually episodic but the underlying inflammation of the airways is continuous. An asthma episode occurs when the lining of the airway swells, muscles tighten, and the secretion of mucus is increased in the airway (American Lung Association, 1999). These events cause narrowing of the airway and the resultant difficulty in breathing. Asthma affects approximately 17 million Americans. The prevalence among children 18 years old or younger is 62 per 1000 individuals. Girls are affected slightly more than boys, with prevalence

rates of 65.3 and 44.4 per 1000, respectively (National Center for Health Statistics, 1970-1996).

Asthma medications reduce the underlying inflammation and reduce the narrowing of the airways. Three classes of medications are used to treat asthma. Anti-inflammatory agents, such as corticosteroids, work to reduce or prevent the inflammation, while bronchodilators, such as adrenergic agonists, act to dilate the airways by relaxing bronchial smooth muscle (American Lung Association, 1999). The newest medications, leukotriene antagonists, act to block the stimulants that constrict the airways.

# Concepts in the Model

The proposed model focuses on family and child variables that influence academic achievement in children with chronic illness. Literature reviewed on the concepts in the model includes family characteristics (demographics, child stressors, family resources), child characteristics (aptitude, illness characteristics, age, gender), parent response (attitude, expectations for achievement), child response (attitude, school self-concept, behavior), and teacher response (expectations for achievement).

# Family Characteristics

There is empirical support that family characteristics are important predictors of academic success among general population children (Mitchell,

Scheier, & Baker, 1993; Steinberg, Dornbusch, & Brown, 1992; Steinberg, Lamborn, Dornbusch, & Darling, 1992). In contrast, there are few studies describing the family characteristics associated with academic achievement in chronically ill children. Based on a review of the literature, family characteristics considered to be important predictors of academic achievement in children with epilepsy are demographic factors, child stressors, and family resources.

# Demographic Factors

Among general population children, family environment is an important factor influencing academic success (Steinberg, Elmen, & Mounts, 1989).

Research has suggested that family environment variables influence individual self-perceptions, which, in turn, influence behaviors related to achievement outcomes.

Socioeconomic status (SES) has consistently been related to educational accomplishments and attainment in young children (Hess & Holloway, 1984;

Patterson, Kupersmidt, & Vaden, 1990). In one of the few studies that addressed these variables in children with epilepsy, Mitchell and colleagues (1991) found sociocultural and environmental factors, particularly parental education and presence of a father in the household, to be important determinants of achievement. Most studies of academic achievement in children with epilepsy do not study SES, or it is not a predictor of outcomes and so is not reported.

In one study, children from families with lower SES had higher rates of psychological disturbance and their mothers had more negative attitudes toward epilepsy compared to families with higher SES (Hoare & Kerley, 1991). According to the proposed theoretical framework, these factors (child behavior problems and negative parental attitudes) will be detrimental to child academic achievement.

#### Child Stressors

Children with chronic conditions may experience stress because of their illness in addition to the stress from the normative life changes that occur. Emotional distress has been linked to disengagement from goal pursuit, perceived helplessness, and withdrawal from situational and task demands (Pryor-Brown & Cowen, 1989). Unresolved stress potentially leads to negative responses and children who are distracted by stressors may be unable to maintain their academic performance. Children experiencing high stress are at risk for problems in academic achievement due to general withdrawal from schoolwork and classroom activities (Wentzel, 1994). Additionally, if the family is under stress, the child can be affected. Austin, Risinger, and Beckett (1992) found that family stress was positively related to child behavior problems in children with epilepsy. Hermann and colleagues (1989) reported that having divorced or separated parents were predictive of behavior problems in children, while Hoare and Kerley (1991) found an association between increased family stress and child behavioral disturbance. In

the proposed model, stress influences child behavior, which, in turn, influences child academic achievement.

Whether there is a direct effect of child stress on academic achievement is unclear, however, the model proposes that stress will negatively influence adaptation. It is proposed that the more important effect of stress, on either the family or the child, may be its influence on the attitudes toward illness (Mitchell, Scheier, & Baker, 1994). For example, increased stress engendered by the epilepsy may lead to more negative attitudes about the condition. This path of stress to negative attitudes to academic achievement proposed in the model has not been investigated. Regrettably, no studies examined stress beginning at the onset of a chronic condition and determined its effect on academic achievement.

# **Family Resources**

Resources appear to play an important role in buffering the untoward effects of epilepsy on child academic achievement. Mitchell and colleagues (1991) found that the best predictors of IQ in a group of 78 children with epilepsy were educational materials in the household, family participation in developing stimulating activities, and increased levels of parental education. Similarly, Austin (1988) found in a study of family characteristics of children with epilepsy and behavior problems that children with the most problems came from families with low satisfaction with family relationships, low intrafamily esteem and

communication, low extended family social support, and low financial efficacy. In the regression analysis, three family variables (high stress, less extended family social support, and low mastery), child female gender, and increased seizure frequency accounted for approximately 30% of the variation in child behavior problems.

In children with asthma, low levels of extended family social support and financial resources also were associated with child behavior problems (Butz et al., 1995). Children in this study were from minority families with low incomes and single-parent households that also placed them at high risk for behavior problems. No studies were found that investigated how families utilize resources to help them deal with new-onset seizures in their children or how these resources interacted with other variables to influence academic achievement.

#### Child Characteristics

Child factors are important predictors of academic success among general population children (Mitchell, Scheier, & Baker, 1993; Steinberg, Dornbusch, & Brown, 1992; Steinberg, Lamborn, Dornbusch, & Darling, 1992). No studies were found that described child factors associated with achievement in chronically ill children or children with new-onset health conditions such as seizures or asthma. Based on a review of related research and theory, the child factors considered

relevant to the development of academic problems in children with seizures are aptitude, illness characteristics, age, and gender.

#### Aptitude

Children with seizures who have normal intelligence consistently score below expected levels in academic testing (Hartlage & Green, 1972), whereas children with asthma who have normal intelligence have average to above average achievement levels (Gutstadt, Gillette, Mrazek, Fukuhara, LaBrecque, & Strunk, 1989; Lindgren et al., 1992). Comparing adolescents with neurological and non-neurological chronic conditions and healthy controls, Howe and colleagues (1993) found the neurological group scored significantly lower on estimates of full-scale IQ than the other two groups.

#### **Illness Characteristics**

Epilepsy. The relationship between illness characteristics and cognitive functioning is poorly understood (Sachs & Barrett, 1995). A few studies have examined the relationship between academic achievement and factors specific to epilepsy, however, the results have been equivocal. One of the problems with past research is that studies have used clinic samples that include high rates of individuals with intractable seizures or complicated cases (Hermann & Whitman, 1984). The majority of people with seizure disorders are well controlled (80%), and only 20% have intractable conditions. Moreover, research suggests that

children with good seizure control score significantly higher on tests measuring intelligence than children with intractable seizures (Farwell, Dodrill, & Batzel, 1985). Thus, the generalizability and applicability of the findings on clinic samples are extremely limited, and do not apply to most children with seizures.

Several studies have identified illness-related variables associated with academic underachievement in children with epilepsy, including increased duration of condition (Louiseau, Strube, Broustet, Battellochi, Gomeni, & Morselli, 1983), and increased seizure frequency (Louiseau et al., 1983; O'Leary, Seidenberg, Berent, & Boll, 1981; Williams et al., 1996a; Williams et al., 1996b). Suurmeijer (1991) found that despite a marked improvement in their illness situation, 109 children with epilepsy did not make improvements in their educational attainment. Instead, the children stayed significantly below a healthy comparison group over a five-year period (Suurmeijer, 1991). These results suggest that change in seizure control may not lead to a direct change in academic achievement.

Conversely, Mitchell and colleagues (1991) found in a study of 78 children with epilepsy that the variables of seizure severity and duration were not strongly related to academic achievement. Huberty, Austin, Risinger, and McNelis (1992) also found no relationship between epilepsy variables and achievement test scores in a sample of 136 children, ages 8 to 12 years. The authors suggest that the lack of significance is due in part to the exclusion of children with mental retardation,

which decreased the heterogeneity of the sample. Secondly, group tests with a more narrow range of content rather than individual tests that have a more broad-based content were used in the study. Results of the Huberty et al. (1992) study, however, are consistent with Seidenberg and colleagues (1986) study using individual test in which little variance was accounted for by the seizure variables.

There has been a very limited number of studies comparing children with different types of seizures across measures of neuropsychological abilities. One study by O'Leary and colleagues (1983) examined 106 children with either generalized or partial seizures. The partial group performed significantly better on only 1 of 13 measures, the Tactual Performance Test-Total Time. A consistent pattern of poorer performance for the partial with secondary generalization seizure group was seen on 11 of the 13 test measures. Hermann, Desai, and Whitman (1988) found similar results when comparing a group of children with complex partial seizures of temporal lobe origin and a group with primary generalized seizures. The group with primary generalized seizures performed significantly worse in writing, mathematics and intelligence. Further analysis showed a consistent inverse relationship between seizure frequency and cognitive functioning (more seizures correlated with poorer performance) for children with generalized seizures but not for children with partial seizures originally in the temporal lobe. These findings suggest that seizure frequency and seizure type are highly

correlated and need to be assessed carefully. One finding that has been consistent across studies, however, is that children with more than one seizure type have more problems with academic achievement than children with only one seizure type (Hermann & Whitman, 1984; Rodin, 1989; Seidenberg et al., 1986).

Research findings concerning the effects of antiepilepsy medications and cognitive functioning have been equivocal. Several studies, however, have come to the same conclusion: two antiepileptic medications (phenytoin and phenobarbital), and polytherapy (more than one antiepilepsy medication) have been implicated as negatively influencing academic achievement in children with epilepsy (Andrewes, Bullen, Tomlinson, Elwes, & Reynolds, 1986; Coenen, Konings, Aldenkaamp, Renier, & van Luijtelaar, 1995; Dodrill, 1988; Forsythe, Butler, Berg, & McGuire, 1991; Stores & Hart, 1976; Trimble & Cull, 1988; Vining, Mellits, & Dorsen, 1987; Williams et al., 1996b). Phenytoin has been associated with intellectual function deterioration (Trimble, 1990) while phenobarbital has been associated with attentional difficulties and decreased short-term memory skills (Vining, Mellits, & Dorsen, 1987).

In contrast, Mitchell and colleagues (1991) found in a study of 78 children with epilepsy that treatment with antiepilepsy medication was not strongly related to academic achievement. More recently, Williams and colleagues (1998) found no

differences in performance on cognitive and behavioral measures for children with new-onset seizures before and after treatment with antiepileptic medications and controls. However, the children in this study had only been on medications for 6 months and so the study cannot rule out that prolonged use of antiepileptic medications may result in cognitive changes.

In another study of the effects of discontinuing medication, Aldenkamp and colleagues (1998) examined cognitive complaints in seizure-free children with epilepsy before and after drug discontinuation of carbamazepine, valproate, or phenytoin. Children reported significant improvement in the areas of concentration, memory problems, drowsiness, depression, aggressiveness, hyperactivity, and tiredness following drug discontinuation. Parents reported significant improvement in their children in the areas of alertness, concentration, tiredness, memory problems, and drowsiness after the medication was stopped. In this study, no differences in cognitive complaints were found based on type of medication used.

From the review of the literature, it can be concluded that antiepileptic medications have the potential to impair cognitive functioning and, therefore, can potentially affect academic achievement in children with epilepsy. Some of the inconsistencies of the findings are due to methodological problems such as absence of prospective design, small sample sizes, lack of control groups, and inclusion of subjects on polytherapy. Based on current studies, however, it appears that

medication alone does not account for the high rate of underachievement and academic problems seen in children with epilepsy. It may be that medications interact with psychosocial factors to influence achievement. Research investigating these interactions and change in academic achievement following the onset of seizures is needed.

A review of literature examining academic achievement in children with various chronic illnesses indicates that children with chronic conditions involving the brain are more at risk for academic performance problems than children with other chronic conditions not involving the brain (Fowler, Johnson, & Atkinson, 1985; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Rutter, Tizard, & Whitmore, 1970; Seidel et al., 1975). Rutter and colleagues (1970) in the Isle of -Wight study provided strong evidence that children with neurologically based conditions were more at risk for adjustment problems than children with other chronic physical conditions. An epidemiological study replicated the finding of greater risk with neurological conditions (Seidel et al., 1975). Recently, when comparing adolescents with neurological and non-neurological chronic conditions and healthy controls, Howe and colleagues (1993) found the neurological group was significantly lower on math, reading and knowledge scores than a healthy control group, and lower on reading and math than the non-neurological group. The strength of these past studies was the identification of children at risk for

academic problems based on their membership in a chronic condition group. The studies are limited, however, by the small samples in each of the condition groups. For example, the Fowler study (1985) included only 37 children with epilepsy, Howe and colleagues had only 19 children with epilepsy, and Rutter and colleagues study (1970) had only 21 children with epilepsy and 54 with asthma.

In a more recent study, Austin and colleagues (1998) found children with epilepsy performed significantly poorer than children with asthma in five areas of academic achievement: Composite, Reading, Mathematics, Language, and Vocabulary. In this study, boys with high severity epilepsy were most at risk for underachievement. Comparison studies between children with seizures and children with other chronic conditions, such as asthma, are important because when differences are found, it indicates that having a neurological condition has additional, unique effects on achievement beyond the effects of a chronic physical condition.

Asthma. The findings of studies on academic achievement in children with asthma have been inconsistent. Variables found to be associated with academic problems in these children include asthma medications, such as theophylline and steroids (Bender, Lerner, Ikle, Corner, & Szefler, 1991), SES (Gutstadt et al., 1989), and behavioral problems (Gutstadt et al., 1989). Freudenberg and colleagues (1980) found that 40 % of the parents of children with asthma reported

that their children had difficulty in school, particularly in reading. Recent studies utilizing standardized tests, however, do not support this finding (Bender, 1995; Gutstadt et al., 1989). Moreover, there are several studies in which children with asthma were doing the best academically among children with chronic conditions (Guerin, 1979; Rutter et al., 1970).

In a classic epidemiological study, Rutter and colleagues (1970) discovered that children with asthma had a verbal intelligence significantly higher than both general population children and those with other physical disorders such as heart disease, diabetes, and epilepsy. Lindgren and colleagues (1992) found children with asthma, some of whom were treated with theophylline, were academically unaffected. Congruently, Weldon and McGeady (1995) found no significant differences in cognition, attention, and learning between children with asthma taking theophylline and children with other chronic illnesses.

<u>Age</u>

Some relationships between age and academic achievement were found in the literature. Younger age at onset of seizures has been associated with higher rates of academic underachievement (Bourgeois, Prensky, Palkes, Talent, & Busch 1983; O'Leary, et al., 1983; Seidenberg, Beck, & Geisser, 1988). Older children were further behind in their achievement levels in word recognition, spelling, arithmetic, and reading comprehension than younger children. These

findings might reflect the tendency for children who are academically deficient to fall further behind over time (Seidenberg et al., 1986), however, there are methodological issues to consider in relation to interpretation of these findings. Few studies differentiate between age of onset and duration of epilepsy, making it difficult to assess the effects of these highly correlated factors individually. It is also difficult to determine with accuracy when the first seizure occurred, particularly for absence seizures or partial seizures. Again, no research studies were found that examined how age was related to academic achievement in children with new-onset seizures or in children with onset of another chronic health condition.

## Gender

In reviewing studies of child adaptation in chronic conditions, exploration of gender differences was the exception rather than the rule. Moreover, when gender differences were explored, the results were equivocal. Some studies reported better adaptation and academic achievement for girls than for boys with epilepsy (Stores & Hart, 1976; Holdsworth & Whitmore, 1974b). The clinical series by Stores and colleagues found boys with all types of seizure disorders had more anxiety, inattention, social isolation, and dependency compared to control boys; only girls with generalized bilateral seizures showed increased inattention and overactivity (Stores, 1977; Stores & Hart, 1976; Stores, Hart, & Piran, 1978).

More recently, in a study of children with epilepsy for more than one year, Austin and colleagues (1998) found that boys were more at risk for academic underachievement than girls. More specifically, boys with high seizure severity had the lowest scores. Similarly, adolescent boys with brain impairment had more externalizing and internalizing symptoms than girls with similar disorders (Howe, Feinstein, Reiss, Molock, & Berger, 1993).

In the Howe et al. (1993) study, however, male adolescents both with and without neurological conditions scored significantly higher on the knowledge subscale of the Woodcock-Johnson Psychoeducational Battery than adolescent females. Moreover, studies by Matthews and colleagues (1982), Williams and colleagues (1996a) and Rutter, Graham and Yule (1970) found no differences in adaptation of children with seizures based on gender. Unfortunately, few studies report a gender effect for achievement outcomes, and no studies reported a gender effect for children with new-onset seizures.

# Parent Response

### Attitude

There is minimal research of the relationship between parental attitudes and child academic achievement. Only one study specifically focused on parental attitudes regarding children with seizures and academic achievement and no study focused on children with new-onset seizures. In an early study, Hartlage and Green (1972) used a global measure of parental attitude to examine the relationship

between attitude and child's academic achievement. Only the factors of "disapproval of activity" and "retardation of development" correlated significantly with low achievement. The lack of significant findings may be due to the insensitivity of the measure. The authors used a broad measure of attitude rather than one specific to academic achievement or attitudes about having a child with epilepsy.

In a related study, Ferrari (1989) investigated the expectations and attitudes of mothers of children with epilepsy. Mothers rated their children with epilepsy to be less reliable, less trusting of others, more likely to have emotional problems, poorer in school performance and performance in sports, more moody, derive less enjoyment from their own company, and less adept at making friends than their healthy sibling. These findings are consistent with previous research (Long & Moore, 1979; Mulder & Suurmeijer, 1977) showing that parents have generally lower expectations for their child with epilepsy than their healthy children.

# **Expectations**

Literature on parent expectations for their child's achievement is scant. In general population children, parent expectations, future aspirations or current expectations for children's academic performance, have been consistently correlated with child academic achievement (Marjoribanks, 1988; Seginer, 1986;

Thompson, Alexander, & Entwisle, 1988). In a study of 10 children with moderate learning difficulties, Au and Pumfrey (1993) found that parent and teacher expectations were in accord with the child's actual academic attainment. The small sample size as well as problems with the measurement of expectations were limitations of the study. Parents were asked to estimate their child's performance on three test materials after they reviewed the materials. Thus, the expectations were task specific rather than expectations for a more broad performance in school.

Only two studies were found that investigated expectations for children with seizures and neither included children with new-onset conditions. In the classic study of children with epilepsy, Long and Moore (1979) found that parents had reduced expectations for academic achievement in their children with seizures, compared to their healthy siblings. Specifically, parents expected their children to have lower academic levels, a diminished ability to concentrate, and fewer employment opportunities. The measurement of expectations in this study also was broad-based and not specific to academic achievement or school success. In the second study, Green and Hartlage (1971) proposed that lower parental expectations for their child with epilepsy might contribute to academic underachievement in the child. Statistically significant correlations between measures of parental acceptance of lower educational performance and the child's

academic achievement were found. In this study expectations were not empirically measured, rather, a review of social work notes described parents as overprotective and accepting. The authors deduced that such attitudes would allow children to accept lower standards of performance for themselves (Green & Hartlage, 1971).

# Child Response

### <u>Attitude</u>

Because children's perceptions have been predictive of achievement in general population children (Mboya, 1989; Schunk, 1989), it is important to assess the perceptions of children with chronic illness. Only two studies were found that examined school-related perceptions in children with epilepsy and neither of these included children with new-onset seizures. Compared with matched samples of children with diabetes or healthy controls, children with epilepsy had significantly poorer self-concepts related to intellectual functioning, were more worried about testing in school, and were more nervous about having a teacher call on them (Matthews, Barabas, & Ferrari, 1983). Moreover, the parents of the children with epilepsy reported that their children had less positive feelings about school compared to the other two groups. In a more recent study, Austin and colleagues (1998) found that children's negative attitudes toward their condition were

significantly related to poorer academic achievement both in children with epilepsy and in those with asthma.

# School Self-concept

General population studies support the idea that positive self-concept and academic achievement are closely correlated (Garzarelli, Everhart, & Lester, 1993; Purkey, 1970). Fitts (1972) suggests that persons with positive self-concepts are apt to use their intellectual resources more efficiently. Mboya (1989) found that global self-concept and, more strongly, self-concept of academic ability were significantly related to academic achievement, supporting the theory that students' perceptions influence the direction, strength, and persistence of their achievement behaviors (Schunk, 1989). Children with positive self-concepts, both global and specifically related to academic ability, had more positive academic achievement than those with negative self-concepts (Mboya, 1989).

From a health perspective, Bailey-Britton (1987) found that better academic performance was associated with positive health self-concepts and fewer sickroom visits in a general population sample of children. Unfortunately, Matthews and colleagues (1983) found that children with epilepsy had significantly poorer self-concepts than did the diabetic and healthy control groups. Surprisingly, adolescents with well-controlled epilepsy had poorer self-images, lower achievement, and lower expectations for the future compared to adolescents with

uncontrolled or more severe epilepsy (Hodgman, McAnarney & Myers, 1979).

The small sample and inclusion of youth with mental retardation limit the generalizability of the results. No studies were found that examined self-concept of children with new-onset seizures in relation to their academic achievement.

## **Behavior**

Behavior problems and underachievement impose tremendous problems in childhood in terms of prevalence, human suffering, and resistance to interventions (Hinshaw, 1992) and, unfortunately, behavior problems are common in children with epilepsy (McDermott, Mani, & Krishnaswami, 1995). Moreover, the relation between behavior problems and underachievement has been strong across research studies. Barkley and colleagues (1990) found that children with externalizing behavior disorders often have difficulties such as grade retention and suspension. Similarly, Hinshaw (1992) found that inattention and hyperactivity were strong correlates of academic difficulties in childhood, while antisocial behavior and delinquency were associated with underachievement in adolescence. Huesmann, Eron, and Yarmel (1987) propose that underlying antecedent variables result in both underachievement and externalizing behaviors, thus providing support for this prospective, longitudinal study.

More recently, Austin and colleagues (1998) found that poorer school adaptive functioning, as rated by the teacher, was significantly associated with

poorer academic achievement in children with epilepsy as well as in children with asthma. No studies were found that explored behavior in children with new-onset seizures or changes in behavior over time following the onset of seizures.

## **Teacher Response**

### **Expectations**

Only a minimal amount of research on teacher factors related to academic achievement in children with epilepsy has been conducted, and no study specifically addressed teacher expectations for academic achievement in children with new-onset seizures. Bagley (1970) reported that teachers underestimated the intellect of children with seizure disorders by approximately one standard deviation. Teachers described children with epilepsy as inattentive, deviant, aggressive, attention-seeking, objectionable, isolated, withdrawn, and more frequently absent from school than general population children (Holdsworth & Whitmore, 1974a). Similar results found by Bennet-Levy and Stores (1988) demonstrated that teachers perceived children with epilepsy to have poorer concentration and mental processing, and to be less alert than their healthy peers.

Interestingly, teachers frequently reported lack of information about epilepsy (Holdsworth & Whitmore, 1974a). In an epidemiological study, 58% of the teachers who lacked experience with epilepsy and 37% of the teachers with experience with epilepsy expected poor academic performance from children with

epilepsy (Pazzaglia & Pazzaglia, 1976). Moreover, Holdsworth and Whitmore (1974a) found teachers to be less demanding of the child with epilepsy than their healthy peers; teachers did not require poor work to be re-done, nor did they assign homework for the child with epilepsy.

In a classic study, Guerin (1979) examined teachers' perceptions of academic and social behavior in children with mild and moderate health conditions. Although the sample size was only 30, children with epilepsy were rated lower in ideas, directions and activities than children with other health conditions. Moreover, 33% of the children with epilepsy were receiving special instruction. In contrast, the sample of children with asthma ( $\underline{n} = 102$ ) was rated as doing as well or better in academic and social domains than children with other chronic physical conditions.

## Summary

Children with chronic physical conditions are more at risk for academic underachievement than their healthy peers (Thompson & Gustafson, 1996).

Moreover, past research comparing academic achievement in different chronic condition groups has shown that children with neurological conditions are more at risk than children with non-neurological conditions (Howe et al., 1993).

The literature provides strong evidence that problems with academic achievement are over-represented in children with epilepsy and a disproportionate

number of children with epilepsy have learning difficulties (Bourgeois, 1998).

Although identified risks include family and child characteristics, and parent, child, and teacher response variables, no study has included all of these factors.

Moreover, no study has described changes in academic achievement following the onset of a chronic condition nor employed a longitudinal approach to explore academic achievement in children with new-onset seizures. Because of these weaknesses, it is necessary to study further what factors are associated with academic achievement in children with new-onset seizures.

### **CHAPTER 3**

### **METHODOLOGY**

Methods used to conduct the research are described in this chapter. The research design and sample selection criteria are explained, including a description of the sample. The procedures for how human subjects' rights were protected is detailed and followed by the procedures for data collection. The last section on instrumentation includes operational definitions of constructs measured within the model. New scales were tested for validity and reliability, and reliability analyses were conducted for established scales.

### Research Design

The study is an extension of an ongoing, prospective, and longitudinal research project funded by the National Institute of Neurological Disorders and Stroke to Joan K. Austin, the principal investigator. The larger study has five data collection points: baseline, 3 months, 6 months, 12 months, and 24 months. Data from the baseline and 12-month data collection periods were used in the study. Baseline data were collected within 6 weeks of a child having a first seizure or being placed on daily asthma medications. Data collected from children and their mothers during the baseline interview were retrospective, providing information from the year prior to the onset of the health condition. The 12-month data provides information from baseline to present. The 12-month period was chosen as

the follow-up data collection point to allow time for change in achievement to occur following the onset of the condition. Within the constraints of the educational system, a yearly assessment concurred with the ability to access standardized achievement test scores obtained by the school on an annual basis as well as the children's grades as reported by the teachers. The assumption that one year allowed opportunity for change in achievement to occur is also supported in the literature (Hinshaw, 1992).

# Sample Selection Criteria

The sample goal for the study was 75 children with new-onset seizures and 75 children with new-onset asthma. To be included in the study, children met the following criteria: (a) between the ages of 8 and 14 years; (b) first recognized seizure-like episode or placement on daily asthma medication indefinitely within the past 6 weeks; (c) no other chronic medical condition requiring long-term care, such as diabetes; (d) IQ of 70 or above (per school records and parent report of IQ or child not mentally handicapped); and, (e) no sibling with a chronic medical condition. Further criteria for inclusion in the seizure group were: (a) seizure-like episode must not have occurred within 1 week following a head injury; (b) seizure-like episode must not have been due to a known metabolic condition; and (c) child could not have had more than two previous febrile seizures. Children who had previous seizures that were unrecognized as such by the family were eligible for

the study. To be included in the asthma sample the subjects met the following additional criteria: (a) first hospitalization or treatment in the emergency room for asthma symptoms; (b) first referral to a specialist for evaluation or management of the asthma; or (c) initial placement on one or more of the following daily medications: Tilade, Cromolyn Sodium, or inhaled steroid. For the larger study, seizure subjects were recruited from emergency rooms, outpatient pediatric clinics, private neurologists and EEG laboratories at three sites: Indianapolis, IN, Memphis, TN, and New Orleans, LA. Asthma subjects were recruited from outpatient pediatric clinics at the same three sites. Several subjects were independently entered into the study after contacting Dr. Austin directly about her research project.

# Description of the Sample

The final sample for the study was 109 children with new-onset seizures and 46 children with new-onset asthma and their mothers. From Indianapolis sites, 103 subjects were recruited (65 seizure and 38 asthma subjects), 50 were recruited from the Memphis site (43 seizure and 7 asthma subjects), and 2 subjects (1 seizure and 1 asthma) were recruited from the New Orleans site. The seizure and asthma samples are described separately in the following sections.

# Seizure Sample

The children with new-onset seizures ranged in age from 8 to 14 years, with a mean age of 10.4 years at baseline. Seizure types reflected in the sample are presented in Table 1. Analyses showed that approximately 30% of the children had experienced only 1 total seizure at the 12-month data collection.

Racial composition of the sample was congruent with the population distribution of the combined sites: 27 (24.8%) were African American, 79 (72.5%) were Caucasian, 2 (1.8%) were Bi-racial, and 1 (.9%) were listed as other. The majority of children lived in households of 3, 4, or 5 persons, and in 2-parent families (n = 74, 67.9%). Only 14 children (12.8%) lived with a mother who had never been married and 10 (9.2%) lived in a divorced household. Mother's age ranged from 23 to 59 years, with a mean of 38.2 years. Education for mothers ranged from 8 to 20 years of school, with an average of 13.9 years. Average income for the families of children with seizures was \$30,000 to \$40,000. SES ranged from 16.4 to 82.2, with a mean of 61.1, which represents an average score on the scale.

### Asthma Sample

The asthma sample was very similar to the seizure sample on the demographic variables measured. Children with asthma ranged in age from 8 to 14

Table 1

Demographic and Seizure Type for Seizure Sample at Baseline

Variable	N	Mean	<u>SD</u>	Percent
Age baseline	109	10.42	1.97	٠.
Generalized tonic-clonic	42			38.5
Absence	11			10.1
Elementary partial	10			9.2
Complex partial	27			24.8
AAM	1			.9
Elementary partial with secondary generalization	5			4.6
Complex partial with secondary generalization	11			10.1
Undetermined	2			1.8

years, with a mean of 10.2 years. Symptom frequency of wheezing and coughing ranged from no episodes for 6 months or more to 30 or more episodes per month. Table 2 contains symptom frequency and other demographic information for the asthma sample.

The distribution for the racial composition was also congruent with population estimates for the combined sites: 10 (21.7%) were African American, 32 (69.6%) were Caucasian, 3 (6.5%) were Bi-racial, and 1 (2.2%) were listed as other. The majority of children with asthma lived in households of 3, 4, or 5 persons, and in 2-parent families (n = 27, 58.7%). Only 2 children (4.3%) lived with a mother who had never been married and 12 (26.1%) lived in a divorced household. Mother's age ranged from 29 to 51 years, with a mean of 37.6 years. Education for mothers ranged from 9 to 20 years of school, with an average of 13.9 years. Average income for the families of children with seizures was \$20,000 to \$30,000. SES ranged from 16.4 to 81.4, with a mean of 60.4, representing an average score on the scale.

## Protection of Human Subjects

A member of the research team contacted potential families and the study was explained to one or both parents, and the child. At the Indianapolis recruitment sites, a member of the research team worked directly with staff in the agencies to identify potential subjects. At the sites in Memphis and New Orleans, a

Table 2

Demographic and Asthma Symptoms for Asthma Sample at Baseline

Variable	<u>N</u>	Mean	<u>SD</u>	Percent
Age baseline	46	10.22	1.93	
Asthma symptoms				
No wheezing or coughing 6 months or >	l			2.2
No wheezing or coughing 3 to 6 months	1			2.2
No wheezing or coughing 1 to 3 months	8			17.4
I-9 wheezing or coughing episodes in past month	21			45.7
10-19 wheezing or coughing episodes in past month	3			6.5
20-29 wheezing or coughing episodes in past month	2			4.3
30 or more wheezing or coughing episodes in past month	10			21.7

nurse from the agency distributed limited information about the study to potential subjects, and parents signed a form giving permission for a nurse from the Indianapolis research team to contact them and provide more information about the study.

During the first telephone contact, information known about the child and the criteria for inclusion were verified, and appropriate families were asked to participate in the study. As part of the informed consent statement read to the families, parents and children were informed of their right to decline participation at any point in the study. Additionally, parents and children were assured that their responses would be confidential and anonymous, and that their decision to participate would not affect their quality of medical care. Consent to participate was audiotaped, and later, parents and children provided written consent to participate in the study and for the research team to obtain data from medical records and from the child's teacher and school (see Appendix A).

Anticipated risks to the participants were minimal. Although self-disclosure was involved, it was not anticipated that the questions would be uncomfortable for the parents or children. Some parents wanted to participate themselves but did not want their children to participate. Other parents did not want the nurse to interview the child over the phone but would allow the questionnaires to be mailed to the child for completion at home. Participants were encouraged to tell the

interviewer if the interview made them feel uncomfortable, or to call the principal investigators, Dr. Joan K. Austin or Dr. David Dunn, to talk about their discomfort. Dr. Austin is a doctoral prepared nurse in psychiatric mental health nursing, and Dr. Dunn is a pediatric neurologist and psychiatrist. No families had reported any discomfort at the time of this writing.

The only direct benefit to participants was the incentive fee of \$20 per interview for parents and \$8 per interview for children. It was explained to the participants that the information they provided might increase understanding of adaptation to chronic illnesses in children. The indirect benefit to participants was the ability to talk to a nurse about the health condition. Additionally, resource information about the child's condition was provided when requested by the families.

### Procedure for Data Collection

Subjects were identified by Clinical Nurse Specialists and nurses working in the hospital settings, by EEG technicians in both the hospitals and private neurologists' offices, and by referral from lay persons aware of the ongoing study. All potential participants who met the criteria were contacted by the project coordinator or a member of the research team within one week of the referral. For the larger study, the participation rate for families who met the criteria was 94%

and the retention rate at 12 months was 96% of those who provided data at baseline.

The majority of the people who chose not to participate cited time constraints as their reason for denial. Some parents who declined stated that they felt the questions would force both themselves and their children to "relive the traumatic experience" of the first illness episode.

During recruitment, a frequently occurring problem at the sites was the extended length of time between the first seizure or onset of asthma and contact with the health care system. For the seizure group, it was sometimes 10 to 12 weeks after the first seizure before the child was able to get an appointment to see the neurologist. The mean length of time since seizure onset to the baseline interview was 35 days, so it was within the six-week criterion for inclusion.

Similarly, the children with asthma would often be treated by their family physician for several months or even years before seeking the services of a specialist. The mean length of time since chronic asthma onset to the baseline interview was only 25 days. Inaccurate telephone and address information given by subjects to the health care workers was an additional source of recruitment problems. Having no telephone in the home was especially problematic for the potential subjects recruited from the Memphis site.

After subjects were enrolled in the study, data were collected by research assistants through structured telephone interviews with the parent(s) and children, and mailed questionnaires to teachers. During the telephone interview, the data collected from the parent(s) and children were entered directly onto the computer via FOXPRO, a computer data management system. Each interview required approximately one hour per parent and approximately 30 minutes per child. For some of the families, particularly those who did not have a phone at the time of the interview, questionnaires were mailed directly to the family members participating with postage-paid envelopes for return mailing. A teacher, identified by the child and/or family as knowing the child best, was mailed a letter explaining the purpose of the study, a release of information for school records signed by the parent(s), and data collection instruments. The teacher was asked to photocopy the child's most recent grades and standardized test scores, and complete a behavior rating scale for the child. Teacher information was difficult to obtain due to staff turn over, incorrect teacher or school information from the parent(s), or teacher refusal to participate. The participation rates for the teachers at baseline and 12 months was 80% and 73%, respectively.

# **Instrumentation**

Operational definitions for the concepts in the theoretical framework are summarized in the following section. Copies of all instruments are contained in

Appendix B. The author developed three instruments for the present study: Child Stressors, Parent Expectations Toward Academic Achievement, and Teacher Expectations for Child's Academic Achievement. Content validity was established by consulting experts in the fields of education, nursing, and statistics (DeVellis, 1991). Validity and reliability (coefficient alpha) information is presented in this section.

### Family Characteristics

Demographic variables. The demographic variables were measured using a form designed for the larger study. Information about age, gender, race, educational levels, and occupation/income was obtained from the mother.

Socioeconomic status (SES) was measured using a method that combines mother's education and the occupation of the head of the household to create one score (Green, 1970). This score has been found to be a valid and reliable indicator of SES in the prediction of health behavior (Green, 1970).

Child stressors. Child stressors were measured using an instrument designed for this study by the author. The 11-item self-report instrument is a modification of the scale developed by Coddington for measuring the child's life events (Coddington, 1972). Children respond with "yes" or "no" for each stressor. A summated total score was calculated with higher scores reflecting more stress.

Scores were recoded 1 (yes) and 0 (no), leaving a possible range of scores from 0

to 10. The range of scores was 0 to 8 for the seizure sample and 0 to 9 for the asthma sample. Mean scores were 2.2 and 2.1 for the seizure sample at baseline and 12 months, respectively. For the asthma sample, mean scores were 2.6 and 2.5 for the two data points, respectively. Because of the nature of the scale reflecting life events that are not necessarily associated or measuring a latent construct, the item-to-total correlations were low to moderate (.14 to .56) and the analyses showed low moderate internal consistency reliabilities (coefficient alpha = .67 at baseline and .68 at 12 months). No items were deleted from the scale.

Family resources. Family resources were measured using selected items from the Family Inventory of Resources for Management (FIRM; McCubbin & Thompson, 1991). The original FIRM was a 69-item self-report instrument that provided information on the family's repertoire of resources in four areas: Esteem and Communication; Mastery and Health; Extended Family Social Support; and Financial Well-Being. The items that were selected for the current study were those from the Esteem and Communication and Mastery and Health subscales.

Parents' respond to these 30 items on 4-point scales of 1 (not at all) to 4 (very well). Validity and reliability have been strong in previous research, and subscales of the FIRM have been correlated with change in child behavior. Analyses for the Mastery and Health subscale also showed strong internal consistency reliability in this study (coefficient alpha = .92 at baseline and .95 at 12 months). Reliabilities

for the Esteem and Communication subscale also were strong, .87 at baseline and .88 at 12 months.

### Child Characteristics

Aptitude. Standard scores from group administered school achievement tests available in the child's school or clinic records were used to measure child aptitude. The majority of the scores came from achievement tests administered by the school system such as the Indiana Statewide Testing for Educational Progress (ISTEP) and the Comprehensive Test of Basic Skills (CTBS).

Illness characteristics. Illness characteristics for the seizure group were seizure frequency, seizure type, and presence or absence and type of antiepilepsy medication(s). For the asthma group the variables were frequency of the asthma symptoms and presence or absence and type of medication(s).

## Parent Response

Parent attitude. Parent attitude was measured using the Semantic Differential Attitude Scale (SDA), a 10-item instrument developed for a previous study by Austin. The SDA uses a format developed by Osgood for measuring attitudes (Osgood, Suci, & Tannebaum, 1957) that contains bipolar adjectives reflecting the evaluative domain, such as "good/bad", "fair/unfair", and disappointing/satisfying." Parents' respond to these items on 7-point scales of 1 (extremely good) to 7 (extremely bad). A total score was used in the data analyses.

The SDA was found to have strong internal consistency reliability in past research (alpha = .77). Reliability analyses for this study showed moderate internal consistency reliability at 12 months (alpha = .68).

Parental attitude also was measured using the Stigma Scale, a 6-item scale developed by Austin based on work by Ryan, Kempner, and Emlen (1980) to measure stigma in others. Parents rated their perceptions of stigma surrounding their children's illness on 7-point scales of 1 (strongly disagree) to 7 (strongly agree). A total score was used in analyses. The scale was found to have good reliability and validity in past research (alpha = .78). The reliability for this study was similar to past studies (alpha = .80).

Parent expectations toward child academic achievement. Expectations were measured using a 5-item instrument developed by the author for this study. Parents rated their expectations for their children's academic performance on 5-point scales of 1 (strongly agree) to 5 (strongly disagree). A summated score was used to indicate higher expectations when a higher score was obtained. No item-to-total correlations were below .59 and the alpha coefficients for the scale were .87 at baseline and .85 at 12 months. Validity was assessed by comparing the scale score to the parent report of academic performance score on the Child Behavior Checklist (Achenbach, 1991a) and the Teacher Expectations for Child's Academic Achievement scales. The correlations were strong,  $\underline{r} = .55$  and .69,  $\underline{p} < .01$ , with

the parent report, and r = .62 and .72, p < .01, with the teacher expectations, for the scale at baseline and 12 months, respectively.

# Child Response

Child attitude. Child attitude was measured using the Child Attitude

Toward Illness Scale (CATIS, Austin & Huberty, 1993). The CATIS is a 13-item scale providing information on how children feel about having a health condition.

Children respond to each statement using 5-point scales of 1 (never) to 5 (very often). The scale has been found to have good reliability (alpha = .82) and validity in past research (Austin et al., 1998). A total score was used in the analyses.

Analysis for this study showed good reliability (alpha = .81).

School self-concept. General self-concept was measured using the Piers-Harris Self-Concept Scale (PH), which measures the children's perceptions of themselves (Piers, 1984). The PH is an 80-item scale providing a total self-concept score and subscale scores measuring behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction. Children are asked to respond "yes" or "no" to each statement. The school self-concept subscale includes 17 items reflecting the child's self-assessment with respect to intellectual and academic tasks, including general satisfaction with school and future expectations. The total score for the PH has been found to have strong validity and reliability (alpha = .77) in past research (Austin, Huberty,

Huster, & Dunn, 1998). Total score reliabilities in this study were strong at baseline (alpha = .92) and 12 months (alpha = .96). Analyses for the school self-concept subscale for this study showed alphas ranging from .70 to .79 at baseline, and .78 to .85 at 12 months for the seizure and asthma samples.

Child behavior. Child behavior problems were measured using the parent's report from the Child Behavior Checklist (CBCL, Achenbach, 1991a), and the teacher's report from the Teacher's Report Form (TRF, Achenbach 1991b). The CBCL and TRF scores were standardized to T-scores (mean 50, SD 10) for mothers and teachers. The norms for the CBCL and TRF are based on age and gender, using the Achenbach scoring program. These behavioral assessment inventories have 118 items that measure behavior problems. Both instruments contain 11 different behavior problem scores, including two Second Order Factors (Internalizing and Externalizing Behavior Problems) and eight syndrome scores (Withdrawal, Delinquent Behavior, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems and Aggressive Behavior). A total behavior problem score is also provided. Respondents use 3point scales from 0 (not true) to 2 (very or often true) to indicate how true each behavioral description has been for the child over the past six months for the parents and over the past 2 months for the teachers.

The CBCL also provides a social competency score and the TRF provides ratings of four adaptive characteristics and the sum of those characteristics for a total adaptive competency score. The total score for the CBCL has been found to have good validity and reliability in past research (alpha = .95, Austin, Risinger, & Beckett, 1992). The TRF has had similar properties (alpha = .92). Internalizing and Externalizing Behavior Problem scores and the total adaptive competency score were used in data analyses.

# **Teacher Response**

Teacher Expectations for Child's Academic Achievement. Teachers were asked to complete a 7-item instrument designed by the author to measure teacher expectations of academic achievement in the child. Teachers respond using 5-point scales of 1 (very likely) to 5 (very unlikely). A summated score was used to indicate higher expectations when a higher score was obtained. One item-to-total correlation was .36 (expectation for increased school absences) but the alpha improved only .01 if the item was deleted. The remaining item-to-total correlations ranged from .50 to .83 and the alpha coefficient for the scale was .87 at 12 months for the 7 items. Comparing the scale with parent and teacher ratings of academic performance as measured by the Child Behavior Checklist and Teacher's Report Form, respectively, assessed validity. At the p = .01 level, the scale was

significantly correlated with the parent rating,  $\underline{r}$ 's = .56 and .64, and the teacher rating,  $\underline{r}$ 's = .63 and .76, at baseline and 12 months, respectively.

## Child Academic Achievement

Child academic achievement was measured using scores from groupadministered tests given during the academic year at school. The tests provide
information about specific academic skills and reflect the curriculum used in the
schools. Although different standardized tests were utilized by the various school
systems, the majority of the schools used one of the following: the Indiana
Statewide Testing for Educational Progress (ISTEP), the Comprehensive Test of
Basic Skills (CTBS), the Iowa Test of Basic Skills (ITBS) and the California
Achievement Tests (CAT). The content of these types of group-administered tests
are similar across grades and the scores tend to be highly correlated. Additionally,
because these tests are nationally normed and based on a normal distribution,
direct comparability is allowed. It was also assumed that children were receiving
similar instruction despite site differences, because all elementary schools follow
the same basic curriculum. Therefore, it was assumed that there would be no
differences between children as a function of the group test they were given.

The tests include measures of basic academic skills, such as reading, language, and math, and often provide different subtests in these basic areas, such

as language mechanics and math computation. A total composite score also is provided, which is an overall measure of achievement. The four scores common to all tests were used in the analyses: Reading, Language, Math, and Total Battery.

The scores for the standardized achievement tests were reported in percentiles, which have a rectangular rather than a normal distribution. It was assumed that the scores for the standardization group followed a normal distribution. Because parametric statistics are not appropriate methods of analysis for percentile data, the percentiles for each test score were converted to standard T-scores with a mean of 50 and standard deviation of 10, which are appropriate for parametric analysis. The conversions were obtained by finding the z-score that corresponded to each percentile rank in the normal distribution and applying it to the T-score conversion formula, which is z \* 10 + 50. Consequently, each percentile was converted to its corresponding T-score, which was then used as the score in analyses.

The teacher's rating of academic performance on the Teacher's Report

Form (Achenbach 1991b) was also used as a measure of academic achievement.

Baseline school performance was obtained from the teacher who best knew the child at least 2 months prior to the onset of the health condition, with standardized scores and grades from that same retrospective time period. Information at 12 months was obtained from the child's current teacher.

## **Data Analyses**

Initially, data were examined for accuracy, completeness, and the presence of outliers using SPSS for Windows, version 9.0. Distributions were examined for normality, skewness, and kurtosis. Subjects with missing data were excluded from only that specific analysis. The analyses for the research questions are detailed in the following section.

Question 1. Are there differences between the groups of children with seizures and those with asthma in academic achievement at baseline?

<u>Hypothesis 1</u>. There will be no differences between the groups in academic achievement at baseline.

Initially, a <u>t</u>-test was conducted to see if the two groups were different by age. The seizure and asthma groups were not different by age but there was a gender difference in age, with girls being older than boys. Therefore, MANCOVA with age as a covariate and gender and illness as fixed factors was used to test for differences on the five dependent achievement variables (Reading, Language, Math, Total Battery, and Teacher Rating of Performance). When the multivariate <u>F</u> was significant, univariate analyses were used to explore differences.

Question 2. Are there differences between the groups of children with seizures and those with asthma in academic achievement at 12 months?

Hypothesis 1. Children with seizures will have poorer academic achievement outcomes than children with asthma at 12 months.

MANCOVA with age as a covariate and gender and illness as fixed factors was used to test for differences on the five achievement variables (Reading, Language, Math, Total Battery, and Teacher Rating of Performance). When multivariate <u>F</u> was significant, univariate analyses were used to find the differences.

Question 3. Are there differences in change in academic achievement over time between children with seizures and those with asthma?

Hypothesis 1. Children with seizures will have more negative change in academic achievement outcomes from baseline to 12 months than children with asthma.

MANCOVA with age and baseline scores as covariates, and gender and illness as fixed factors was used to test for differences on the five dependent variables at 12 months (Reading, Language, Math, Total Battery, and Teacher Rating of Performance). When multivariate <u>F</u> was significant, univariate analyses were used to find the differences.

Question 4. How much variance do variables of family characteristics (demographics, child stressors, family resources), child characteristics (aptitude, illness characteristics, age, gender), parent response (attitudes, expectations), child response (attitude, school self-concept, behavior), and teacher response

(expectations) account for in child academic achievement (standardized scores, teacher performance ratings) at 12 months for the seizure sample?

Hypothesis 1. Family characteristics of higher SES, greater number of years of parent education, lower child stressors, and higher family resources, will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 2. Child characteristics of higher aptitude and less severe seizure conditions will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 3. Parental response of more positive attitude and higher expectations for their child's achievement will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 4. Child response of more positive attitude, more positive school self-concept, more adaptive competencies, and lower (internalizing and externalizing) behavior problems will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 5. Teacher response of more positive expectations for the child's academic achievement will be significantly related to higher academic achievement in children with seizures at 12 months.

Cross-sectional analyses of the 12-month data were conducted for the seizure sample to evaluate the relationship of the variables to academic achievement. The cross-sectional analyses consisted of several components. First, univariate analyses were conducted to evaluate the relationships among the variables, using the Total Battery and the Teacher Rating of Performance as the dependent variables. The goal was to reduce the number of independent variables that would be entered in the final regression model. The relationships between academic achievement and categorical variables, such as gender, race and illness characteristics, were explored using t-tests to test whether the academic achievement scores differed across the categories specified by the variable. The associations between continuous variables and academic achievement scores were assessed using Pearson correlation coefficients. In addition, correlational analyses among the continuous variables were carried out for identification of overlapping constructs, assuring that collinearity was not a concern in the subsequent analyses. Second, variables found to be significantly related ( $p \le .20$ ) to the academic achievement variables were considered in a series of multivariate regression models (Tabachnick & Fidell, 1996).

#### CHAPTER 4

#### RESULTS

The results are organized in two major sections consisting of a description of study variables and the results of the analyses addressing each research question and hypothesis. Prior to analysis, all variables were examined through various SPSS programs for accuracy of data, missing values, and fit between the distributions and the assumptions of multivariate analysis. Frequency distributions were examined to determine appropriateness of the data for further analysis. Skewness and kurtosis were determined to be not significantly different from the normal distribution (see Appendix C). In addition, no cases were deleted because of univariate or multivariate outliers.

Data analyses were conducted using SPSS multivariate analysis of covariance (MANCOVA), multivariate analysis of variance (MANOVA), analysis of variance (ANOVA), analysis of covariance (ANCOVA), Pearson's r correlation coefficient (PEARSON CORR), t-test (T-Test), and multiple regression (REGRESSION). MANCOVA and MANOVA were used to identify groups of variables with a significant relationship with the academic achievement variables of standardized achievement test scores (Reading, Language, Math, and Total Battery) and the Teacher Rating of Performance. ANOVA was used to examine the differences among the groups (seizures and asthma/girls and boys) on the

achievement variables, with ANCOVA used to test the differences while controlling for covariates. Pearson's correlation was used to examine the strength of association among the independent and dependent variables. Lastly, multiple regression was used to determine the amount of variance the independent variables accounted for in the prediction of academic achievement in children with seizures.

### **Description of Study Variables**

In this section, the major independent and dependent variables are described for each sample (seizures and asthma). Tables 3 through 6 contain descriptive information on the independent variables for both samples, with the exception of some demographic variables that were presented in Tables 1 and 2 in Chapter 3. Table 7 contains descriptive information on the dependent variables.

### Independent Variables in the Model

The independent variables in the model were: family characteristics (demographics, child stressors, and family resources), child characteristics (aptitude, illness characteristics, age, and gender), parent response (attitude and expectations for achievement), child response (attitude, school self-concept, and behavior), and teacher response (expectations for achievement).

#### Family Characteristics

<u>Demographic variables</u>. Information about educational level and SES was obtained from the mothers (Table 3). Mean educational level of the mothers was

Table 3

<u>Description of Family and Child Characteristic Variables for Seizure and Asthma Samples</u>

			Seizi n = 46			Asthma (n = 28 - 46)			
Variable	Range	Baseline	12 months		Baseline		12 months		
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	SD	<u>M</u>	<u>SD</u>
Mother Education	8-20	13.9	2.8	_		14.0	2.7		
SES	16.4- 82.2	61.1	11.5			60.4	13.3		
Child Stressors	0-9	2.2	2.2	2.0	2.0	2.8	2.3	2.7	2.6
Family Resource of Mastery & Health	0-3	2.0	.6	2.1	.6	1.9	.6	2.1	.6
Family Resource of Esteem & Communication	0-3	2.4	.5	2.4	.5	2.5	.4	2.4	.5

13.9 years for the seizure sample and 14.0 years for the asthma sample, reflecting approximately 2 years of college education. SES scores were 61.1 and 60.4 for the seizure and asthma samples, respectively, which represent average scores on the scale.

Child stressors. Child stressors were measured using an 11-item self-report instrument that children respond to with "yes" or "no" for each stressor, leaving a possible range of scores from 0 to 10. Mean scores indicate that the children in the seizure sample experienced approximately 2 stressors in the year prior to each data collection. Children in the asthma sample experienced slightly less than 3 stressors in the past year. Table 3 contains data for both samples.

Family resources. Family resources were measured using selected items from the Mastery and Health and Esteem and Communication subscales of the Family Inventory of Resources for Management (FIRM; McCubbin & Thompson, 1991). Scoring for these scales was anchored to the response items. Most mean scores for both samples (Table 3) fell between 2 (minimal) and 3 (moderate), indicating minimal to moderate levels of family resources. Scores for Mastery and Health tended to be lower than scores for Esteem and Communication for both samples.

#### **Child Characteristics**

Aptitude. Standard scores from group-administered school achievement tests from the child's school or clinic records measured child aptitude. Only 37 (34%) of the children had aptitude scores available and, therefore, these scores were eliminated from further analysis. The reason for the large number of missing values was that the aptitude was not included as part of the results for the majority of tests administered.

<u>Illness characteristics/age/gender</u>. Information about seizure type for the seizure sample, asthma symptom frequency for the asthma sample, and age and gender for both samples was presented in Chapter 3.

# Parent Response

Parent attitude. Parent attitude was measured at 12 months using the 10item Semantic Differential Attitude Scale. The mean scores for both samples fell
slightly below 4 (neither bipolar adjective), reflecting neutral to very slightly
positive attitudes about their child's illness. Parental attitude also was measured at
12 months using the 6-item Stigma Scale. The mean scores of 2.5 and 2.4 for the
seizure and asthma samples, respectively, fell between 2 (moderately disagree) to 3
(slightly disagree), reflecting low perceptions of stigma. Table 4 contains the
descriptive information about these scales.

Table 4

Description of Parent Response Variables for Seizure and Asthma Samples

				zures 1 - 97)				sthma 28 - 41)	
Variable	Range	Baseli	ne	12 mc	onths	Baselin	е	12 mon	ths
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	SD	<u>M</u>	<u>SD</u>
Attitude- Semantic Differential	2.4-4.8			3.9	.32			3.8	.46
Attitude- Stigma	1-7			2.5	1.3			2.4	1.3
Expectations	5-25	18.0	4.6	18.9	4.6	19.9	3.9	20.2	3.3

Parent expectations toward child academic achievement. Expectations were measured using a 5-item instrument on which parents rated their expectations for their children's academic performance. A summated score, with a range of 5 to 25, was used to indicate higher expectations when a higher score was obtained. As shown in Table 4, means for the seizure and asthma samples at baseline reflected relatively high expectations for achievement. There was a trend for more variability and lower scores for the seizure sample compared to the asthma sample.

# Child Response

Child attitude. Child attitude was measured at 12 months using the 13-item Child Attitude Toward Illness Scale (Table 5). The mean score for both samples was 3.8, which fell between 3 (sometimes) to 4 (often), indicating a slightly positive attitude.

School self-concept. Self-concept was measured using the 80-item Piers-Harris Self-Concept Scale. The subscale of intellectual and school status was used in the analyses. Mean scores for the seizure and asthma samples were 14.1 and 14.7 at baseline, and 14.4 and 14.9 at 12 months, respectively. These scores reflect a relatively high self-concept. There was a trend for more variability in the seizure sample. The five other subscale scores and the total self-concept scores are presented in Table 5.

Table 5

Description of Child Response Variables for Seizure and Asthma Samples

				ures				hma		
			<del></del>	<u>8-104)</u>				10-44)		
Variable	Range	Basel	ine	12 m	12 months		Baseline		12 months	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	SD	<u>M</u>	SD	
Attitude	1.85 <b>-</b> 5.0			3.8	.60			3.8	.54	
Self-concept										
Behavior	1-16	14.0	3.1	14.1	3.0	14.5	1.8	14.8	1.9	
Intellectual and school status	3-17	14.1	2.9	14.4	3.3	14.7	2.3	14.9	2.5	
Physical appearance and attributes	2-14	0.8	2.5	11.2	2.8	11.3	1.8	11.2	2.5	
Anxiety	0-14	10.0	3.2	11.0	3.1	10.9	2.9	11.3	2.9	
Popularity	2-15	9.7	2.5	10.4	2.5	10.3	2.2	10.6	2.0	
Happiness and satisfaction	3-11	9.0	1.5	9.0	1.8	9.6	.61	9.4	1.2	
Total self- concept	22-87	66.8	11.3	68.9	12.8	69.2	9.3	70.9	10.1	

Child behavior. Child behavior was measured using the mother's report from the Child Behavior Checklist (CBCL) and the teacher's report from the Teacher's Report Form (TRF). The CBCL and TRF scores were standardized to T-scores with a mean of 50 and a standard deviation of 10. The CBCL provides behavior problem scores, including two Second Order Factors (Internalizing and Externalizing Behavior Problems) and eight syndrome scores (Withdrawal, Delinquent Behavior, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems and Aggressive Behavior). Higher behavior problem scores reflect more problems. The TRF provides a rating of total adaptive competency. Higher scores for adaptive competency reflect greater competency or fewer problems. In general, with few exceptions, the behavior problem means for both samples were about ½ standard deviation above the population norm at baseline. There also was a general trend for behavior problem scores to be lower at 12 months for both samples. For the seizure sample the total adaptive competency score was slightly below the population mean. This score for the asthma sample was very near the population mean. All of these scores are presented in Table 6.

Table 6

Description of Child Response Variables for Seizure and Asthma Samples

				ures				sthma	
37. *.1.1.	<u> </u>	D!		8-108)	1	D1		35-46)	- AL -
Variable	Range	Baseli		12 mc		Baseli		12 mor	
<u></u>		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Child Behavior								•••	
Internalizing Behavior Problems	31-83	54.7	10.4	52.7	10.7	56.0	11.1	50.4	9.9
Externalizing Behavior Problems	30-77	52.8	10.6	52.6	10.3	52.0	10.8	51.4	9.5
	50.07	<b>63</b> 0	0.6		7.0	66.7		540	<i>-</i> 1
Withdrawal	50-97	57.0	8.6	55.5	7.8	55.7	6.5	54.0	6.1
Delinquent	50-76	55.0	6.6	54.2	6.2	55.5	6.4	54.3	5.7
Behavior									
Somatic	50-89	54.9	6.3	54.6	5.9	59.2	10.2	54.9	6.5
Complaints									
Anxious/Depressed	50-90	57.0	8.4	55.8	7.3	57.3	9.8	53.7	5.5
Social Problems	50-90	57.2	8.6	56.6	8.5	55.0	6.9	55.8	7.4
Thought Problems	50-76	55.0	7.4	53.8	7.0	52.8	5.3	52.0	5.6
Attention Problems	50-92	59.0	9.5	58.5	9.5	57.7	8.9	56.1	7.7
Aggressive	50-82	56.1	8.3	56.1	8.3	55.6	6.3	54.9	6.7
Behavior									
Total Behavior Problems	24-81	55.8	10.0	54.2	11.0	55.0	10.8	51.5	9.7
Total Adaptive Competency	35-65	47.9	9.4	47.4	8.6	50.0	10.6	49.5	9.8

# Teacher Response

Teacher Expectations for Child's Academic Achievement. Teachers completed a 7-item instrument to measure expectations of academic achievement in the child. A summated score, with a range from 7 to 35, was used to indicate higher expectations when a higher score was obtained. Mean scores for the seizure and asthma samples at baseline were 23.0 and 22.1, and at 12 months were 25.1 and 26.0, respectively. These scores reflect slightly higher expectations for the child at 12 months compared to baseline. Data for this scale are presented in Table 7.

## Dependent Variables in the Model

The dependent variables in the model were achievement test scores for Reading, Language, Math, and Total Battery obtained from the child's schools. The Teacher Rating of Performance, a reflection of the child's overall academic functioning, was obtained from the child's teachers and also was used as a dependent variable.

# Child Academic Achievement

Achievement tests scores and Teacher Rating of Performance. Child academic achievement was measured using scores from school-administered group tests given during the academic year and performance ratings from the Teacher's Report Form (TRF). Mean scores for the two samples at both data collections

Table 7

<u>Description of Teacher Response and Academic Achievement Variables for Seizure and Asthma Samples</u>

	_			ures 0-92)			Asthma ( <u>n</u> = 11-37)		
Variable	Range	Baselin	Baseline 12		12 months		ne	12 months	
	_	<u>M</u>	SD	<u>M</u>	<u>SD</u>	<u>M</u>	SD	<u>M</u>	SD
Teacher Expectations for Achievement Achievement Test Scores	9-35	23.0	8.2	25.1	6.6	22.1	8.8	26.0	6.9
Reading	27-73	54.9	11.3	54.9	10.8	56.3	9.0	54.2	11.8
Language	27-73	56.5	11.1	54.8	10.8	57.1	8.3	52.6	9.9
Math	31-73	53.9	11.7	53.3	10.7	59.3	9.3	53.2	10.4
Total Battery	27-73	55.9	11.6	54.7	10.7	57.9	8.4	53.1	9.7
Teacher Rating of Performance	35-65	49.2	9.4	48.4	9.6	51.3	9.1	50.9	9.4

were within one standard deviation of the mean (Table 7), indicating that on average the children were performing slightly above the average range. Teacher Rating of Performance for the seizure sample was 49.2 at baseline and 48.4 at 12 months, and for the asthma sample was 51.3 at baseline and 50.9 at 12 months. These scores are within ½ standard deviation of the mean, also indicating average performance.

At baseline, approximately 27% of the seizure sample and 37% of the asthma sample had missing achievement test scores. At 12 months, the percentage of missing data was larger, with 48% for the seizure sample and 50% for the asthma sample. One of the reasons for the large number of missing data is that the majority of school systems did not test children prior to the 2<sup>nd</sup> or 3<sup>rd</sup> grade, so that testing was not completed on children younger than age 8 or 9. Second, testing was not administered on an annual basis, so if a child was 11 when the onset of the condition occurred, there might not have been testing done in the year prior to the onset. One other possible explanation for the missing data is that children who are receiving special educational services are exempt from taking the group-administered school tests. In this sample, approximately 13% of the sample was receiving special services at baseline and 17% of the sample was at 12 months.

## **Preliminary Analyses**

Preliminary analyses were conducted to determine which factors needed to be controlled for in further analyses. Independent sample <u>t</u>-tests indicated no differences between the samples of children with seizures and children with asthma on the major independent variables at baseline and 12 months: family characteristics (demographics, child stressors, and family resources), child characteristics (illness characteristics, age, and gender), parent response (attitudes and expectations), child response (attitude, school self-concept, and behavior), and teacher response (expectations).

There was a significant difference, however, in age by gender, with girls being older than boys (mean age girls = 10.72, mean age boys = 9.97,  $\underline{t}$  = 2.143,  $\underline{p}$  = .017). Further investigation showed that girls with asthma were significantly older than boys with asthma (mean age girls = 10.74, mean age boys = 9.58,  $\underline{t}$  = 2.028,  $\underline{p}$  = .05), but age of children with seizures did not differ by gender. As the child's age at baseline was significantly different between girls and boys, age was included as a covariate in future analyses where appropriate.

## Results of Analyses

The following section contains each research question and hypotheses, the analyses used to examine the data, and the results obtained. The findings for each question are summarized following the results.

#### Question 1

Are there differences between the groups of children with seizures and those with asthma in academic achievement at baseline?

<u>Hypothesis 1</u>: There will be no differences between the groups in academic achievement at baseline.

Data analyses were conducted using SPSS multivariate analysis of covariance (MANCOVA), multivariate analysis of variance (MANOVA), analysis of variance (ANOVA), analysis of covariance (ANCOVA), and <u>t</u>-test (T-Test).

Between-samples analyses. MANCOVA was performed on the five academic achievement variables (standardized achievement test scores of Reading, Language, Math, and the Total Battery, and Teacher Rating of Performance), using gender and illness as the fixed factors and age at baseline as the covariate. A significant effect was found for age,  $\underline{F}(5, 89) = 2.38$ ,  $\underline{p} < .05$ , with younger children performing better than older children. No statistically significant gender-by-illness interaction effect was found, nor was there a main effect for gender or illness. To reduce the number of missing cases in the analyses, further analysis using ANCOVA was used to examine differences by illness with age as the covariate. Results indicated that children with asthma were performing significantly higher on Math than children with seizures  $\underline{F}(1, 110) = 4.87$ ,  $\underline{p} < .05$ . As shown in Table 8, there also was a trend for children with asthma to outperform children

with seizures on the four other achievement variables, however, these differences did not reach statistical significance.

Approximately one third of the seizure sample had experienced only one seizure at 12 months and had not been placed on medication. It is unlikely that this group of children will develop epilepsy. Therefore, to further investigate the differences between children with asthma and children likely to develop epilepsy, children experiencing only one seizure and no medications were excluded from this specific analysis. Differences between the seizure subsample (those with epilepsy) and the asthma sample were examined using  $\underline{t}$ -tests. There continued to be a significant difference between the groups on Math ( $\underline{t} = 2.91$ ,  $\underline{p} < .01$ ). There was also the same trend for the asthma sample to be performing better than the seizure subsample on all other achievement measures.

Further exploration between the samples involved categorizing the seizure sample into two groups, children with prior seizures and children with no prior seizures, and comparing them with the children with asthma. Children with asthma were doing significantly better in Math than children with prior seizures ( $\underline{t} = 2.70$ ,  $\underline{p} < .01$ ), but not better than children with no prior seizures.

Table 8

Baseline Differences of Seizure and Asthma Samples using ANCOVA to Adjust for Age

	<u>n</u>	<u>M</u>	SD	<u>F</u>	Þ
Reading					·
Seizure	83	54.9	11.3	.38	.54
Asthma	29	56.4	9.0		
Language					
Seizure	81	56.5	11.1	.05	.83
Asthma	27	57.2	8.3		
Math					
Seizure	84	53.9	11.7	4.87	.03
Asthma	29	59.3	9.3		
Total					
Battery					
Seizure	80	55.9	11.6	.58	.45
Asthma	27	57.9	8.4		
Teacher					
Rating of					
Performance	<b>;</b>				
Seizure	91	49.2	9.4	1.32	.25
Asthma	37	51.3	9.1		

ANCOVA was then performed on each of the five academic variables with gender as the fixed factor and age as the covariate. Girls were found to score significantly higher than boys on the academic achievement test scores of Reading,  $\underline{F}(1, 534) = 4.77$ ,  $\underline{p} < .05$ , and Total Battery,  $\underline{F}(1, 480) = 4.18$ ,  $\underline{p} < .05$ . Although there also was a trend for girls to score higher than boys on all other achievement variables, these differences were not statistically significant (Table 9).

Within-sample analyses for asthma sample. Exploration of academic achievement by gender was performed for the asthma sample using a series of independent <u>t</u>-tests (Table 10). There was a trend for girls to perform better than boys especially in Language; however, only the Total Battery score reached statistical significance ( $\underline{t} = 2.27$ ,  $\underline{p} < .05$ ). No differences were found based on presence or absence and type of asthma medications.

Frequency of asthma symptoms was recoded to reflect active and inactive conditions. Children were placed in the active category if they had experienced wheezing or coughing within the past month. Children in the inactive group had not experienced any wheezing or coughing in the past 1 to 6 months. Evaluation of asthma condition using inactive or active symptoms was conducted using MANCOVA with age and gender as covariates and symptom frequency as the fixed factor. No interaction effect for age and gender or main effect for age.

Table 9

Gender Differences in Achievement in Combined Samples using ANCOVA to Adjust for Age at Baseline

	<u>N</u>	<u>M</u>	SD	<u>F</u>	Þ
Reading					
Girls	64	57.1	10.3	4.77	.03
Boys	48	52.7	11.0		
Language					
Girls	63	57.8	9.6	1.96	.16
Boys	45	55.0	11.5		
Math					
Girls	65	56.9	10.3	3.01	.09
Boys	48	53.2	12.3		
Total					
Battery					
Girls	62	58.2	9.9	4.19	.04
Boys	45	53.9	11.7		
Teacher					
Rating of					
Performance					
Girls	70	51.1	9.1	2.91	.09
Boys	58	48.3	9.5		

Table 10

Gender Differences in Academic Achievement in the Asthma Sample using t-tests at Baseline

	<u>n</u>	<u>M</u>	SD	<u>t</u>	df	р
Reading						
Girls	17	58.4	8.9	1.60	26.5	.12
Boys	13	53.3	8.5			
Language						
Girls	16	59.2	8.5	1.96	23.9	.06
Boys	12	52.8	8.5			
Math						
Girls	17	60.8	7.7	1.31	19.7	.21
Boys	13	55.8	11.7			
Total						
Battery						
Girls	16	60.3	8.3	2.27	24.5	.03
Boys	12	53.3	7.9			
Teacher						
Rating of						
Performance	e					
Girls	21	52.2	9.8	.73	34.6	.47
Boys	16	50.1	8.3			

gender, or symptoms was found. Independent <u>t</u>-tests confirmed no statistical differences between children with active and children with inactive symptoms.

Within-sample analyses for seizure sample. For the children with seizures, a series of independent t-tests showed that girls tended to score higher than boys especially in Reading, however, no differences were statistically significant (Table 11). A 2 X 2 between-subjects MANOVA was then performed on the five achievement variables, with prior seizures and gender as the independent variables. No statistically significant interaction effect between prior seizures and gender was found. There was a trend, however, for girls with no prior seizures to have the highest scores and boys with prior seizures to have the lowest scores on the achievement variables (Table 12). In addition, ANOVA conducted on the dependent variables confirmed no statistically significant differences on the achievement variables. Further analyses using independent t-tests showed no significant differences between children with no prior seizures and children with prior seizures (Table 13).

A seizure condition severity rating was calculated to categorize the children with seizures into three groups: one seizure, controlled, and uncontrolled. Children were placed in the one seizure group if they had experienced only one seizure and had not been placed on medication. Children in the controlled group had experienced one seizure, were placed on medication(s), and had no further

Table 11

Gender Differences in Academic Achievement in the Seizure Sample using t-tests at Baseline

	<u>n</u>	<u>M</u>	SD	<u>t</u>	df	р
Reading	<del></del>					
Girls	46	56.8	10.8	1.91	73.6	.06
Boys	37	52.0	11.9			
Language						
Girls	46	57.4	10.0	.88	64.2	.39
Boys	35	55.1	12.4			
Math						
Girls	47	55.6	10.9	1.57	71.6	.12
Boys	37	51.6	12.5			
Total						
Battery						
Girls	45	57.6	10.5	1.53	65.0	.13
Boys	35	53.5	12.8			
Teacher						
Rating of						
Performanc	е					
Girls	47	50.8	8.9	1.65	87.0	.10
Boys	44	47.5	9.7			

Table 12

Gender Differences in Achievement in Children with No Prior Seizures and Children with Prior Seizures using MANOVA at Baseline

		Girls		Boys	<u>F</u>	p
	(ī	<u>1</u> = 45)		$(\underline{\mathbf{n}}=34)$		
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Reading						
No Prior	57.4	11.5	53.5	13.1	.32	.86
Prior Szs	55.5	9.3	51.5	11.4		
Language						
No Prior	58.0	10.0	56.2	11.0		
Prior Szs	55.8	10.8	54.2	14.6		
Math						
No Prior	57.2	10.5	53.1	12.8		
Prior Szs	53.1	11.6	50.9	12.7		
Total						
Battery						
No Prior	58.4	10.3	55.0	13.1		
Prior Szs	55.3	11.1	52.1	13.1		
Teacher						
Rating of						
Performance						
No Prior	50.9	8.5	48.1	8.2		
Prior Szs	51.3	10.5	49.7	9.2		

Table 13

<u>Differences in Academic Achievement in Children with No Prior Seizures and Children with Prior Seizures using t-tests at Baseline</u>

	N	<u>M</u>	SD	<u>t</u>	Þ
Reading		<del></del>			
No Prior Szs	56	55.4	11.9	80	.43
Prior Szs	27	53.3	10.5		
Language					
No Prior Szs	54	57.2	10.2	79	.43
Prior Szs	27	54.9	12.9		
Math					
No Prior Szs	56	55.0	11.6	-1.23	.22
Prior Szs	28	51.6	11.9		
Total Battery					
No Prior Szs	53	56.9	11.4	-1.21	.23
Prior Szs	27	53.5	12.1		
Teacher Rating of					
Performance					
No Prior Szs	60	48.6	9.3	.88	.39
Prior Szs	31	50.4	9.7		

seizures. The children in the uncontrolled seizure group had experienced more than one seizure even though they were on medication(s). MANOVA was performed on the five academic achievement variables, using gender and severity as the fixed factors. No statistically significant gender-by-severity interaction effect was found, nor was there a main effect for severity.

To reduce the number of missing cases, further analysis using ANOVA was performed on the five academic variables, with severity as the fixed factor.

Although children in the one seizure group tended to score higher on all achievement variables, results did not reach statistical significance (Table 14).

To explore differences by seizure type, seizure types were combined to reflect either generalized or partial seizures. Children with tonic-clonic seizures, absence seizures or atonic, akinetic, or myoclonic seizures were placed into the generalized group ( $\underline{n} = 53$  or 48.6%). Children with elementary partial or complex partial seizures with or without secondary generalization were placed in the partial group ( $\underline{n} = 54$  or 49.5%). MANOVA was then performed on the five achievement variables, with seizure type (generalized or partial) and severity (one seizure, controlled, and uncontrolled) as the fixed variables. No statistically significant interaction between seizure type and severity was found, nor was there a main effect for seizure type. Cell sizes were very small for the one seizure and controlled

Table 14

Baseline Comparison Among Seizure Condition Severity Groups by ANOVA

	$(\underline{\mathbf{n}}=8$	80 - 91)	<u>F</u>	p
	<u>M</u>	SD		
Reading				
One Sz	56.3	10.5	.14	.87
Controlled	54.4	12.1		
Uncontrolled	54.6	11.5		
anguage				
One Sz	61.1	10.6	1.54	.22
Controlled	55.1	10.9		
Uncontrolled	55.6	11.2		
ath				
One Sz	59.4	9.2	2.22	.12
Controlled	54.3	13.1		
Uncontrolled	52.4	11.6		
otal Battery				
One Sz	59.9	10.2	1.01	.37
Controlled	54.6	12.7		
Uncontrolled	55.1	11.7		
eacher Rating				
f Performance				
One Sz	51.6	9.2	.93	.40
Controlled	46.9	8.7		
Uncontrolled	49.3	9.7		

groups. ANOVA conducted on the achievement variables confirmed no statistically significant differences (Table 15). Additionally, no differences were found based on the medications the children were taking.

Next, MANOVA was performed on the five academic achievement variables, with seizure type (generalized or partial) and gender as the fixed variables. No statistically significant interaction between seizure type and gender was found. ANOVA analyses conducted on each of the academic achievement variables confirmed no statistically significant differences.

### Summary

The hypothesis that there were no differences between the samples was not supported. Results indicated that children with seizures were performing lower on Math than children with asthma. Moreover, girls as a group were doing better than boys as a group in Reading and Total Battery, however, there was not a gender-by-illness interaction effect at baseline. Girls with asthma were doing better than the boys with asthma on the Total Battery, but the children's frequency of asthma symptoms and type of medication were not associated with academic performance. There were no differences between the girls and boys with seizures on any of the academic achievement measures. Additionally, the existence of prior unrecognized seizures, severity of the seizure condition, seizure type, and medication did not affect academic achievement in this sample.

Table 15

Baseline Comparison between Seizure Type and Severity using MANOVA

	One Seizure		Controlled		Uncontrolled	
	<u>Gen</u> ( <u>n</u> = 4) <u>M</u>	Part ( <u>n</u> = 7) <u>M</u>	Gen ( <u>n</u> = 5) <u>M</u>	Par ( <u>n</u> = 9) <u>M</u>	Gen ( <u>n</u> = 26) <u>M</u>	Part ( <u>n</u> = 19) <u>M</u>
Reading	60.3	55.3	58.8	52.0	54.2	54.2
Language	70.8	57.4	56.6	54.2	54.7	55.7
Math	68.0	55.0	57.8	52.3	53.7	50.6
Total Battery	68.0	56.3	58.2	52.7	55.0	53.8
Teacher Rating of Performance	59.0	49.1	50.6	47.3	50.3	48.6

 $\underline{F}$  (12, 120) = 1.033,  $\underline{p}$  = .423

#### Question 2

Are there differences between the groups of children with seizures and those with asthma in academic achievement at 12 months?

Hypothesis 1: Children with seizures will have poorer academic achievement outcomes than children with asthma at 12 months.

Data analyses were conducted using SPSS multivariate analysis of covariance (MANCOVA), multivariate analysis of variance (MANOVA), analysis of variance (ANOVA), analysis of covariance (ANCOVA), and <u>t</u>-test (T-Test).

Between-sample analyses. MANCOVA was performed on the five academic achievement variables, using gender and illness as the fixed factors and age at baseline as the covariate. A significant effect was found for age,  $\underline{F}$  (5, 59) = 2.31,  $\underline{p}$  < .05, with younger children doing better than older children on the achievement measures. No statistically significant gender-by-illness interaction effect was found, nor was there a main effect for gender or illness. To reduce the number of missing cases in the analyses, further analysis on each academic area using ANCOVA was used to examine differences by illness with age as the covariate. Results indicated no statistical differences between the samples (Table 16). Independent  $\underline{t}$ -tests confirmed no statistical differences.

Table 16

12-Month Differences of Seizure and Asthma Samples using ANCOVA to Adjust for Age

	<u>n</u>	<u>M</u>	<u>SD</u>	<u>F</u>	₽
Reading			<del></del>		
Seizure	57	54.9	10.8	.11	.75
Asthma	23	54.2	11.8		
Language					
Seizure	57	54.8	10.8	.81	.37
Asthma	23	52.6	9.9		
Math					
Seizure	58	53.3	10.7	.01	.94
Asthma	23	53.2	10.4		
Total					
Battery					
Seizure	55	54.7	10.7	.50	.48
Asthma	23	53.1	9.7		
Teacher					
Rating of					
Performance					
Seizure	80	48.4	9.6	1.80	.18
Asthma	33	50.9	9.4	•	

To further investigate the differences between children with asthma and children with epilepsy, as stated previously, the children experiencing only one seizure and no medications were excluded from this specific analysis. Differences between the seizure subsample (epilepsy) and the asthma sample were examined using <u>t</u>-tests. There were no significant differences between these groups based on this categorization.

Further exploration between the samples involved children with prior seizures, children with no prior seizures, and children with asthma. Again, there were no significant differences among the groups.

ANCOVA was performed on the five academic variables individually, with gender as the fixed factor and age as the covariate. No statistically significant differences were found (Table 17). Independent <u>t</u>-tests confirmed no statistical differences.

Within-sample analyses for asthma sample. Further exploration of academic achievement by gender was performed for the asthma sample using a series of tests. As shown in Table 18, there were no significant differences between girls and boys. Evaluation of asthma condition using active and inactive symptom groups was conducted using MANCOVA with age and gender as covariates and symptoms as the fixed factor. No interaction effect for age and gender or main

Table 17

Gender Differences in Achievement in Combined Samples using ANCOVA to Adjust for Age at 12-months

	<u>n</u>	<u>M</u>	SD	<u>E</u>	<u>p</u>
Reading	<del></del>				-
Girls	42	55.2	10.7	.28	.60
Boys	38	54.2	11.5	.20	.00
Language					
Girls	43	55.6	10.9	1.89	.17
Boys	37	52.5	10.0		
Math					
Girls	43	54.1	10.2	.63	.43
Boys	38	52.4	11.0		
Total					
Battery					
Girls	42	55.3	10.5	1.08	.30
Boys	36	53.0	10.2		
Teacher					
Rating of					
Performance					
Girls	63	49.1	9.8	.06	.81
Boys	50	49.3	9.3		

Table 18

Gender Differences in Academic Achievement in the Asthma Sample using t-tests at 12-months

	<u>n</u>	<u>M</u>	SD	<u>t</u>	df	Þ
Reading						
Girls	11	52.6	12.5	50	20.3	.62
Boys	13	55.1	11.2			
Language						
Girls	11	54.6	9.8	.94	20.8	.36
Boys	12	50.8	10.0			
Math						
Girls	11	53.5	10.2	.09	21.6	.93
Boys	13	53.2	10.7			
Total						
Battery						
Girls	11	53.5	10.9	.21	19.5	.84
Boys	12	52.7	9.0			
Teacher						
Rating of						
Performance	<u> </u>					
Girls	20	50.5	10.9	41	30.9	.69
Boys	13	51.7	6.6			

effect for age, gender, or symptoms was found. There were no differences found based on type of medication.

Within-sample analyses for seizure sample. Using a series of t-tests to examine academic achievement by gender within the seizure sample showed that although girls tended to score higher than boys on the achievement variables, no differences approached statistical significance (Table 19). A 2 X 2 between-subjects MANOVA was performed on the five academic achievement variables, with prior seizures and gender as the independent variables. No statistically significant interaction effect was found between prior seizures and gender, nor was there a main effect for prior seizures.

Although girls with no prior seizures tended to have the highest scores and boys with prior seizures tended to have the lowest scores on the achievement variables (Table 20), results did not reach statistical significance. In addition, ANOVA analyses conducted on the achievement variables confirmed no statistically significant differences between the groups. Further analyses using tests showed no significant differences based on prior seizure status (Table 21).

Next, MANOVA was performed on the five academic achievement variables, using gender and severity as the fixed factors. No statistically significant gender-by-severity interaction effect was found, nor was a main effect found for

Table 19

Gender Differences in Academic Achievement in the Seizure Sample using t-tests at 12-months

	N	<u>M</u>	SD	<u>t</u>	df	Þ
Reading		<del>_</del>				
Girls	30	56.2	10.1	1.05	52.0	.30
Boys	27	53.1	11.6			
Language						
Girls	31	56.3	11.3	1.07	54.9	.29
Boys	26	53.3	10.0			
Math						
Girls	31	54.3	10.5	.92	54.0	.36
Boys	27	51.7	11.1			
Total						
Battery						
Girls	30	56.0	10.6	1.08	50.7	.28
Boys	25	52.9	10.9			
Teacher						
Rating of						
Performance	•					
Girls	41	48.3	9.6	08	77.6	.94
Boys	39	48.5	9.8			

Table 20

Gender Differences in Achievement in Children with No Prior Seizures and Children with Prior Seizures using MANOVA at 12-months

	G	irls		Boys	<u>F</u>	<u>p</u>
	(n = 30)			$(\underline{\mathbf{n}} = 25)$	_	_
	<u>M</u>	SD	<u>M</u>	SD		
Reading						
No Prior	56.3	10.8	54.4	13.8	.68	.61
Prior Szs	56.0	8.7	51.4	8.4		
Language						
No Prior	56.0	12.0	54.9	10.8		
Prior Szs	57.1	10.9	50.1	8.5		
Math						
No Prior	54.9	10.8	52.5	13.1		
Prior Szs	53.1	11.0	50.1	7.3		
Total						
Battery						
No Prior	55.9	10.8	54.0	12.5		
Prior Szs	56.4	10.6	50.9	7.4		
Teacher						
Rating of						
Performance						
No Prior	48.5	9.6	51.1	7.8		
Prior Szs	50.0	9.8	49.2	10.5		

Table 21

<u>Differences in Academic Achievement in Children with No Prior Seizures and Children with Prior Seizures using t-tests at 12 months</u>

	<u>n</u>	<u>M</u>	SD	<u>t</u>	df	p
Reading						
No Prior Szs	39	55.3	11.9	.64	45.8	.53
Prior Szs	18	53.6	8.4			
Language						
No Prior Szs	39	55.5	11.2	.68	37.7	.50
Prior Szs	18	53.6	9.8			
Math						
No Prior Szs	40	53.6	11.6	.54	41.4	.59
Prior Szs	18	52.1	9.1			
Total Battery						
No Prior Szs	38	55.1	11.5	.57	38.2	.58
Prior Szs	17	53.5	9.2			
Teacher Rating						
of Performance						
No Prior Szs	51	48.3	8.8	11	48.3	.92
Prior Szs	29	48.6	11.0			

severity. Further analysis using ANOVA was performed on the five academic variables, with the three levels of seizure condition severity (one seizure, controlled, and uncontrolled) as the fixed factor. No significant differences were found, although children in the one seizure group tended to score higher than children in the controlled or uncontrolled groups (Table 22).

Exploration of academic achievement using MANOVA was performed on the five academic achievement variables, with seizure type (generalized or partial) as the fixed factor. No significant main effect was found for seizure type.

MANOVA was then performed on the five academic achievement variables, with seizure type (generalized or partial) and severity (one seizure, controlled, and uncontrolled) as the fixed variables. No statistically significant interaction between seizure type and severity was found, nor were there main effects for seizure type or severity found (Table 23). ANOVA analyses conducted on the achievement variables individually confirmed no statistically significant differences. Small cell sizes make these results most tentative.

MANOVA was performed on the five academic achievement variables, with seizure type and gender as the fixed variables. No statistically significant interaction between seizure type and gender was found. ANOVA conducted on the achievement variables individually confirmed no statistically significant differences.

Table 22

12-Month Comparison Among Seizure Condition Severity Groups using ANOVA

	$(\underline{\mathbf{n}} = 5)$	55 - 80)	<u>F</u>	Ď	
	<u>M</u>	<u>SD</u>			
Reading					
One Sz	57.3	13.8	.28	.75	
Controlled	54.9	7.8			
Uncontrolled	54.3	11.1			
Language					
One Sz	54.2	11.4	.09	.91	
Controlled	53.9	11.0			
Uncontrolled	55.3	10.9			
Math					
One Sz	53.4	11.9	.17	.85	
Controlled	54.8	9.8			
Uncontrolled	52.7	10.9			
Total Battery					
One Sz	55.2	12.2	.03	.97	
Controlled	55.1	9.7			
Uncontrolled	54.5	10.9			
Teacher Rating					
of Performance					
One Sz	48.8	7.1	.10	.90	
Controlled	47.4	11.0			
Uncontrolled	48.6	9.8			

Table 23

12-Month Comparison between Seizure Type and Severity using MANOVA

	One S	Seizure	Cor	ntrolled	Unco	ntrolled
,	<u>Gen</u> ( <u>n</u> = 2) <u>M</u>	Part ( <u>n</u> = 5) <u>M</u>	Gen ( <u>n</u> = 4) <u>M</u>	Par ( <u>n</u> = 7) M	Gen ( <u>n</u> = 13) M	Part ( <u>n</u> = 18) <u>M</u>
Reading	67.5	48.2	58.8	53.9	53.1	55.1
Language	66.0	45.6	54.5	53.3	57.5	53.1
Math	55.5	49.6	53.8	56.0	54.5	50.8
Total Battery	63.0	48.0	55.8	54.7	55.2	53.3
Teacher Rating of Performance	52.0	45.4	54.0	50.6	51.8	48.3

 $\underline{F}$  (12, 78) = 1.572,  $\underline{p}$  = .118

Additionally, no differences in the academic achievement variables were found based on type of antiepileptic medication.

## Summary

The hypothesis that children with seizures would have poorer academic achievement outcomes than children with asthma at 12 months was not supported. Analyses indicated that there were no differences between the samples, nor were there differences between the girls and boys. Additional analyses indicated no differences based on asthma symptoms or medications, prior unrecognized seizures, seizure condition severity, seizure type, or antiepilepsy medication.

### Question 3

Are there differences in change in academic achievement over time between children with seizures and those with asthma?

Hypothesis 1: Children with seizures will have more negative change in academic achievement outcomes from baseline to 12 months than children with asthma.

Data analyses were conducted using SPSS analysis of covariance (ANCOVA) and paired <u>t</u>-tests (Paired T-Test). Results for the between-sample analyses are followed with the results for the within-sample analyses.

Between-sample analyses. A series of ANCOVA adjusting for age and baseline academic achievement scores were used to test whether the change from baseline to 12-months differed between the seizure and asthma samples. Gender

and illness were used as the fixed factors. Change from baseline to 12 months was explained by the baseline measure for all academic areas. In other words, when the achievement score at baseline was controlled, neither gender nor illness accounted for significant variance in change in academic achievement. There also were no significant effects found for age or a gender-by-illness interaction.

Using paired <u>t</u>-tests to examine differences in the combined samples between the girls and boys, indicated that girls significantly declined in Reading, Language, Math, and Total Battery (Table 24). Boys, as a group, significantly declined in Language and Total Battery (Table 25).

Within-sample analyses for asthma sample. Further exploration using a series of paired t-tests, indicated children with asthma significantly declined in Language, Math, and Total Battery. More specifically, girls with asthma significantly declined in Math and boys with asthma significantly declined in Language and Total Battery (Table 26).

Within-sample analyses for seizure sample. Using a series of paired t-tests, the children with seizures showed significant declines in Reading, Language, Math, and Total Battery. Examining the sample by gender showed that girls with seizures significantly declined in Reading, Language, Math, and Total Battery, and boys with seizures significantly declined in Language only (Table 27).

Table 24

Change in Academic Achievement in Girls with Seizures using Paired t-tests

	Baseline		12- N	12- Months		alues			
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>t</u>	Þ	
Reading	58.3	10.8	56.1	10.2	-2.14	6.31	-2.04	.05	
Language	59.1	9.0	56.7	10.8	-2.41	6.24	-2.35	.03	
Math	59.3	10.0	55.3	9.9	-3.97	6.55	-3.69	.00	
Total Battery	59.7	10.0	56.5	10.2	-3.19	4.94	-3.88	.00	
Teacher Rating of Performance	51.2	9.2	50.0	9.8	-1.25	6.81	-1.37	.18	

Table 25

Change in Academic Achievement in Boys with Seizures using Paired t-tests

	Baseline		12- Months		Change Values			
	<u>M</u>	SD	<u>M</u>	SD	<u>M</u>	SD	ţ	P
Reading	55.7	9.3	54.0	11.2	-1.67	7.99	-1.14	.26
Language	57.9	9.8	53.3	9.2	-4.62	7.52	-3.31	.00
Math	55.9	11.1	53.0	9.0	-2.90	10.10	-1.57	.13
Total Battery	57.0	10.3	53.5	8.7	-3.46	7.77	-2.36	.03
Teacher Rating of Performance	49.2	9.7	48.5	8.9	72	7.19	69	.49

Table 26

Change in Academic Achievement in Asthma Sample using Paired t-tests

	Bas	eline	12- N	<b>Months</b>	Change	e Values		
	<u>M</u>	SD	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>t</u>	р
Reading	54.9	8.5	54.5	11.1	40	6.92	22	.83
Girls	54.6	10.2	54.3	11.4	29	4.79	16	.88
Boys	55.3	7.5	54.8	11.6	50	8.72	16	.88
Language	57.1	8.0	52.9	8.8	-4.20	7.21	-2.26	.04
Girls	57.7	10.5	56.9	9.6	86	7.43	31	.77
Boys	56.6	5.8	49.5	6.8	-7.13	5.99	-3.37	.01
Math	60.5	7.0	53.6	8.2	-6.87	8.31	-3.20	.01
Girls	62.3	7.2	55.9	10.0	-6.43	7.18	-2.37	.06
Boys	58.9	7.0	51.6	6.4	-7.25	9.68	-2.12	.07
Total								
Battery	57.9	7.0	53.3	8.1	-4.67	6.06	-2.99	.01
Girls	59.0	9.2	55.9	10.0	-3.14	21.26	-1.53	.18
Boys	57.0	5.0	51.0	5.7	-3.50	19.91	-2.57	.04
Teacher								
Rating of								
Performance	51.8	8.7	51.9	8.4	.10	6.12	.09	.93
Girls	52.2	9.3	52.6	9.8	.39	6.03	.27	.79
Boys	51.1	8.5	50.7	5.8	36	6.53	19	.86

Table 27

Change in Academic Achievement in Seizure Sample using Paired t-tests

	Baseline		12-	Months	Change	e Values		
	<u>M</u>	SD	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>t</u>	р
Reading	57.7	10.6	55.4	10.6	-2.37	7.12	-2.38	.02
Girls	59.2	10.9	56.6	10.1	-2.59	6.62	-2.11	.04
Boys	55.8	10.0	53.7	11.3	-2.09	7.89	-1.24	.23
Language	59.0	9.7	55.9	10.6	-3.14	6.81	-3.29	.00
Girls	59.5	8.8	56.7	11.2	-2.77	6.02	-2.52	.02
Boys	58.4	11.0	54.7	9.7	-3.67	7.95	-2.12	.05
Math	57.0	11.3	54.4	9.9	-2.52	8.08	-2.25	.03
Girls	58.6	10.6	55.2	10.1	-3.40	6.38	-2.92	.01
Boys	54.8	12.2	53.5	9.9	-1.32	9.99	62	.54
Γotal								
Battery	58.7	11.0	55.8	10.0	-2.90	6.35	-3.19	.00
Girls	59.8	10.4	56.6	10.4	-3.21	4.92	-3.51	.00
Boys	57.0	11.8	54.5	9.6	-2.45	8.12	-1.35	.19
Геасhег								
Rating of								
Perform	49.7	9.7	48.3	9.6	-1.45	7.25	-1.72	.09
Girls	50.8	9.3	48.7	9.6	-2.03	7.09	-1.76	.09
Boys	48.6	10.0	47.8	9.7	83	7.46	67	.51

## **Summary**

The hypothesis that children with seizures would have more negative change in academic achievement outcomes from baseline to 12 months than children with asthma was not supported. Although there were no differences between the two samples, results indicated that girls, declined in Reading, Language, Math, and Total Battery. Boys declined in Language and Total Battery. Results indicated that girls with asthma declined in Math and boys with asthma declined in Language and Total Battery. The girls with seizures declined in Reading, Language, Math, and Total Battery, and the boys with seizures declined in Language only.

# **Preliminary Analyses**

Prior to conducting analyses to answer question 4, preliminary analyses were performed for the purposes of data reduction. In the first step, each group of variables was explored for relationships with two of the dependent variables: Teacher Rating of Performance and Total Battery achievement test scores. There were several reasons for the choice of these dependent variables. First, the four standardized achievement test scores were highly correlated with the Teacher Rating ( $\underline{r} > .57$ ,  $\underline{p} < .01$ ). Second, the Teacher Rating of Performance had the largest number of cases of any of the dependent measures ( $\underline{n} = 80$ ). The Total Battery was used as a dependent variable because several of the independent

variables (child adaptive competency and teacher expectations), as well as the dependent variable of Teacher Rating of Performance, were completed by the teacher, and so the potential for rater bias was high. Therefore, using the standardized test score of Total Battery reduced that bias. Additionally, because the Total Battery score consists of the Reading, Language, and Math composites, it is reflective of general functioning and is similar to the Teacher Rating of Performance in that regard. The Total Battery score also had the largest number of cases ( $\underline{n} = 55$ ) of the four achievement test scores.

Correlation tables were examined to identify significant variables for inclusion in the multiple regression equations. The independent variables selected were those found to have correlations with p values of  $\leq$  .20 with the achievement variables. Variables that were not related to the two dependent variables were dropped from further analyses.

## Question 4

How much variance do variables of family characteristics (demographics, child stressors, family resources), child characteristics (illness characteristics), parent response (attitude, expectations for achievement), child response (attitude, school self-concept, behavior), and teacher response (expectations for achievement), account for in child academic achievement (Total Battery

achievement test score and Teacher Rating of Performance) at 12 months for the seizure sample?

Hypothesis 1: Family characteristics of higher SES, greater number of years of parent education, lower child stressors, and higher family resources, will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 2: The child characteristic of less severe seizure conditions will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 3: Parental response of more positive attitude and higher expectations for their child's achievement will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 4: Child response of more positive attitude, more positive school self-concept, more adaptive competencies, and lower (internalizing and externalizing) behavior problems will be significantly related to higher academic achievement in children with seizures at 12 months.

Hypothesis 5: Teacher response of more positive expectations for the child's academic achievement will be significantly related to higher academic achievement in children with seizures at 12 months.

# Relationships of Variables in the Model

According to the hypotheses, the independent variables were tested for relationships with Teacher Rating of Performance and Total Battery test scores.

These relationships are described in the following section.

Family characteristics. Higher SES and higher mother education were significantly related to higher Total Battery scores, but not to the Teacher Rating of Performance. Lower child stressors scores were significantly correlated with Teacher Rating scores. Family resources were not related to either achievement variable (Table 28).

Child characteristics. As previously stated, aptitude was dropped from further analyses due to the low number of cases. Seizure condition severity and type of medication were not considered in this analysis because previous results showed no significant differences in academic achievement scores based on these variables. Seizure frequency (number of seizures) could not be used in the analyses because it was confounded with seizure type. For example, a child having 30 absence (staring spells) seizures has a much less severe condition than a child having 30 tonic-clonic seizures.

<u>Parent response</u>. More positive parental attitude was significantly related to the Total Battery. Higher parental expectations were significantly related to both

Table 28

<u>Correlations of Family and Child Characteristic Variables with Total Battery and Teacher Rating of Performance</u>

	Total Battery	Teacher Rating
SES	.39**	.17
Mother Education	.40**	.06
Child stress	07	30**
Mastery & Health	.08	.08
Esteem & Communication	.14	.03

<sup>\* &</sup>lt;u>p</u> < .05. \*\* <u>p</u> < .01.

the Total Battery and the Teacher Rating of Performance. Parent attitude of stigma was not related to either achievement variable (Table 29).

Child response. More positive child attitude, more adaptive competencies, and fewer externalizing behavior problems were significantly associated with higher Total Battery and Teacher Rating of Performance. Higher school self-concept and fewer internalizing problems were significantly related to Teacher Rating of Performance, but not to the Total Battery score. Child attitude of stigma was not related to either achievement variable (Table 29).

<u>Teacher response</u>. Higher teacher expectations were significantly related to higher Total Battery and Teacher Rating of Performance (Table 29).

# Multiple Regression Analyses

There were 11 variables that met the criterion for inclusion in the regression equation: the family characteristic variables of SES and child stress; the parent response variables of attitude, stigma, and expectations; the child response variables of attitude, school self-concept, and behavior (adaptive competency, internalizing problems and externalizing problems); and the teacher response variable of expectations. For purposes of data reduction, several variables were dropped from the equation. Parent stigma was dropped because it had low correlations with Total Battery ( $\underline{r} = -.272$ ,  $\underline{p} < .05$ ) and was not significantly correlated with Teacher Rating of Performance.

Table 29

<u>Correlations of Family, Child and Teacher Response Variables with Total Battery and Teacher Rating of Performance</u>

	Total Battery	Teacher Rating
Parent Attitude	.34*	.19
Parent Stigma	18	18
Parent Expectations	.70**	.61**
Child Attitude	.28*	.39**
Child Stigma	.02	02
Child School Self-Concept	.23	.38**
Child Adaptive Competencies	.63**	.71**
Internalizing Problems	14	25*
Externalizing Problems	34*	28*
Teacher Expectations	.65**	.74**

<sup>\*</sup>  $\underline{p} < .05$ . \*\*  $\underline{p} < .01$ .

The internalizing and externalizing problem scores were highly correlated with each other ( $\underline{r}$  = .643,  $\underline{p}$  ≤ .01), and so the decision was made to drop one of the measures for the regression because of possible collinearity problems. Externalizing Problems was kept in the analyses because it was more highly correlated with the two dependent variables than Internalizing Problems. Thus, 9 variables entered the final regression equation. The correlation matrix of these 9 variables is presented in Table 30.Two multiple regressions were completed using SPSS multiple regression (REGRESSION). One used Teacher Rating of Performance as the dependent variable and one used the Total Battery score as the dependent variable.

Teacher Rating of Performance. The hierarchical method (SPSS ENTER) for multiple regression was used to allow entering of the independent variables in blocks based on the theoretical framework. The family (SES and child stress) characteristic variables were entered in the first block, and the parent (attitude, expectations), child (attitude, school self-concept, adaptive competency, externalizing behavior), and teacher (expectations) response variables were entered in the second block. The results of this method revealed that parent expectations, child adaptive competency, externalizing behavior, and teacher expectations accounted for a significant amount of the variance in Teacher Rating of Performance, with an Adjusted  $\underline{R}^2 = .599$  (Table 31).

Table 30

<u>Correlation Matrix of Independent Variables in the Multiple Regressions</u>

	SES	Str	Раг	Par	Tea	Chi	Sch	Ad	Ext
			Att	Exp	Exp	Att	SC	Com	Beh
SES	1.00								
Str	.09	1.00							
Par Att	.21*	03	1.00						
Par Exp	.03	26*	.23*	1.00					
Tea Exp	.15	43**	.22*	.69**	1.00				
Chi Att	.03	16	.12	.43**	.42**	1.00			
Sch SC	12	25*	.04	.35**	.40**	.45**	1.00		
Ad Com	.21*	27**	.29**	.49**	.68**	.37**	.23*	1.00	
Ext Beh	.05	.30**	23*	49**	50**	33**	32**	37**	1.00

p < .05. \*\* p < .01.

# Legend of Independent Variables:

SES=Socioeconomic status

Str=Child Stress

ParAtt=Parent Attitude

ParExp=Parent Expectations

TeaExp=Teacher Expectations

ChiAtt=Child Attitude (CATIS)

SchSC=School Self-Concept

AdCom=Adaptive Competency

ExtBeh=Externalizing Behavior

Table 31

<u>Teacher Rating of Performance Regressed on the Independent Variables</u>

Variables	Beta	<u>t</u>	р	
SES	.07	.83	.41	
Child Stress	.03	.34	.74	
Parent attitude	06	66	.51	
Parent expectations	.25	2.16	.04	
Child attitude	02	24	.81	
School self- concept	.08	.87	.39	
Adaptive competency	.47	4.19	.00	
Externalizing problems	.19	1.94	.06	
Teacher expectations	.29	2.09	.04	

Adjusted 
$$\underline{\mathbf{R}}^2 = .599$$
  
 $\underline{\mathbf{F}}$  (9, 65) = 11.79,  $\mathbf{p} < .001$ .

Total Battery. A second regression equation was computed using the Total Battery achievement score as the dependent variable. Using the same hierarchical method, the results revealed that SES, parent expectations, and child adaptive competency accounted for a significant amount of the variance in Total Battery, with an Adjusted  $\underline{R}^2 = .734$  (Table 32).

## Summary

To answer the research question of how much variance do variables of family and child characteristics, and parent, child, and teacher response account for in child academic achievement at 12 months for the seizure sample, a series of correlations and two multiple regressions were conducted.

The first hypothesis that the family characteristics of higher SES, greater number of years of parent education, lower child stressors, and higher family resources, would be significantly related to higher academic achievement in children with seizures at 12 months was partially supported. Higher SES and higher mother education were significantly related to higher Total Battery scores, but not to the Teacher Rating of Performance. Lower child stressors were related to higher Teacher Rating, however, family resources were not related to either achievement variable.

The second hypothesis that child characteristics of higher aptitude and less severe seizure conditions would be significantly related to higher academic

Table 32

<u>Total Battery Regressed on the Independent Variables</u>

Variables	Beta	<u>t</u>	р	
SES	.20	2.45	.02	
Child Stress	11	-1.31	.20	
Parent attitude	.03	.37	.71	
Parent expectations	.47	4.65	.00	
Child attitude	07	74	.47	
School self-concept	00	01	.99	
Adaptive competency	.30	2.89	.01	
Externalizing problems	03	37	.72	
Teacher expectations	.19	1.68	.10	

Adjusted  $\underline{R}^2 = .734$  $\underline{F}$  (9, 46) = 15.14,  $\underline{p}$  < .001. achievement in children also was not supported. As stated previously, aptitude could not be analyzed because of the large number of missing data. In prior analyses, severity and medications were not related to any academic achievement variables.

The third hypothesis that parental response of more positive attitudes and higher expectations for their child's achievement would be significantly related to higher academic achievement in children with seizures was partially supported.

Results indicated that more positive parental attitude was related to higher Total Battery, higher parental expectations were related to both higher Total Battery and Teacher Rating of Performance, but parent stigma was not related to either achievement variable.

The hypothesis that child response of more positive attitude, more positive school self-concept, more adaptive competencies, and fewer (internalizing and externalizing) behavior problems would be significantly related to higher academic achievement also was partially supported. More positive child attitude, more adaptive competencies, and fewer externalizing behavior problems were associated with higher Total Battery and Teacher Ratings. Higher school self-concept and fewer internalizing problems were related to higher Teacher Rating, but not to the Total Battery score. Child stigma was not related to either achievement variable.

The final hypothesis that teacher response of higher expectations for the child's academic achievement would be significantly related to higher academic achievement in children with seizures at 12 months was supported. Higher teacher expectations were related to both higher Total Battery and higher Teacher Rating of Performance.

To test how much variance the independent variables accounted for in academic achievement in children with seizures at 12 months, two multiple regression analyses were conducted. Parent expectations, child adaptive competency, externalizing behavior, and teacher expectations accounted for a significant amount of the variance in Teacher Rating of Performance in the first model. The second model showed that SES, parent expectations, and child adaptive competency accounted for a significant amount of the variance in Total Battery.

#### CHAPTER 5

SUMMARY, DISSCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

This chapter begins with a summary of the study and follows with a discussion of the major findings. The final part of this chapter is composed of conclusions and recommendations for further research and clinical practice.

# Summary of the Study

Children with seizures exhibit great variability in patterns of academic achievement. It is not known why some children do better than others or when changes in academic achievement occur. The primary purpose of this study was to identify factors related to academic achievement in children with new-onset seizures and to examine change in achievement over the first 12 months. A secondary purpose was to examine differences in academic achievement between children with new-onset seizures and those with new-onset asthma. The sample for the study was 109 children with new-onset seizures and 46 children with new-onset asthma and their mothers. The children ranged in age from 8 to 14 years, with a mean age of 10.4 years for the children with seizures and 10.3 years for the children with asthma.

Baseline data were collected within 6 weeks of a child having a first seizure or being placed on daily asthma medications. Data collected during the baseline interview were retrospective, providing information from the year prior to the

onset of the health condition. The 12-month data provided information for the period of baseline to one year after the onset of the condition.

The Double ABCX Model of Family Adjustment was used as a source theory to guide the selection of factors for the proposed study (McCubbin & Patterson, 1983). In the extended model developed for this study, the major concepts from the Double ABCX Model were retained with the primary outcome changed to individual child academic achievement. Information was collected on the independent variables of family characteristics (demographics, child stressors, family resources), child characteristics (aptitude, illness characteristics, age, gender), parent response (attitude, expectations for achievement), child response (attitude, school self-concept, behavior), and teacher response (expectations for achievement). The dependent variables for the study were child academic achievement test scores on reading, language, math, and total battery, and the teacher's rating of the child's academic performance. Data were collected via computer assisted telephone interviews. Data were analyzed using multivariate and univariate statistics.

At baseline children with seizures had lower Math scores than children with asthma. Moreover, in both samples, girls were doing better than boys in both Reading and Total Battery. In the asthma sample girls had higher scores than the boys on the Total Battery. Frequency of asthma symptoms and presence or

absence and type of asthma medication were not associated with academic achievement. In the seizure sample there were no differences between the girls and boys on any of the academic achievement measures. Additionally, the existence of prior unrecognized seizures, severity of the seizure condition, seizure type, and presence or absence and type of antiepilepsy medication were not related to academic achievement.

Data analyses examining the 12-month data indicated that there were no differences between the children with seizures and those with asthma, nor were there differences between the girls and boys. Additional analyses indicated that asthma symptoms, asthma medications, prior unrecognized seizures, seizure condition severity, antiepilepsy medications, or seizure type were not associated with academic achievement at 12 months.

In general, over the first 12 months after the condition onset, there was a decline in academic achievement for all children. Children with seizures did not show more of a decline in academic achievement outcomes, however, than children with asthma. Girls in both samples significantly declined in Reading, Language, Math, and Total Battery and boys declined in Language and Total Battery. In the asthma sample, girls declined in Math and boys declined in Language and Total Battery. In the seizure sample, girls declined in Reading, Language, Math, and Total Battery and boys declined in Language.

Factors associated with higher teacher ratings of the child's performance were parent expectations, child adaptive competency, externalizing behavior problems, and teacher expectations for the child's achievement. In contrast, SES, parent expectations, and child adaptive competency were significantly associated with the child's Total Battery achievement score.

Results of the analyses suggest that factors other than illness condition variables influence academic achievement in children with new-onset seizures or asthma. One of the strengths of this study was utilizing a multietiological perspective that included both psychosocial and illness variables in one model. The findings indicate that for these new-onset samples, psychosocial factors are more strongly associated with academic achievement than medical or illness factors. This trend was stronger for the seizure sample, as the model testing analyses showed no seizure variables to be associated with academic achievement. Recommendations for future research include following the children for a longer period of time to determine if psychosocial factors continue to be more strongly associated with academic achievement than illness factors. It is recommended that clinical assessments include psychosocial as well as illness factors in both samples.

#### Discussion

In this section, main findings of the study and an integration of the findings with the literature are presented. Three main findings are discussed: differences

between the seizure and asthma samples at baseline and at 12-months; change in achievement over time for both samples; and factors associated with academic achievement in the seizure sample at 12 months.

# Differences Between the Samples

Because the baseline measurement of academic achievement reflected the period prior to the onset of the condition, it was anticipated that the samples would not differ in academic achievement. Although children with seizures were found to be doing significantly worse than children with asthma only in one area (math), there was a trend for children with seizures to be performing worse in all academic areas, as well as in the teacher's rating of their performance. Even though no previous research has compared these two samples prior to condition onset, the direction of results is similar to that found in chronic samples. For example, Austin et al. (1998) found that children with epilepsy had significantly lower reading, math, language, vocabulary, and composite scores than children with asthma.

Results are also consistent with studies showing academic problems in children with epilepsy. For example, Holdsworth and Whitmore (1974b) found that children with epilepsy were below average to seriously behind in their subject performance as measured by standardized tests or school examinations. Feeman and Hagen (1990) found in a cross-sectional study that children with seizures

scored lower on reading and mathematics than both their healthy siblings and a healthy control group. Finally, Bain (1986) found that children with seizures performed less well than their healthy siblings on general intelligence tests and academic fundamentals.

These findings suggest that some of the problems found in chronic samples may originate early in the course of the disorder. Their poorer performance might be explained by Aicardi's (1996) theory of subclinical discharges or seizure activity. According to Aicardi, even though subclinical discharges do not produce seizure activity, they can lead to brief periods of unawareness or transient cognitive impairment (TCI), which in turn, can interfere with cognitive functioning and academic performance. Although results did not reach statistical significance, the trend for children with prior seizures to be doing worse than children with no prior seizures is consistent with this theory. One could argue that children with prior seizures were more likely to have subclinical seizures than children without prior seizures. Children who had been having subclinical discharges prior to their first recognized seizure might have already had negative cognitive changes that could lead to decreased academic achievement scores early in the course of the disorder.

A limitation of the study was the inability to discern those children who had prior seizure activity that was unrecognized and children who truly had new-onset

seizure activity. To accurately assess the impact of the onset of a seizure condition, future research should be designed to include only those children without any suspected prior seizure activity. Having a "true" new-onset sample would allow researchers to examine more clearly what changes in academic achievement occur following the onset of the condition.

The findings of the cross-sectional analyses at 12 months showing no differences between the samples of children with seizures and those with asthma are somewhat contrary to previous research. Austin, Huberty, Huster and Dunn (1999) found that adolescents with epilepsy scored significantly lower in reading, language, vocabulary, mathematics, and composite than a comparison asthma sample. An earlier study by Austin, Huberty, Huster, and Dunn (1998) also found that children who had been treated for seizures for at least one year were doing significantly worse academically than children who had been treated for asthma for at least one year.

The sample in this study is different from the chronic samples in both of Austin's studies because 30% of the children in this study had experienced only one seizure and were not placed on medication. Thus, data from the one seizure group may have diluted the seizure sample data. Because the one seizure group is less likely to develop epilepsy than those with repeated seizures, one would expect that they would have fewer academic achievement problems. Additionally,

characteristics of this new-onset sample may be different from a chronic sample in that they do not show achievement to be associated with seizure variables. Perhaps not enough time has elapsed for the disorder to have had its full impact on the child or family. Small samples sizes in the current study could also have limited the ability to detect small differences.

Interestingly, mean scores on the achievement tests for both samples were close to the mean of 50, indicating that the children as a group were performing in the average range and were not underachieving. The finding that children with asthma were performing well is consistent with the literature that shows few illness-related academic problems in this population (Bender, 1995; Fowler, 1985). That the children with seizures were doing well is also consistent with the literature on children with uncomplicated conditions and one seizure type (Rodin, 1989), which characterizes this sample of children. The children in this study were selected based on the criterion of having an IQ greater than 70, and so were of average ability as a group and, therefore, likely to be doing well in school.

Moreover, the children had no comorbid conditions so they were otherwise healthy children who were not at risk for underachievement.

## Gender Differences

Gender differences with girls doing better than boys in both samples might be explained from a developmental perspective. With a mean age of approximately 10 years, girls are in the stage of development where they are progressing physically and emotionally at a faster rate than boys. Moreover, the superior academic performance of girls is consistent with results in the general population showing that preadolescent girls have higher achievement scores than boys of the same age (Stetsenko, Little, Gordeeva, Grasshof, & Oetingen, 2000).

Prior studies involving children with chronic epilepsy also have found gender differences with lower academic achievement for boys than for girls.

Seidenberg et al. (1986) found that boys had poorer achievement in language-related academic areas and performed significantly worse than girls on measures of word recognition and spelling. Stores and Hart (1976) found that the reading skills for boys with epilepsy were poorer than for the girls across both generalized and focal seizure types. Holdsworth and Whitmore (1974b) found more boys than girls among their epilepsy sample to be experiencing education difficulties in general.

Findings of gender differences are important for identifying children who are at risk for academic problems. Austin and colleagues (1998) found that boys were more at risk for academic underachievement than girls. In that study, boys with high seizure severity had the lowest scores. Although severity was not related to academic achievement in the present study, results indicated that boys, regardless of illness, consistently had the lowest scores on achievement variables. Across all groups, boys with seizures had the lowest scores in Reading and Math,

and on the Teacher's Rating of Performance and boys with asthma had the lowest scores in Language and Total Battery. Based on the findings from this study, it appears that male gender may be a risk factor for academic underachievement.

In summary, there was only one area (math) that showed statistically significant differences between the children with seizures and those with asthma, however, in general, children with seizures performed worse that children with asthma at baseline and at 12 months. Moreover, boys as a group consistently performed worse than girls. These findings suggest that further research needs to be conducted to examine the influence of gender and illness on academic achievement in children with new-onset health conditions.

# Change in Academic Achievement Over Time

Based on the assumption that the features and characteristics of seizures, including neural disturbances, would influence the efficacy of learning and information acquisition, it was anticipated that children with seizures would have a greater decline in academic achievement performance from baseline to 12 months than children with asthma. That the children with seizures did not decline more than the children with asthma was unexpected. Furthermore, since asthma is not a neurological disorder it was unexpected to find the asthma sample showing a decline in academic achievement similar to the seizure sample. This interesting finding of decline in achievement following the onset of both seizure and asthma

conditions might reflect an important pattern among children with chronic illnesses.

Even though there was not a statistical difference in the amount of change between the two samples, the significant decline in both samples is extremely important. Because both samples of children declined in academic achievement over 12 months, it may be that all children experience an adjustment period following the onset of an illness condition. Families and children may focus on the illness and the treatment regimen, rather than focusing on the academic tasks during the initial period following diagnosis. If this is true, the decline may be of a transitory nature and, therefore, it would be anticipated that the scores would return to baseline levels after this period of adjustment is completed. The academic achievement of the children with seizures, however, may never return to baseline levels if there is an additional neurological basis to their decline. Future research that measures academic achievement for a longer period of time, such as 2, 3, or 4 years after onset, is recommended to determine if this decline is transitory or persistent.

One of the most difficult aspects of conducting the study was collecting data from the children's schools. Testing results were often unavailable for the time frame specified in the design. The optimal period for baseline assessment would have been within 2 months prior to the onset of the condition, however,

baseline data included test results from as far out as 2 years prior to the onset.

Similarly, a stronger design would have the follow-up testing at very near to the 12-month anniversary of the condition onset. Again, there was great variability in the timing of the testing such that the 12-month data included testing ranging from 6 months to 18 months following the onset. This variability may have diluted the significance of the findings. Future research should control the timing of the testing so that data are more valid. Moreover, testing should be conducted on an individualized level rather than using group-administered tests obtained from the school. This design feature also would increase the validity of the data as well as provide consistent data for each participant.

Another possible reason that children with seizures did not decline more significantly than the children with asthma is the efficacy of seizure medications. In children who were having subclinical electrical discharges prior to the first recognized seizure, the administration of medication might have improved cognitive functioning. Some parents commented during data collection interviews that they saw an improvement in their child's concentration, memory, and school grades following the initiation of medication. This was particularly true for the children with absence seizures who previously had been missing information and instructions during their brief periods of unconsciousness. It may be that children tested prior to starting on medication (baseline) might have been negatively

influenced by the seizure activity. Children tested at 12 months would have cognitively improved with medication. Future research should include testing children prior to and after the initiation of medication to assess the change in achievement in relation to medication.

In summary, more research needs to be conducted that examines change in academic achievement over time following the onset of a health condition.

Findings from the study strongly indicate that decline in achievement occurred in these two samples of children. Future studies should investigate changes in academic achievement in common chronic illnesses of childhood such as seizures, asthma, and diabetes. Comparing such groups would allow one to determine if there is pattern of decline common to all children following the onset of a chronic health condition, or if a specific illness carries more risk of decline than other illnesses.

Factors Associated with Academic Achievement in the Seizure Sample

Nine major variables were significantly correlated with either the teacher's
rating of the child's performance or the total battery academic achievement score.

The family characteristic variables of SES and child stress, the parent response
variables of attitude and expectations toward the child's achievement, the child
response variables of attitude, school self-concept, adaptive competency, and
externalizing behavior, and the teacher response variable of expectations for child

achievement were associated with the achievement variables. In all cases, the direction of the relationships between each variable and the academic achievement variable was in the direction predicted by the theoretical framework.

Various combinations of the nine variables were tested to choose the model that did the most concise job predicting child academic achievement. The model that emerged as the best for predicting the teacher's ratings contained four variables. Higher parent expectations, more child adaptive competencies, fewer child externalizing behavior problems, and higher teacher expectations for achievement were associated with higher ratings of performance by the teachers. The model was successful in predicting 60% of the variance in academic achievement as measured by the teacher's rating. The model that emerged as the best predictor of the total battery achievement test score contained three variables. Higher SES, higher parent expectations, and more child adaptive competencies were related to higher scores. This model was successful in predicting 73% of the variance.

The large amount of variance in academic achievement accounted for by the variables provides support for the model developed for the study. The model proposed that parent expectations would be related to child academic achievement and results indicated that expectations were strongly correlated with both the teacher's ratings and the child's performance on the test. Parent expectations have

not been previously studied in children with new-onset seizures. There is limited data on the relationships between expectations and academic achievement in children with chronic seizures. The classic study by Long and Moore (1979) found that parents had lower school performance expectations for their child with epilepsy compared to their healthy siblings. Specifically, parents expected their children to have lower academic levels and a diminished ability to concentrate. Green and Hartlage (1971) found significant correlations between measures of parental acceptance of lower educational performance and the child's academic achievement.

Because of the strong findings on parent expectations, future research should include this factor in examining predictors of academic achievement in children. A weakness in this study was the failure to measure expectations at baseline. Measuring expectations prior to the onset of an illness condition and again after a period of time following the onset, would allow an examination of the change in expectation in conjunction with the change in the child's health status and academic performance.

In the model, teacher expectations were proposed to be directly related to child academic achievement. Analyses showed a strong correlation between teachers' expectations and their ratings of the child's performance with higher teacher expectations being associated with higher ratings of performance. One

could argue that because the teacher completed both of these instruments, that the correlation was inflated because of response bias. Because teacher expectations also were highly correlated with the child's performance on the total battery, helps address concerns about response bias.

No studies were found that explored teacher expectations for children with new-onset seizures, however, teacher attitudes have been found to be poor for the academic performance of children with epilepsy. Bennet-Levy and Stores (1988) found that teachers perceived children with epilepsy to have poorer concentration and mental processing, and to be less alert than their healthy peers. Guerin (1979) found that teachers rated children with epilepsy lower in ideas, directions and activities than children with other health conditions. Bagley (1970) reported that teachers underestimated the intellects of children with seizure disorders by approximately one standard deviation, and Holdsworth and Whitmore (1974a) found teachers to be less demanding of the child with epilepsy than of their healthy peers.

It has already been noted that teacher expectations were not measured at baseline on all children in this study. It would be valuable in future research to measure teacher expectations prior to their knowing that the child had developed an illness condition and then again after they were aware of the condition to determine how much expectations are biased by attitudes about illness.

In the model developed for the study, it was proposed that child behavior would be correlated with academic achievement. The findings that positive child behavior (adaptive competency) was positively correlated with achievement, and that negative behavior (externalizing behavior problems) was negatively correlated with achievement, support the model. The behavior findings also were consistent with the literature. Austin and colleagues (1998) examined factors related to academic achievement in children with seizures and found that school adaptive competency was significantly related to achievement variables. The adaptive competency score is comprised of scores measuring the child's happiness, learning, appropriate behavior, and working habits at school. When developing interventions for improving academic achievement, these areas appear to be important facets about the child that should be included.

The relationship between behavior problems, especially externalizing problems, and underachievement has been consistently strong in previous research studies (Barkley, Fischer, Edelbrock, & Smallish, 1990; Hinshaw, 1992). The findings from the current study justify using behavioral assessments for screening children who may be at risk for academic problems. Because children with seizures are at risk for underachievement and given that past research has shown an association between brain impairment and externalizing symptom areas (Howe et al., 1993), it is imperative that children with seizures who display externalizing

behavior problems receive a thorough assessment of their academic progress to prevent or reduce decline in academic achievement.

It was proposed in the model that socioeconomic status (SES) would be related to parent and child responses, which in turn, would be related to child academic achievement. The finding that higher SES was related to higher performance ratings by the teacher is consistent with several studies. In children with epilepsy, SES factors, particularly parental education, were found to be important determinants of achievement (Mitchell et al., 1991). In general population studies, an association was found between socioeconomic status (SES) and educational accomplishments and attainment in young children (Hess & Holloway, 1984; Patterson, Kupersmidt, & Vaden, 1990).

Unfortunately, nursing interventions can do little to directly improve the socioeconomic situation of families, however, they can assist families in stretching their financial resources through medication programs and free clinics. Nurses can also provide information for parents to obtain job training and welfare benefits as needed. Lack of financial resources, for instance, could prevent a child from receiving the prescribed antiepilepsy medication, possibly causing seizure activity to increase and academic performance to decrease. Therefore, although SES has not consistently been related to academic achievement in children, future research

should include this factor to insure that a thorough assessment of the family situation is completed.

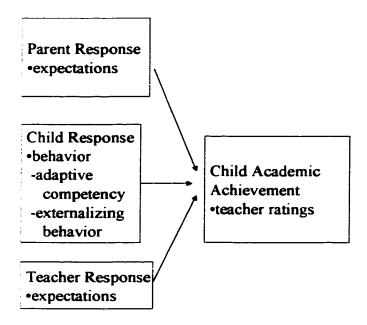
Analyses provided strong support for the model and for the inclusion of psychosocial factors when assessing children with seizures. Although many of the variables were not included in the regression equations, the high correlations of the independent variables with the achievement variables generally support the usefulness of this model. Several unavoidable problems, such as small sample size and missing data, reduced the statistical power. A larger sample size would have allowed inclusion of more variables in the regression models and possibly shown more of the variables in the model to be predictive of academic achievement.

Based on the findings, the models of academic achievement in children with seizures were revised (Figures 2 and 3).

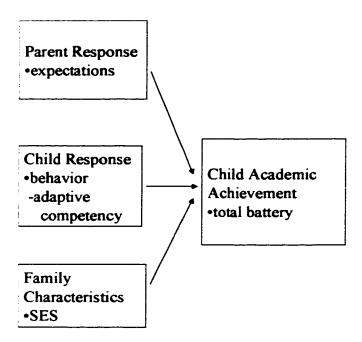
The design of this study does not permit the unequivocal assertion that the independent variables affected academic achievement. In nonexperimental research such as this, alterative explanations for the relationship between the independent and dependent variables must be considered. For example, reverse causation may have occurred, where the children's academic achievement influenced the parents' and teachers' expectations for their achievement. A stronger design would have collected expectations at the onset of the condition. Additionally, the measures of

<u>Figure 2</u>. Revised Mode! of Academic Achievement in Children with Seizures:

# **Teacher Ratings**



<u>Figure 3.</u> Revised Model of Academic Achievement in Children with Seizures: Total Battery



expectations need further development and testing to make sure the expectations are based on future academic performance rather than based on current or past performance.

#### Conclusions and Recommendations

Parent Expectations Toward Child Academic Achievement and Teacher Expectations for Child's Academic Achievement were instruments developed by the author for the study. These instruments were found to have good reliability and validity, and were found to be highly correlated with academic achievement in children with seizures. No previous research has examined parent or teacher expectations for academic achievement in children with new-onset seizures. Moreover, no studies were found that described the development of instruments to measure these factors. Thus, the development of these instruments is an important contribution to this area of research.

Both instruments have strong potential for use in future research, but first need further development and testing. The language needs to be more concise to assure that expectations are for future performance rather than based on past performance. Additionally, further testing using a test-retest design to examine the instruments for sensitivity to change is needed. Sensitivity to change is particularly important for assessing children with new-onset conditions who may have a decline in academic performance following the onset of the condition.

The model testing at 12 months showed that psychosocial variables were stronger predictors of academic achievement than seizure variables in children with seizures. This is an extremely important finding that has clinical relevance. So often in the clinical setting, children are assessed solely from a medical or illness perspective. If the child's seizures are well controlled on antiepilepsy medication and the child is having few or no side effects from the medication, the case is considered a success. A more thorough assessment that includes psychosocial factors might bring to the surface problems, such as academic underachievement, that the child is experiencing.

Furthermore, when it is realized that the child is having problems in school, factors other than seizure activity and medications must be assessed. Based on the findings of this study, it appears that psychosocial factors play a more prominent role in academic achievement than do seizure variables. Therefore, clinical assessments for children with seizures must include both illness and psychosocial components.

It was unexpected that children with asthma would decline in academic performance at 12 months following the onset of their condition. That both samples of children had significant declines in their academic performance in this study is perhaps a phenomenon that occurs following the onset of a potentially chronic condition. The period following diagnosis may be associated with a general

lowering of scores. Whether this decline is temporary or permanent should be examined in future research. A longitudinal study that continues to assess children for several years after diagnosis would answer the question of how stable this decline is for children with chronic illnesses.

The decline in academic achievement over the first 12 months following the condition onset for both samples of children was significant. Moreover, should the decline continue, children would quickly fall into a situation requiring special academic services, such as tutoring or learning disabled classes, or repeating grade levels. From an educational perspective, the decline merits concern and should alert teachers and counselors that frequent assessments of academic progress need to occur.

In summary, knowledge of the nature and degree of academic underachievement in children is crucial, for they are in the process of acquiring skills that are necessary for further academic achievement and subsequent psychosocial development. Impairment of this process has potential far reaching effects for the child, family, and society. Identification of the factors associated with academic achievement in children, especially those with a chronic condition such as epilepsy, will enable early development and implementation of appropriate interventions at a time when they can have the greatest impact.

For professionals working with children with epilepsy several points should be apparent. Not all children have problems keeping up in school, however, given the high rates of academic achievement problems, assessment in this area of development is appropriate. Additionally, boys appear to be more at risk for academic problems than girls, and so they may need to be preferentially targeted for assessment. Closely examining standardized achievement testing from the school to review progress is the minimum assessment that should be conducted. If questions remain after examining these data, then a more thorough neuropsychological evaluation, including individual neurocognitive testing, is warranted. The results can be used to develop an intervention and remedial program specifically tailored for the child.

Nurses working in the field of chronic childhood illness are responsible for developing programs and interventions to assist children and their families to attain the highest level of quality of life possible. One of the primary tasks for the school age child is to learn and succeed in school. When factors block or reduce the child's ability to complete this task, it is the nurse's responsibility to help the child overcome these obstacles. Based on the findings of this research, nursing assessments need to include psychosocial as well as illness factors in order to develop interventions that will be successful in facilitating academic achievement in children with new-onset conditions.

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Appendix A: Consent Forms

Study	No.	:
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# IUPUI INFORMED CONSENT STATEMENT for

Project

Title: <u>New-Onset Seizures and Asthma: Factors Affecting</u>
Adaptation

You are asked to participate in a research study, entitled "New-Onset Seizures and Asthma: Factors Affecting Adaptation." The purpose of this study is to learn about the factors that influence behavior in children with new-onset seizures or asthma. Some children who have a seizure or asthma have changes in behavior and we are interested in discovering what factors influence these changes. If you agree to participate, you will be one of approximately 360 families who will be participating in the study.

To learn about your experience, we would like to interview you about you and your family. The phone interviews should last about one hour and 30 minutes. We would like to audiotape about 10 minutes of your interview. We will also ask you to sign permission forms granting us permission to obtain information from your child's medical records and your child's teacher. If your child is at least 8 years old, we would like for him/her to be interviewed about him/herself and your family for about 30 minutes. We would be contacting you and your child (if 8 years or older) four more times (3, 6, 12, and 24 months) over the next 2 years to repeat the telephone interviews. Subsequent interviews would be about one hour.

We do not expect these interviews to be uncomfortable for you or your child. If you should find the interview makes you uncomfortable, please tell the interviewer immediately and she/he will talk to you about your discomfort. You or your discomfort or any other questions that your discomfort or any other questions that you might have about the study. The information in the study records and on the audiotape will be kept confidential and will be made available only to persons conducting the study unless you specifically give your permission in writing to do otherwise. If the results of this study are published, neither you nor your child will be identified.

#### **CONSENT:**

I have been given an opportunity to ask questions about this study; answers to such questions (if any) have been satisfactory. The information in the study records and on the audiotape will be kept confidential and will be made available only to persons conducting the study unless I specifically give my permission in writing to do otherwise. If the results of this study are published, I will not be identified.

Subject's Initials

In consideration of all the above, I give my consent to participate in this research study, and for my child to participate in the research. I understand that I or my child may drop out of or be withdrawn from the study without fear of changing the investigator's interest or the quality of medical care which I or my child may seek or receive in the future from the doctors participating in the study. I will be paid \$20, and my child will be paid \$8 for completing each of the five telephone interviews. I will be paid a total of \$100, and my child will be paid a total of \$40.

I acknowledge receipt of a copy of this informed consent

# CHILD CONSENT (age 8 years or older):

statement.

I have been able to ask my parents questions about this study, and they have explained the study to me. I am willing to participate in the study. I know my answers will be kept secret. If the results of this study are published, I will not be named. I will be paid \$8 for completing each of the five telephone interviews for a total of \$40.

If I am worried or if I shou Joan Austin or Dr. David Dunn at	collect.
SIGNATURE OF CHILD	DATE



# METHODIST HOSPITAL OF INDIANA, INC.

# INDIANAPOLIS, INDIANA

# PATIENT RESEARCH CONSENT FORM

PLEASE READ THIS INFORMATION CAREFULLY AND MAKE SURE THAT YOU UNDERSTAND IT BEFORE SIGNING YOUR NAME TO THE FINAL PAGE.

You,, agree to be part of a research				
project. I, Joan K. Austin and my staff are doing it. The name of this research project is CHILDHOOD				
EPILEPSY: FACTORS AFFECTING ADAPTATION.				
·				
PURPOSE: The reason you are being asked to take part in this study is because your child had either a seizure-like episode or was placed on daily asthma medication in the past 6 weeks. The investigators hope to learn about the factors that influence behavior in children with new-onset seizures or asthma.				
PROCEDURES:				
The usual procedures you can expect if you take part in this research study are 5 telephone interviews over a 2-year period. The first interview will be about 1 hour and 15 minutes. Future interview will be about 1 hour. If your child is 8 years or older, he/she will also be asked to complete interviews. These interviews will last about 20-30 minutes.				
You will be involved in this study for 2 years. The entire study will take 4 years to complete. 360 patients are to be entered into this study.				
BENEFITS/RISKS:				
There are no direct benefits to you for being in this project. However, by taking part in this study, you will help to increase scientific and medical knowledge.				
You have been told there could be some discomforts to you or your child. These include possible discomfort in talking about feelings. If you or your child is uncomfortable, either <u>Joan K. Austin</u> or <u>David W. Dunn</u> will talk with you about your feelings.				
2/5/96 Parent's Initials Approved by IRB: FEB 0 6 1996 168				

Childhood Epilepsy: Factors Affecting Adaptation

Joan Austin Page 2

#### **NEW INFORMATION:**

If new information arises, I, <u>Joan K. Austin</u> will tell you. You may choose to stop or continue in the project based on this information.

### **ALTERNATIVE TREATMENT:**

Not taking part in this study is an alternative.

#### **CONFIDENTIALITY:**

Your medical records contain information to help the research people. They will look at your records. They will keep them private just like other hospital records. They may use all of your medical data for scientific or educational presentations. They are not to say who you are in those lectures or writings.

# **QUESTIONS AND FURTHER INFORMATION:**

If you believe you have suffered any injury as a result of being in this project, you may contact me <u>Joan</u>
Austin at Vou can also call me with questions about this project.

### **VOLUNTARY PARTICIPATION:**

Your decision whether or not to take part in this study will not hurt your future care at this hospital. Even if you decide to participate, you may stop and withdraw from the study at any time.

If you withdraw from taking part in this research project you will not jeopardize the treatment of your medical condition at Methodist Hospital of Indiana.

I, <u>Joan Austin</u>, may take you out of the project for any reason in your best medical interest. I may also remove you from the study should you fail to complete the interview.

# **COMPENSATION:**

You will be paid a total of \$100 (\$20 per interview) for being in this project. The participating child will receive \$40 (\$8 per interview).

There is no cost to you to take part in this study.

2/5/96 Approved by IRB: FEB 0 6 1996	169	Parent's Initials
Approved by INB. 122	,	

Childhood Epilepsy: Factors Affecting Adaptation Joan Austin Page 3

I understand I will receive a copy of this consent form.

### **PARTICIPANT'S AGREEMENT:**

This study has been explained to me. I voluntarily agree to take part in this study. I had the opportunity to ask questions about this study. I understand future questions I may have about this study or my rights will be answered by <u>Joan K. Austin</u>.

I have read this form and understand its meaning. By signing this consent I agree to volunteer to take part in this research study.

Signature of Child (if applicable)

Date

Signature of Parent

Date

Signature of Witness

Date

/jia
IRB45:con-austin

Approved by IRB: FEB 0 6 1996

#### COMMUNITY HOSPITALS INDIANAPOLIS

#### INFORMED CONSENT STATEMENT

for

NEW-ONSET SEIZURES: Factors Affecting Adaptation

PI: Joan K. Austin, DNS, RN, FAAN

You are asked to participate in a research study, entitled "New-Onset Seizures: Factors Affecting Adaptation." The purpose of this study is to learn about the factors that influence behavior in children with new-onset seizures. Some children who have a seizure have changes in behavior. We are interested in discovering what factors influence these changes. If you agree to participate, you will be one of approximately 360 families who will be participating in the study.

We would like to interview you and your family, to learn about your experience. The phone interviews should last about one hour and 30 minutes. We would like to audiotape about 10 minutes of your interview. We will also ask you to sign permission forms granting us permission to obtain information from your child's medical records and your child's teacher. If your child is at lest 8 years old, we would like for him/her to be interviewed about him/herself and your family for about 30 minutes. We would be contacting you and your child (if 8 years old or older) four more times (3,6,12, and 24 months) over the next 2 years to repeat the telephone interviews. Subsequent interviews would be about one hour.

We do not expect these interviews to be uncomfortable for you or your child. If you should find the interview makes you uncomfortable, please tell the interviewer immediately and she/he will talk to you about your discomfort. You or your child may also call either Dr. Joan Austin or Dr. David Dunn at collect to talk about your discomfort or any other questions that you might have about the study. The information in the study records and on the audiotape will be kept confidential and will be made available only to persons conducting the study unless you specifically give your permission in writing to do otherwise. If the results of this study are published, neither you nor your child will be identified.

### CONSENT:

I have been given an opportunity to ask questions about this study; answers to such questions (if any) have been satisfactory. The information in the study records and on the audiotape will be kept confidential and will be made available only to persons conducting the study unless I specifically give my permission in writing to do otherwise. If the results of this study are published, I will not be identified.

In consideration of all the above, I give my consent to participate in this research study, and for my child to participate in the research. I understand that I or my child are free to refuse to participate in this study or to withdraw at any time for any reason and that our decision will NOT affect our care. I also understand that, at any time, our doctor can withdraw us from this study. I will be paid \$20, and my child will be paid \$8 for completing each of the five telephone interviews. I will be paid a total of \$100, and my child will be paid a total of \$40.

If I have any questions regarding my rights as a subject in a research study. I should contact the Institutional Review Board Chairperson, David M. Buckingham, Ph.D. at Study has been reviewed by an institutional review board for the protection of the rights of human subjects in research studies, in accordance with federal regulations.

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Page 1	Subject's Initials
Lake I	200 CCF 2 TITUTE

## JOAN K. AUSTIN

I acknowledge receipt of a copy of this informed co	ensent statement.
PARENTS SIGNATURE	DATE
PARENTS SIGNATURE	DATE
SIGNATURE OF WITNESS	
CHILD CONSENT (age 8 years or older):	
am willing to participate in the study. I know my	this study, and they have explained the study to me. answers will be kept secret. If the results of this study 88 for completing each of the five telephone interview
If I am worried or if I should have any questions, I collect.	can call Joan Austin or David Dunn at
SIGNATURE OF CHILD	DATE
SIGNATURE OF PARENT	DATE

INDIANA	UNIVERSITY
$\mu u u u u u$	CALABARACA



Indiana University

Purdue University Indianapolis

Date:			

	Dear	<del></del> :	
SCHOOL OF NURSING	UNIVERSITY SCHOO parent(s) identified you you please complete the 2 months prior to addressed stamped enthese forms be completed in the second	ng conducted by Dr. Joan L OF NURSING, Indians as the teacher who know the enclosed forms, ratio and reto velope. It is SO VERY. ted as soon as possible for BLE for you to return the ME COLLECT (if long	apolis, Indiana. The is their child best. Would ing the child's behavior for urn them in the enclosed selection with the securate study results. forms by the date specified
	INDIANA UNIVERSITY	<ol><li>If you should have any</li></ol>	nstitutional Review Board at questions, please feel free EASE return these forms by
	Joan K. Austin, DNS, Professor and Principal	•	
RESEARCH OFFICE 1111 Middle Drive Indianapolis, Indiana	about my child at school	ssion for my child's teach I, and to release informati out my child's school beh	on from the school records
46202-5107 317-274-8254	NAME		(mother's signature)
J.11-61 T-06JT	NAME		(father's signature)
ated on the campus of	WITNESS	173	DATE

PRINCIPAL INVESTIGATOR \_\_\_\_\_

# INDIANA UNIVERSITY



Date:	

SCHOOL OF NURSING	Dear:	
	on the family's experience with childhood information on asthma history in the stu	
	the asthma in the enclosed self-address have any questions, contact Dr. Joan K.	
	Sincerely,	
	Joan K. Austin, DNS, RN, FAAN Principal Investigator IU SCHOOL OF NURSING	David W. Dunn, MD Co-Investigator IU SCHOOL OF MEDICINE
	I give my permission to have med asthma released to Drs. Joan K. Austin a	<del>-</del>
RESEARCH OFFICE	Name	(mother's signature)
1111 Middle Drive Indianapolis, Indiana	Name	(father's signature)
46202-5107	Principal Investigator	
317-274-8254	Date	
zted on the campus of Indiana University Purdue University Indianapolis	doctor1a.ltr 174	

# INDIANA UNIVERSITY



_	_4				
υ	ate:	 	 	 	

SCHOOL OF NURSING	Dear:	
	on first seizures being conducted by Dr. at the INDIANA UNIVERSITY MEDICA information on <b>EEG findings</b> in the students.	L CENTER. We are including by.  The EEG results in the enclosed self-nould have any questions, contact Dr.
	you possibly can. Thanks so much! Sincerely,	
	Joan K. Austin, DNS, RN, FAAN Principal Investigator I U SCHOOL OF NURSING	David W. Dunn, MD Co-Investigator I U SCHOOL OF MEDICINE
	I give my permission to have reco	rds on my child's EEG released to Drs.
Research Office	Name	(mother's signature)
1111 Middle Drive Indianapolis, Indiana 46202-5107	NamePrincipal Investigator	
317-274-8254	Date	
sted on the campus of Indiana University Purdue University Indianapolis	175 doctor1s.ltr	

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Appendix B: Instruments

## New-Onset Seizure and Asthma Study

### BASELINE DEMOGRAPHICS / FACE PAGE

Family Na	me:				Family N	umber:	_
	dianapolis mphis				Study Gr	oup: A=Asthma S=Seizur	
Address:	str		<del></del>		t #		
	SCI	eet .		αþ	'C #		
•	cit	у	st -	zip	<del></del>		
Phone:		(home)			(al	ternative)	
Interview	Date:	_//	_		Visit: _	В	
Who lives	in the hou	sehold:					
Name	Relationsh to Affecte Child	_	Gender (F/M)	Race	Years of Education	•	
		//					
			<del></del>				
		'					
						<del></del>	
		//					
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		//	<del></del>				
	<del></del>	//			<del></del>		
Code Relat	F=Father  tionship to  SM=Step-B	r C=Affec Affected Ch Mother GM=G Father GF=G	ild as f randmoth	ollows er A=	Aunt S=Si	bling SE=Se	lf O=Other lf-Sibling
	as follows an-American sian			=Nativ ≃Bi-Ra	e American cial	7=Other	

If there is no Mother Study Participant in the above table:	or no Fa	ther Study F	Participant listed
Does child see his/her mother/father	regularly	? YES NO	
If YES, obtain the following infor	mation:		
Name:first			
		last	
Address: street		apt #	
city	st	zip	
Phone:(home)			(alternative)
Gender: (F/M) Race:	i=Africa 2=Caucas		5=Native Americar 6=Bi-Racial 7=Other
Years of Education:	St	tudy Partici	pant: M=Mother F=Father
Date of Birth://			
Do any family members have a chronic il	lness?	es no	
If yes, list names:			
۵			
	Participar eparated ther	nt:	
If married or living with someone, n	umber of y	years:	-
Child's Physician:		Phone:	
Address:	·	<u> </u>	
street	ci	ity s	t zip

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Child's Teacher:		Phone	e:	····-
Address:				
	street	city	st	zip
Additional Teacher:		P	none:	
Address:	street	_ ·		
	street	city	st	zip
Child's School:		Phone	e:	<del></del>
Address:		_	<del></del>	
	street	city	st	zip
ame / Address / Pho	ne Number of Persor	ns to Contact for	YOUR New	Address
lame / Address / Pho ind/or Phone Number	in the Event of a (	Change:		
	in the Event of a (	Change:		
ontact 1:	in the Event of a (	Change: Phone	e:	
and/or Phone Number Contact 1: Address:	in the Event of a C	Phone city	e:	zip
Address:	in the Event of a C	Change: Phone city Phone	e:	zip
Address:	in the Event of a C	Change: Phone city Phone	st	zip
nd/or Phone Number ontact 1:  Address: ontact 2:	in the Event of a C	Change: Phone city Phone	st	zip
Address:	in the Event of a C	Change: Phone city Phone	st	zip

Reason for dropping out of the study:

	code:
to your household income last	o live in your house, which category is closest year? (Include things such as SSI, Child Support, isability Compensation, and money coming in from
Total family income in pas	st year before taxes:
	6 = 50,000-59,999
2 = 10,000-19,999	7 = 60,000-69,999
3 = 20,000-29,999	8 = 70,000-79,999
4 = 30,000-39,999 5 = 40,000-49,999	9 = 80,000 or More
n addition to income, do you m	receive help from any of the following:
Welfare, including A	AFDC
Food .Stamps	
MEDICAID or MEDICARE	
Public Housing	
wic	

2

Date:	<u></u>	Intervi	ewer's	Initials:	<del></del>	
Family No:	Family Mer	nber:	<u>c_</u>	Visit:	( B, 12,	24)

### CHILD STRESSORS

Instructions: The following statements are things that sometimes happen to kids. As I read each statement, I would like you to tell me "yes" or "no" if this has happened to you in the past year. If the event has happened, I would like you to tell me how much it bothered you. I will ask you to answer with "none", "some", or "a lot".

		<u>Happened</u> Y=Yes N=No	Bothered You 1 = None 2 = Some 3 = A lot
1.	Changed to a new school.	Y/N	None Some A lot
2.	Serious illness or injury of a family member.	Y/N	None Some A lot
3.	Serious illness or injury of self.	Y/N	None Some A lot
4.	Brother or sister left home.	Y/N	None Some A lot
5.	Trouble with a teacher.	Y/N	None Some A lot
6.	Failed a grade.	<b>Y/N</b> 181	None Some A lot

		<u>Happened</u> Y=Yes N=No	Bothered You 1 = None 2 = Some 3 = A lot		
7.	Increase in the number of arguments with parents.	Y/N	None	Some	A lot
8.	Had failing grades on a report card.	Y/N	None	Some	A lot
9.	Had lower grades than expected.	Y/N	None	Some	A lot
10.	Trouble with classmates.	Y/N	None	Some	A lot
11.	Being cut from an extracurricular activity that you wanted to be involved in (such as band or an athletic team).	Y/N	None	Some	A lot

Date: Interviewer's Initials:				
Family No: Family Member: (M, F) Vis	sit:	В		
FAMILY RESOURCES				
I will now be reading to you a list of "Family Statements" one at a time "family" means your immediate family (mother and/or father and childres "HOW WELL DOES THE STATEMENT DESCRIBE YOUR FAMILY DURING THE 6 MONTHS PRIOR TO THE FIRST SEIZURE-LIKE ASTHMA DIAGNOSIS?"	n). I Y SIT	want UAT	to ki	now
Your answers will be based on the following responses:  1 = Not At Ali 2 = Minimally 3 = Moderately 4 = Very Well				
1. Being physically tired much of the time is a problem in our family.	1	2	3	4.
2. We have to nag each other to get things done.	1	2	3	4
3. We do not plan too far ahead, because many things turn out to be a matter of good or bad luck anyway.	1	2	3	4
4. It seems that members of our family take each other for granted.	1	2	3	4
5. Sometimes we feel we don't have enough control over the direction our lives are taking.	1	2	3	4
6. Certain members of our family do all the giving, while others do all the taking.	1	2	3	4
7. We seem to put off making decisions.	1	2	3	4
8. Our family is under a lot of emotional stress.	1	2	3	4

2 3 4

to share concerns.

9. Many things seem to interfere with family members being able

Your answers will be based on the following responses:

1 = Not At All

2 = Minimally

3 = Moderately

4 = Very Well

10. It seems that we have more illness (colds, flu, etc.) in our family than other people do.	1	2	3	4
11. In our family, some members have many responsibilities while others don't have enough.	1	2	3	4
12. It is upsetting to our family when things don't work out as planned.	1	2	3	4
13. Being sad or "down" is a problem in our family.	1	2	3	4.
14. It is hard to get family members to cooperate with each other.	1	2	3	4
15. Many times we feel we have little influence over the things that happen to us.	1	2	3	4
16. We have the same problems over and over we don't seem to learn from past mistakes.	1	2	3	4
17. There are things at home we need to do that we don't seem to get done.	1	2	3	4
18. We seem to be so involved with work and/or school activities that we don't spend enough time together as a family.	1	<b>2</b>	3	4
19. Friends seem to enjoy coming to our house for visits.	1	2	3	4
20. When we make plans, we are almost certain we can make them work.	1	2	3	4

2 = Minimally 3 = Moderately 4 = Very Well	,			
21. In our family, we understand what help we can expect from each other.	1	2	3	4
22. When we face a problem, we look at the good and bad of each possible solution.	1	2	3	4
23. No matter what happens to us, we try to look at the bright side of things.	1	2	3	4
24. In our family, it is "okay" for members to show our positive feelings about each other.	1	2	3	4
25. We seem to be happier with our lives than many families we know.	1	2	3	4
26. It is "okay" for family members to express sadness by crying, even in front of others.	1	2	3	4
27. We discuss our decisions with other family members before carrying them out.	1	2	3	4
28. We get great satisfaction when we can help one another in our family.	1	<b>2</b>	3	4
29. The members of our family respect one another.	1	2	3	4
30. Members of our family are encouraged to have their own interests and abilities.	1	2	3	4

Your answers will be based on the following responses:

1 = Not At All

	· Date:		Intervi	ewer's	s Initia	als:		-		
	Family No:	Family Member	·	( M,	F)	Visit: _		(6,	12,	24)
		FAMILY	RESOUR	CES						
'ዥ ''⊦	vill now be reading to you amily" means your immedi IOW WELL DOES THE URING THE PAST 6 MON	iate family (moth STATEMENT	er and/or fa	ather a	and cl	hildren).	l w	ant 1	o kn	ment, ow
	Your answers will be	based on the fo 1 = Not A 2 = Minin 3 = Mode 4 = Very	At All nally erately	ponse	es:					
1.	Being physically tired mu	uch of the time is	s a problem	in ou	r fami	ly.	1	2	3	4
2.	We have to nag each oth	her to get things	done.				1	2	3	4
3.	We do not plan too far al a matter of good or b		-	turn	out to	be	1	2	3	4
4.	It seems that members o	of our family take	each other	for g	ranted	d.	1	2	3	4
5.	Sometimes we feel we do our lives are taking.	on't have enougl	h control ov	er the	e dired	ction	1	2	3	4
6.	Certain members of our the taking.	family do all the	giving, whil	e oth	ers do	all	1	<b>2</b>	3	4
7.	We seem to put off making	ng decisions.					1	2	3	4
8.	Our family is under a lot	of emotional stre	ess.				1	2	3	4
9.	Many things seem to inte	erfere with family	Hembers t	peing	able		1	2	3	4

Your answers will be based on the following responses:

1 = Not At All

2 = Minimally 3 = Moderately 4 = Very Well

10. It seems that we have more illness (colds, flu, etc.) in our family than other people do.	1	2	3	4
11. In our family, some members have many responsibilities while others don't have enough.	1	2	3	4
12. It is upsetting to our family when things don't work out as planned.	1	2	3	4
13. Being sad or "down" is a problem in our family.	1	2	3	4
14. It is hard to get family members to cooperate with each other.	1	2	3	4
15. Many times we feel we have little influence over the things that happen to us.	1	2	3	4
16. We have the same problems over and over we don't seem to learn from past mistakes.	1	2	3	4
17. There are things at home we need to do that we don't seem to get done.	1	<b>2</b>	3	4
18. We seem to be so involved with work and/or school activities that we don't spend enough time together as a family.	1	2	3	4
19. Friends seem to enjoy coming to our house for visits.	1	2	3	4
20. When we make plans, we are almost certain we can make them work.	1	2	3	4

Your answers will be based on the following responses:

1 = Not At All

2 = Minimally

3 = Moderately

4 = Very Well

21. In our family, we understand what help we can expect from each other.	1	2	3	4
22. When we face a problem, we look at the good and bad of each possible solution.	1	2	3	4
23. No matter what happens to us, we try to look at the bright side of things.	1	2	3	4
24. In our family, it is "okay" for members to show our positive feelings about each other.	1	2	3	4
25. We seem to be happier with our lives than many families we know.	1	2	3	4
26. It is "okay" for family members to express sadness by crying, even in front of others.	1	2	3	4
27. We discuss our decisions with other family members before carrying them out.	1	2	3	4
28. We get great satisfaction when we can help one another in our family.	1	· 2	3	4
29. The members of our family respect one another.	1	2	3	4
30. Members of our family are encouraged to have their own interests and abilities.	1	2	3	4
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Fam	nily No:	_ Family Member:	(M, F)	Visit:	_ (B, 3, 6, 12, 24)	
	HE	ALTH CONDITION FORI			PISODES	
comp abou	plete description uts past	me questions about the se n of what happened before health history. I will be as ou can remember. Take yo	, during, and sking you a se	after eries of ques	_'s episode, and also itions, and I want you	) u to
Des	cription of Seiz	ure-Like Episode				
1.	What was	doing right before the	episode?:W	/as.he/she.a	sleep:or.awake?	
2.	Didh	ave any kind of waming tha	at an episode	would occu	r? If yes, describe.	
3.	What was the	first thing you saw?				
4.		se consciousness (pass ou	ut) during the	episode?		
5.	Didfa	ll to the ground?				
	١	/es No				
<b>6</b> .		ive any unusual movement movements of the face, ar				nts.

- 7. Did you notice any eye blinking, lip smacking, unusual sounds, or trouble talking during the episode? If yes, describe.
- 8. Did the episode involve one side of the body or both? Was one side more involved than the other. If yes, please describe.

- 9. How long did the episode last? (Be sure and help them separate the active episode from the aftermath.)
- 10. Did \_\_\_\_\_ have more than one episode in a row? If yes, describe.

11. How did \_\_\_\_\_ act immediately after the episode?

12. About how long did it take for \_\_\_\_\_ to return to his/her usual behavior?

	Date:/Interviewer's Initials:
	Family No: Family Member: ( M, F ) Visit:B
<u>Seizı</u>	ure-Like Episode Frequency and Medication
13.	What was the date of's first seizure-like episode?
	· .
14.	How many seizures has had?
15.	How many of each kind has he/she had?
	Mind 4 Pagariba
	Kind 1 Describe
	Kind 2 Describe
	Kind 3 Describe
	Nild 5 Describe
If more	e than one kind, use the Health Condition Form / Seizure-Like Episode to describe.
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	Family No:	Family Member: (M, F) Visit: B				
16.	How many total seizu with medication?	re-like episodes hashad prior to this, but were not treated				
	If more than 0					
	16a. At the time, did	16a. At the time, did you think the episode(s) might be a seizure? (Y / N)				
	16b. Did you seek n	nedical attention? (Y / N)				
17.	What was the date of	's first neurological visit?				
18.	What was the name of	of the neurologist who treated?				
19.	From where were you	referred to this study?				
	C = Community P = Pappas W = Wishard R = Riley M = Methodist	ME = Memphis EEG				
	If other, please	specify:				

Family	y No: Family Mer	mber:(M, F) Visit:B
20.	Has been placed on n	nedication for the episodes? (Y / N)
	If yes, date started on medic	cation:
	What medication is	on now?
		(Y/N)
	Depakene / Depakote	<del></del>
	Dilantin	
	Klonopin	
	Lamictal	
	Mysoline	
	Neurontin	<del></del>
	Phenobarbital	
	Tegretol	
	Zarontin	<del></del>
	Other	l iet·

	Family No:	Family Member:	(M, F)	Visit:B
	if yes, what are ti	rom medication a problem? ne main side effects?	, , , , , , , , , , , , , , , , , , , ,	_
Do n	ot read the followin	g responses. nes that the respondent nam		*****
	Problems Restlessr Shaky Ha Sleepines Tiredness Trouble v Unsteadin Upset Sto	on in Concentrating d Sleep d Sleep d Blurred Vision de	h)	

	Date:/ Interviewer's Initials:
Family No:	Family Member: (M, F) Visit: B
	HEALTH CONDITION FORM 1 ASTHMA
I now want t	to ask you some questions about's asthma.
1	Which of the following best describes 's condition?  1 = No wheezing or coughing episodes for 6 months or more.  2 = No wheezing or coughing episodes for 3 months to almost 6 months.  3 = No wheezing or coughing episodes for 1 month to almost 3 months.  4 = 1 - 9 wheezing or coughing episodes in past month.  5 = 10 - 19 wheezing or coughing episodes in past month.  6 = 20 - 29 wheezing or coughing episodes in past month.  7 = 30 or more wheezing or coughing episodes in past month.
2	What is the number of hospitalizations for asthma that has had in the past 6 months?
	(without admission)
3	What is the number of emergency room visits ( <u>without admission</u> ) that has had in the past 6 months?
4	How many days has missed school in the past 6 months because of problems related to asthma?

5a.	Which of the	ne following medications has talentes are currently taken daily?	ken in the past 6 months,
Past 6 (Y/N)		•	
		_ Theophylline, Theodur, Slophylline, A Slobid, Theoclear, Uniphyl, Ur	
		Alupent, Metaprel (oral)	
		_ Alupent, Metaprel (inhaled)	
	. <u></u>	Ventolin, Albuterol, Proventil, Volma	x (oral)
		_ Ventolin, Albuterol, Proventil, Maxair	(inhaled)
		_ Intal (Cromolyn Sodium) (inhaled)	•
<del></del>		_ Tilade (inhaled)	
		_ Serevent (inhaled)	
		_ Prednisone, Prelone, Pediapred (ora	al steroids)
		_ Azmacort, Vanceril, Beclovent, Aerot	oid (inhaled steroids)
		_ Atrovent	-
		_ Antihistamines	
		Other	
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Famil	iy No:	Family Mem	ber:	<del></del>	_ (M,	F)	Visit:	<u>_B</u> _
<b>5</b> b.	When did	begin daily r	medicati	on for	asthma	a? <u> </u>		<u></u>
6.	How much of a j the past 6 month		ide effe	cts fro	m asthr	ma mi	<b>edicatio</b> r	n been in
	No Problem 1	2 3	4	5	6	7	Serious	Problem
Pleas	e answer the nex	1=   2=   3=   4=	NEVER RAREL' SOMET OFTEN	(moons) (moons) (mes) (m	nthly) (weeki )	у)		nce daily)
IN TH	IE PAST 6 MOI	NTHS						
7	_	did night sym 's sleep?		<b>xoughi</b> i	ng, whe	ezinç	g, breath	ilessness)
8	How ofter	didn	ed to ta	ike ext	ra med	licine	during t	he night?
9	How ofter	did's	asthma	limit hi	s/her p	hysic	al activit	ies?
10	How often	did ne	ed to ta	ke ext	ra med	licine	during p	hysical
11	How often	did c	omplain	of tigh	tness ir	n the (	chest?	

Date: Interviewer's Initials:
Family No: (M, F) Visit: (3, 6, 12, 24)
PARENT ATTITUDE SCALE
I am now going to ask you to tell me how you feel when you think about's seizure / asthma condition.
1. All things considered, I find's seizure / asthma condition
1 = extremely beneficial 2 = quite beneficial 3 = slightly beneficial 4 = neither beneficial nor harmful 5 = slightly harmful 6 = quite harmful 7 = extremely harmful
2. All things considered, I find's seizure / asthma condition
1 = extremely rewarding 2 = quite rewarding 3 = slightly rewarding 4 = neither rewarding nor punishing 5 = slightly punishing 6 = quite punishing 7 = extremely punishing
3. All things considered, I find's seizure / asthma condition
1 = extremely good 2 = quite good 3 = slightly good 4 = neither good nor bad 5 = slightly bad 6 = quite bad 7 = extremely bad 198

4.	All things considered,	I find	's seizure / asthma	condition	
		1 =	extremely unfair		
			quite unfair		-
			slightly unfair		
			neither unfair nor fair		
			slightly fair		
			quite fair		
		7 =	extremely fair		
5.	All things considered,	l find	's seizure / asthma	condition	
		1 =	extremely sad		
			quite sad		
			slightly sad		
			neither sad nor happy		
			slightly happy		
		6 =	quite happy		
		7 =	extremely happy		
6.	All things considered,	l find	's seizure / asthma	condition	
			extremely comfortable		
		2 =	quite comfortable		
		3 =	slightly comfortable		
		4 =	neither comfortable nor unc	omfortable	
			slightly uncomfortable		
			quite uncomfortable		
		7 =	extremely uncomfortable		
7.	All things considered,	I find	's seizure / asthma	condition	
		1 =	extremely disappointing		
		2 =	quite disappointing		
		3 =	slightly disappointing		
			neither disappointing nor sa	itisfying	
			slightly satisfying		
			quite satisfying		
		7 =	extremely \$2 tisfying		

8. All things considered, I find	seizure / asthma	condition	
2 = 3 = 4 = 5 = 6 =	extremely useless quite useless slightly useless neither useless nor useful slightly useful quite useful extremely useful		
9. All things considered, I find	's seizure / asthma	condition	
2 = 3 = 4 = 5 = 6 =	extremely cruel quite cruel slightly cruel neither cruel nor kind slightly kind quite kind extremely kind		
10. All things considered, I find	d's seizure / asthma	condition	
2 = 3 = 4 = 5 = 6 =	extremely pleasurable quite pleasurable slightly pleasurable neither pleasurable nor pair slightly painful quite painful extremely painful	nful	

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	Date://	Interviewer's Initials:	
Fa	mily No: Family N	Member: ( M, F ) Visit: (3, 6, 12, 24	4)
	\$	STIGMA SCALE	
	se tell me how much you <b>ag</b> ments.	ree or disagree with each of the following 10	
Sidic		ill be based on the following responses:	
		1 = Strongly Disagree	
		2 = Moderately Disagree	
		3 = Slightly Disagree	
		4 = Neither Disagree nor Agree	
	•	5 = Slightly Agree	٠
		6 = Moderately Agree	
		7 = Strongly Agree	
1.	People who know that him/her differently.	has a seizure / asthma condition, treat	
		1 = Strongly Disagree	_
		2 = Moderately Disagree	
		3 = Slightly Disagree	
		4 = Neither Disagree nor Agree	
		5 = Slightly Agree	
		6 = Moderately Agree	
		7 = Strongly Agree	
2.		at I say to people about's n, they usually have their minds made up	
		1 = Strongly Disagree	_
		2 = Moderately Disagree	
		3 = Slightly Disagree	
		4 = Neither Disagree nor Agree	
		5 = Slightly Agree	
		6 = Moderately Agree	
		7 = Strongly Agree	
3.	•	ve him/herself because of the	
	seizure / asthma condition	<del></del>	_
		1 = Strongly Disagree 2 = Moderately Disagree	
		3 = Slightly Disagree	
	•	4 = Neither Disagree nor Agree	
		5 = Slightly, Agree	
		6 = Moderately Agree	
		7 = Strongly Agree	
		<del>- ,                                   </del>	

4.	Because of the seizure / asthma condition, will have problems in finding a husband or wife.  1 = Strongly Disagree 2 = Moderately Disagree 3 = Slightly Disagree 4 = Neither Disagree nor Agree 5 = Slightly Agree 6 = Moderately Agree 7 = Strongly Agree	
5.	In many people's minds, a seizure / asthma condition attaches a stigma or a label to	
6.	feels different from other children because of the seizure / asthma condition.  1 = Strongly Disagree 2 = Moderately Disagree 3 = Slightly Disagree 4 = Neither Disagree nor Agree 5 = Slightly Agree 6 = Moderately Agree 7 = Strongly Agree	
7.	feels embarrassed about the seizure / asthma condition.  1 = Strongly Disagree  2 = Moderately Disagree  3 = Slightly Disagree  4 = Neither Disagree nor Agree  5 = Slightly Agree  6 = Moderately Agree  7 = Strongly Agree	·

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8.	feels ashamed to tell other children about the seizure / asthma condition.  1 = Strongly Disagree 2 = Moderately Disagree 3 = Slightly Disagree 4 = Neither Disagree nor Agree 5 = Slightly Agree 6 = Moderately Agree 7 = Strongly Agree	
9.	feels other children are uncomfortable with him/her because of the seizure / asthma condition.  1 = Strongly Disagree 2 = Moderately Disagree 3 = Slightly Disagree 4 = Neither Disagree nor Agree 5 = Slightly Agree 6 = Moderately Agree 7 = Strongly Agree	
10.	feels other children would prefer not to be with him/her because of the seizure /asthma condition.  1 = Strongly Disagree 2 = Moderately Disagree 3 = Slightly Disagree 4 = Neither Disagree nor Agree 5 = Slightly Agree 6 = Moderately Agree 7 = Strongly Agree	

Family No: Family Member: (M, F) Visit: (B, 12	2, 24)
Child with condition	
Parent Expectations Toward Child Academic Achievement	
Instructions: I will now be reading to you a list of statements one at a time. It to tell me how well each statement describes your expectations for	
1=strongly disagree	
2=disagree 3=neutral	
4=agree 5=strongly agree	
I expect that will get good grades in school.	
2. I expect that will need extra help with school work at home.	
3. I expect that will have learning problems in school.	
4. I expect that will need special classes in school.	
5. I expect will need to be held back a grade in school.	

expecteds 9/30/97 jc

	Date:/Interviewer's Initials:	
Fami	ily No: Family Member: C	
Seizu	ire	
	CHILD ATTITUDE IOWARD ILLNESS SCALE	
I would now like to ask you how you feel about your seizure condition. If there is anything you do not understand, please ask me about it. For each question, tell me which best describes your feelings. I want you to answer EVERY question, even if some are hard to decide. There are no right or wrong answers. Only YOU can tell me how you REALLY feel.		
1.	How often do you feel that your seizures are your fault?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often	
2.	How often do you feel that your seizures keep you from doing things you like to do?  1 = Never 2 = Not Often 3 = Sometimes 4 = Often 5 = Very Often	
3.	How often do you feel that you will always be sick?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often	
4.	How often do you feel happy even though you have seizures?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often	

5.	How often do you feel different from others because of your seizures?  1 = Never 2 = Not Often 3 = Sometimes 4 = Often 5 = Very Often
6.	How often do you feel bad because you have seizures?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
7.	How often do you feel sad about being sick?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
8.	How often do you feel that your seizures keep you from starting new things?  1 = Never 2 = Not Often 3 = Sometimes 4 = Often 5 = Very Often
<b>9</b> .	How often do you feel just as good as other kids your age even though you have seizures?  1 = Never 2 = Not Often 3 = Sometimes 4 = Often 5 = Very Often

10.	How good or bad do you feel it is that you have seizures?  1 = Very Good  2 = A Little Good  3 = Not Sure  4 = A Little Bad  5 = Very Bad
11.	How fair or unfair is it that you have seizures?  1 = Very Fair  2 = A Little Fair  3 = Not Sure  4 = A Little Unfair  5 = Very Unfair
12.	How sad or happy is it for you to have seizures?  1 = Very Sad  2 = A Little Sad  3 = Not Sure  4 = A Little Happy  5 = Very Happy
13.	How bad or good do you feel it is to have seizures?  1 = Very Bad 2 = A Little Bad 3 = Not Sure 4 = A Little Good 5 = Very Good

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	- Date://	_	Interviewe	r's Initials:_		_		
Fami	nily No: Family Mo	ember:	С	Visit:	_(3,	6,	12,	24)
Asth	nma							
	CHILD ATTITUD	E ION	VARD JLL	NESS SC	<b>ALE</b>			
anyth which some	uld now like to ask you how you hing you do not understand, ple h best describes your feelings. e are hard to decide. There are you REALLY feel.	ease ask I want y	me about ou to answ	it. For each ver EVERY-	questi questic	ion, on, e	tell m ven i	f.
1.	2 3 4	our asthm = Never = Not Of = Someti = Often = Very O	ten imes	ault?				
2.	2 3 4	our asthm = Never = Not Of = Someti = Often = Very O	ten imes	ou from doir	ig thin	gs		
3.	2 : 3 : 4 :	ou will alv = Never = Not Off = Someti = Often = Very O	ten imes	:k?				

4.	How often do you feel happy even though you have asthma?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
5.	How often do you feel different from others because of your asthma?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
6.	How often do you fee! bad because you have asthma?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
7.	How often do you feel sad about being sick?  1 = Never  2 = Not Often  3 = Sometimes  4 = Often  5 = Very Often
8.	How often do you feel that your asthma keeps you from starting new things?  1 = Never 2 = Not Often 3 = Sometimes 4 = Often 5 = Very Often

9.	How often do you feel just as good as other kids your age even though you have asthma?
	1 = Never
	2 = Not Often
	3 = Sometimes 4 = Often
	5 = Very Often
10.	How good or bad do you feel it is that you have asthma?
	1 = Very Good
	2 = A Little Good 3 = Not Sure
	4 = A Little Bad
	5 = Very Bad
11.	How fair or unfair is it that you have asthma?
	1 = Very Fair 2 = A Little Fair
	2 = A Little Fair 3 = Not Sure
	4 = A Little Unfair
	5 = Very Unfair
12.	How sad or happy is it for you to have asthma?
	1 = Very Sad 2 = A Little Sad
	3 = Not Sure
	4 = A Little Happy
	5 = Very Happy
13.	How bad or good do you feel it is to have asthma? 1 = Very Bad
	2 = A Little Bad
	3 = Not Sure
	4 = A Little Good
	5 = Very Good
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Date:	Interviewer's Initia	ls:
Family No:	Family Member: C	Visit:B_

# THE WAY I FEEL ABOUT MYSELF (Piers-Harris)

Here is a group of sentences that tell how some people feel about themselves. I will read each sentence, and I want you to decide whether or not it describes the way you feel about yourself. If the sentence is true or mostly true, the answer will be "Yes". If it is false or mostly false, the answer will be "No". Remember - - there are no right or wrong answers. Only you can tell us how you feel about yourself. Think about how you FELT BEFORE your seizure / you started taking daily medication for asthma.

Y = Yes (true or mostly true) N = No (false or mostly false)

Yes	No	1.	My classmates make fun of me.
Yes	No	2.	I am a happy person.
Yes	No	3.	It is hard for me to make friends.
Yes	No	<b>4</b> .	I am often sad.
Yes	No	<b>5</b> .	I am smart.
Yes	No	<b>6</b> .	I am shy.
Yes	No	<b>7</b> .	I get nervous when the teacher calls on me.
Yes	No	8.	My looks bother me.
Yes	No	9.	When I grow up, I will be an important person.
Yes	No	10.	I get worried when we have tests in school.
Yes	No	11.	i am unpopular.
Yes	No	12.	I am well behaved in school.
Yes	No	13.	It is usually my fault when something goes wrong.
Yes	No	14.	I cause trouble to my family.

Yes No 15. I am strong.

Yes No 16. I have good ideas.

Yes No 17. I am an important member of my family.

Yes No 18. I usually want my own way.

Yes No 19. I am good at making things with my hands.

Yes No 20. I give up easily.

Yes No 21. I am good in my school work.

Yes No 22. I do many bad things.

Yes No 23. I can draw well.

Yes No 24. I am good in music.

Yes No 25. I behave badly at home.

Yes No 26. I am slow in finishing my school work.

Yes No 27. I am an important member of my class.

Yes No 28. I am nervous.

Yes No 29. I have pretty eyes.

Yes No 30. I can give a good report in front of the class.

Yes No 31. In school, I am a dreamer.

Yes No 32. I pick on my brother(s) and sister(s).

Yes No 33. My friends like my ideas.

Yes No 34. I often get into trouble.

Yes No 35. I am obedient at home.

Yes No 36. I am lucky.

- Yes No 37. I worry a lot.
- Yes No 38. My parents expect too much of me.
- Yes No 39. I like being the way I am.
- Yes No 40. I feel left out of things.
- Yes No 41. I have nice hair.
- Yes No 42. I often volunteer in school.
- Yes No 43. I wish I were different.
- Yes No 44. I sleep well at night.
- Yes No 45. I hate school.
- Yes No 46. I am among the last to be chosen for games.
- Yes No 47. I am sick a lot.

(

- Yes No 48. I am often mean to other people.
- Yes No 49. My classmates in school think I have good ideas.
- Yes No 50. I am unhappy.
- Yes No 51. I have many friends.
- Yes No 52. I am cheerful.
- Yes No 53. I am dumb about most things.
- Yes No 54. I am good-looking.
- Yes No 55. I have lots of energy.
- Yes No 56. I get into a lot of fights.
- Yes No 57. I am popular with boys.
- Yes No 58. People pick on me.

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Yes No 59. My family is disappointed in me.
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- Yes No 62. I am picked on at home.
- Yes No 63. I am a leader in games and sports.
- Yes No 64. I am clumsy.
- Yes No 65. In games and sports, I watch instead of play.
- Yes No 66. I forget what I learn.
- Yes No 67. I am easy to get along with.
- Yes No 68. I lose my temper easily.
- Yes No 69. I am popular with girls.
- Yes No 70. I am a good reader.
- Yes No 71. I would rather work alone than with a group.
- Yes No 72. I like my brother(s) and sister(s).
- Yes No 73. I have a good body.
- Yes No 74. I am often afraid.
- Yes No 75. I am always dropping or breaking things.
- Yes No 76. I can be trusted.
- Yes No 77. I am different from other people.
- Yes No 78. I think bad thoughts.
- Yes No 79. I cry easily.
- Yes No 80. I am a good person.

			•
Yes	No	81.	I am happy with my height and weight.
Yes	No	<b>82</b> .	I would like to have more friends.
Yes	No	<b>83</b> .	I do a lot of things with my friends.
Yes	No	84.	Most people my age like me.
Yes	No	<b>85</b> .	I am happy with the way I do most things.
Yes	No	<b>86</b> .	I do very well at all kinds of sports.
Yes	No	<b>87</b> .	I wish I could be a lot better at sports.
Yes	No	<b>88</b> .	I think I could do well at just about any new sports activity I haven't tried before.
Yes	No	89.	I feel that I am better at sports than others my age.
Yes	No	90.	I don't do well at new outdoor games.

pierab.wod 9/01/95 k

	Date:/	Interviewer's Initials:					
Family No:	Family Member:_	C	Visit:	_ (3, 6,	12,	24)	

# THE WAY I FEEL ABOUT MYSELF (Piers-Harris)

Here is a group of sentences that tell how some people feel about themselves. I will read each sentence, and I want you to decide whether or not it describes the way you feel about yourself. If the sentence is **true or mostly true**, the answer will be "Yes". If it is **false or mostly false**, the answer will be "No". Remember - - there are no right or wrong answers. Only you can tell us how you feel about yourself.

Y = Yes (true or mostly true) N = No (false or mostly false)

Yes	No	1.	My classmates make fun of me.
Yes	No	2.	I am a happy person.
Yes	No	3.	It is hard for me to make friends.
Yes	No	4.	I am often sad.
Yes	No	5.	I am smart.
Yes	No	6.	I am shy.
Yes	No	7.	I get nervous when the teacher calls on me.
Yes	No	8.	My looks bother me.
Yes	No	9.	When I grow up, I will be an important person.
Yes	No	10.	I get worried when we have tests in school.
Yes	No	11.	I am unpopular.
Yes	No	12.	I am well behaved in school.
Yes	No	13.	It is usually my fault when something goes wrong.
Yes	No	14.	I cause trouble to my family.

Yes No 15. I am strong.

Yes No 16. I have good ideas.

Yes No 17. I am an important member of my family.

Yes No 18. I usually want my own way.

Yes No 19. I am good at making things with my hands.

Yes No 20. I give up easily.

Yes No 21. I am good in my school work.

Yes No 22. I do many bad things.

Yes No 23. I can draw well.

Yes No 24. I am good in music.

Yes No 25. I behave badly at home.

Yes No 26. I am slow in finishing my school work.

Yes No 27. I am an important member of my class.

Yes No 28. I am nervous.

Yes No 29. I have pretty eyes.

Yes No 30. I can give a good report in front of the class.

Yes No 31. In school, I am a dreamer.

Yes No 32. I pick on my brother(s) and sister(s).

Yes No 33. My friends like my ideas.

Yes No 34. I often get into trouble.

Yes No 35. I am obedient at home.

Yes No 36. I am lucky.

Yes No 37. I worry a lot.

Yes No 38. My parents expect too much of me.

Yes No 39. I like being the way I am.

Yes No 40. I feel left out of things.

Yes No 41. I have nice hair.

Yes No 42. I often volunteer in school.

Yes No 43. I wish I were different.

Yes No 44. I sleep well at night.

Yes No 45. I hate school.

Yes No 46. I am among the last to be chosen for games.

Yes No 47. I am sick a lot.

Yes No 48. I am often mean to other people.

Yes No 49. My classmates in school think I have good ideas.

Yes No 50. I am unhappy.

Yes No 51. I have many friends.

Yes No 52. I am cheerful.

Yes No 53. I am dumb about most things.

Yes No 54. I am good-looking.

Yes No 55. I have lots of energy.

Yes No 56. I get into a lot of fights.

Yes No 57. I am popular with boys.

Yes No 58. People pick on me.

Yes No 59. My family is disappointed in me.

Yes No 60. I have a pleasant face.

Yes No 61. When I try to make something, everything seems to go wrong.

Yes No 62. I am picked on at home.

Yes No 63. I am a leader in games and sports.

Yes No 64. I am clumsy.

Yes No 65. In games and sports, I watch instead of play.

Yes No 66. I forget what I learn.

Yes No 67. I am easy to get along with.

Yes No 68. I lose my temper easily.

Yes No 69. I am popular with girls.

Yes No 70. I am a good reader.

Yes No 71. I would rather work alone than with a group.

Yes No 72. I like my brother(s) and sister(s).

Yes No 73. I have a good body.

Yes No 74. I am often afraid.

Yes No 75. I am always dropping or breaking things.

Yes No 76. I can be trusted.

Yes No 77. I am different from other people.

Yes No 78. I think bad thoughts.

Yes No 79. I cry easily.

Yes No 80. I am a good person.

Yes	No	81.	I am happy with my height and weight.
Yes	No	82.	I would like to have more friends.
Yes	No	83.	I do a lot of things with my friends.
Yes	No	84.	Most people my age like me.
Yes	No	85.	I am happy with the way I do most things.
Yes	No	<b>86.</b> -	I do very well at all kinds of sports.
Yes	No	87.	I wish I could be a lot better at sports.
Yes	No	88.	I think I could do well at just about any new sports activity I haven't tried before.
Yes	No	89.	I feel that I am better at sports than others my age.

I don't do well at new outdoor games.

90.

# **NOTE TO USERS**

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Appendix C: Table of Skewness and Kurtosis

Appendix C: Table of Skewness and Kurtosis

	N	Skewness		Kurtosis	
	Statistic	Statistic	Std.	Statistic	Std.
			Error		Error
SEVERITY	109	-1.018	.231	613	.459
FRMASTB	154	401	.195	523	.389
FRESTMB	154	-1.069	.195	.911	.389
FRMAST12	138	830	.206	.313	.410
FRESTM12	138	-1.787	.206	5.084	.410
STIGP12	138	.821	.206	.220	.410
STIGC12	138	.955	.206	133	.410
PARATT12	138	-1.549	.206	3.629	.410
TMEANAB	128	.078	.214	996	.425
TADAPTB	124	.148	.217	-1.232	.431
TMEANA12	113	.059	.227	-1.102	.451
TADAPT12	113	.253	.227	934	.451
TINTERNB	154	.335	.195	199	.389
TEXTERNB	154	.010	.195	438	.389
TINTER12	140	.027	.205	653	.407
TEXTER12	140	.339	.205	141	.407

SES	148	-1.320	.199	3.520	.396
CATIS12	138	967	.206	.903	.410
PHTOTALB	148	-1.107	.199	1.065	.396
PHTOTA12	138	-1.584	.206	2.412	.410
CSI	51	.966	.333	2.836	.656
TREADING	112	093	.228	383	.453
TLANG	108	341	.233	060	.461
TMATH	113	225	.227	853	.451
TTOTBATT	107	339	.234	266	.463
CSI12	46	.196	.350	735	.688
TREAD12	80	.212	.269	915	.532
TLANG12	80	.095	.269	670	.532
TMATH12	81	.138	.267	354	.529
TTOTBA12	78	.213	.272	754	.538
STRESSB	74	.880	.279	.015	.552
STRESS12	132	1.332	.211	1.453	.419
PEXPB	79	713	.271	151	.535
PEXP12	135	773	.209	.455	.414
TEXPB	41	019	.369	-1.392	.724
TEXP12	128	352	.214	725	.425

# **CURRICULUM VITAE**

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Degree	Year	Major	Degree Granting Institution	<u>Mentor</u>
BSN	5/85	Nursing	DePauw University	
MS	12/90	Education	Indiana University	
MSN	5/96	Nursing	Indiana University	Joan K. Austin
PhD	6/00	Nursing	Indiana University	Joan K. Austin

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# PROFESSIONAL EXPERIENCE:

Staff Nurse	1985	1988	Medical Nursing	Indiana University Hospital	Cheri Howard
Research Assistant/ Project Manager	1987	present	Psychiatric Mental Health Nursing	Indiana University School of Nursing	Joan K. Austin

# **HONORS/AWARDS**:

Induction into Sigma Theta Tau, Alpha Chapter (Nursing's Honor Society)	1991
Epilepsy Foundation of America Behavioral Sciences Student Fellowship	1992
Who's Who Among Students in American Universities and Colleges	1993, 1996
Association of Child and Adolescent Psychiatric Nurses Graduate Student Award	1996
Lee D. Fuller Award	1996

Predoctoral NIH Institutional Research Grant Fellowship (award #2T32NR07066-06) from January 1, 1997, to June 31, 1998

Predoctoral National Research Service Award (grant number 1 F31 NR07233-01) from September, 1998 to September, 2000

Graduate Student Organization Educational Enhancement Grant

1999

Journal of Child and Adolescent Psychiatric Nursing Writing Award

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#### PROFESSIONAL ACTIVITIES:

Reviewer for Journal of Child and Adolescent Psychiatric Nursing, 1998 to present

Member of American Epilepsy Society, 1998 to present

Member of Midwest Nursing Research Society, 1999

#### **PUBLICATIONS:**

### **Abstracts**

Austin, J. K., & McNelis, A. M. (1990). Family characteristics associated with adaptation to epilepsy and asthma. Proceedings of the 14th Annual Meeting of the Midwest Nursing Research Society, Indianapolis, IN.

Austin, J. K., Risinger, M. W., & McNelis, A. M. (1991). Family, seizure, and gender variables associated with child behavior problems. <u>American Epilepsy Society Proceedings</u>. <u>Epilepsia</u>, 32, Supplement 3, 29.

Austin, J. K., & McNelis, A. M. (1996). Childhood epilepsy: Psychosocial care needs. <u>Journal of Neuroscience Nursing</u>, 28(6), 393.

Austin, J. K., Dunn, D. W., Rose, D. F., McNelis, A. M., Olson, K., & Huster, G. R. (1996). Pediatric epilepsy: Assessment of psychosocial care. <u>American Epilepsy Society Proceedings, Epilepsia, 37.</u> Supplement 5, 11.

McNelis, A.M., Musick, B., Austin, J., Dunn, D., & Creasy, K. (1998). Psychosocial care needs of children with new-onset seizures. <u>Journal of Neuroscience Nursing</u>, 30(3), 161-165.

# <u>Publications</u> (\* = refereed journal)

- \*Huberty, T. J., Austin, J. K., Risinger, M. W., & McNelis, A. M. (1992). Classroom performance and adaptive skills in children with epilepsy. <u>Journal of School Psychology</u>, 30, 331-342.
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- \*Austin, J. K., Smith, M. S., Risinger, M. W., & McNelis, A. M. (1994). Childhood epilepsy and asthma: Comparison of quality of life. Epilepsia, 35(3), 608-615.
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- McNelis, A. M., Huster, G., Michel, M., Hollingsworth, J., Eigen, H., & Austin, J. K. (2000). Factors associated with self-concept in children with asthma. <u>Journal of Child and Adolescent Psychiatric Nursing</u>, 13(2), 55-68.
- Austin, JK, Dunn, DW, Huster, GR, McNelis, AM, & Shore, CP (2000). Pilot test of Be Seizure Smart: A family seizure management program. Final report submitted to the Neuroscience Nursing Foundation.

# **Presentations**

- Zander, J. H., Michel, M. H., Austin, J. K., Henrie, S., McNelis, A., & Eigen, H. Factors associated with poor adaptation to childhood asthma. Presented at the Annual Meeting of the American Thoracic Society, Cincinnati, OH, May 15, 1989.
- Austin, J. K., & McNelis, A. M. Family characteristics associated with adaptation to epilepsy and asthma. Presented at the 14th Annual Meeting of the Midwest Nursing Research Society, Indianapolis, IN, April 24, 1990.
- Austin, J. K., McNelis, A., Zander, J., Haber, L., & Lynn, A. Childhood epilepsy and asthma: Factors associated with adaptation. Presented at the 17th Annual Patient Care Research Colloquium, Indianapolis, IN, November 16, 1990.
- Austin, J. K., Risinger, M. W., & McNelis, A. M. (1991). Family, seizure, and gender variables associated with child behavior problems. Presented at the 1991 Annual Meeting of the American Psychological Society, Philadelphia, PA, December 9, 1991.

- McNelis, A. Children and adolescents with epilepsy and their siblings. Presented at the Indiana University School of Nursing Student Research Day, Indianapolis, IN, February 12, 1993.
- McNelis, A. Children and adolescents with epilepsy and their siblings: Differences in coping and adaptation. Presented at the 1993 Annual Meeting of the North Central Sociological Association, Toledo, OH, April 18, 1993.
- McNelis, A. Children and adolescent with epilepsy and their siblings: Differences in coping and adaptation. Presented at the Indiana University 20th Annual Nursing Research Conference, Indianapolis, IN, September 24, 1993.
- McNelis, A. Factors predicting self-concept in youth with epilepsy. Presented at the Indiana University 22nd Annual Nursing Research Conference, Indianapolis, IN, September 15, 1995.
- McNelis, A. Factors predicting self-concept in youth with asthma. Presented at the Indiana University 22nd Annual Nursing Research Conference, Indianapolis, IN, September 15, 1995.
- McNelis, A. <u>Factors affecting self-concept in youth with epilepsy and asthma</u>. Presented at the Indiana University School of Nursing Student Research Day, Indianapolis, IN, December 11, 1995.
- Austin, J. K., Dunn, D. W., Rose, D. F., McNelis, A. M., Olson, K., & Huster, G. R. (1996). Childhood epilepsy. Psychosocial care needs. Presented at the American Epilepsy Society Conference, San Francisco, CA, December 7, 1996.
- McNelis, A.M., & Austin, J.K. (1997). Development of the psychosocial care needs of children with new-onset seizures scale. MNRS, 22nd Annual Research Conference, Columbus, OH.
- McNelis, A.M., Musick, B., Austin, J., Dunn, D., & Creasy, K. (1998). Psychosocial care needs of children with new-onset seizures. 24<sup>th</sup> Annual Nursing Research Conference. Indianapolis, IN, November 6, 1998.
- McNelis, A.M., & Austin, J.K. (1999). Academic achievement in children with seizures. MNRS, 23rd Annual Research Conference, Indianapolis, IN, April 11, 1999.

#### TEACHING EXPERIENCE:

Lecturer for Dr. Joan K. Austin, 1990-1991.

Preceptor for research assistants on Dr. Austin's grants, 1986 to present.

# **COMMUNITY SERVICE:**

American Heart Association Volunteer, 1989-1995

Advisory Committee for Dr. Joan Austin's First Seizure Study, 1992-1995

Substitute teacher at St. Matthew Grade School, 1997-1998

Parent/Faculty Association - Chairperson of Grant Writing Committee, 1997-1999

Terre Vista neighborhood Association Secretary, 1996 to 1997; Co-Vice President, 1997-1999

Parent Volunteer- St Matthew School, 1995 to present