Adolescents with Epilepsy: The Relationship Between Perceptions of Parenting, Self-Concept, and Self-Assessment Scores of Depression

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ADOLESCENTS WITH EPILEPSY:
THE RELATIONSHIP BETWEEN PERCEPTIONS OF PARENTING, SELF-CONCEPT, AND SELF-ASSESSMENT SCORES OF DEPRESSION

By

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ABSTRACT

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SCORES OF DEPRESSION

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Adolescents with chronic diseases must accomplish the management of their healthcare decisions and practices; those with epilepsy also deal with the uncertainty of seizure disorders and the stigma linked to this disease. This secondary analysis of data examined psychosocial variables for adolescents with epilepsy within the developmental-contextual framework proposed by Holmbeck and Shapera (1999). No statistically significant differences were found between the mean Piers-Harris scores, self-assessment scores on the Children’s Depression Inventory (CDI) or the Revised Family APGAR for the subgroups of males, females, younger (9 to 11.44 years) or older (11.45 to 14 years) adolescents. Perceptions of parenting, length of time since diagnosis, entrance into the study and gender were also unrelated. However, 25.75% of those studied demonstrated a score on the CDI above 12, revealing clinical need for assessment and follow-up of depressive symptoms.
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The feedback given by this thesis committee to assist me in the completion of this study has been very helpful. All of the hours spent reading the drafts and giving input are greatly appreciated and have allowed this thesis to be completed.
Dedication

This work is dedicated to my family, my husband Scott, sons Zachary, Trevor, Thaddeus, and Caleb, and to my parents, Dave and Mary. Without their love, patience, sacrifice, and support this project would have been impossible to complete.
Table of Contents

List of Tables........................................................................................................................................ viii
List of Figures........................................................................................................................................ ix
List of Appendices................................................................................................................................ x

CHAPTER

1 INTRODUCTION.................................................................1
   Purpose.................................................................................................................................6

2 CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW.......8
   Conceptual Framework.................................................................................................8
      Primary Developmental Changes of Adolescence.................................11
         Biological/Pubertal..............................................................12
         Psychological/Cognitive................................................13
         Social Role Changes.............................................................14
      Interpersonal Context of Adolescent Development.................15
         Family................................................................................15
         Peers...........................................................................16
         School........................................................................16
         Work........................................................................17
      Demographic and Intrapersonal Moderating Variables............17
      Developmental Outcomes of Adolescence.............................18
         Achievement.....................................................................19
         Autonomy.........................................................................21
         Identity...........................................................................24
         Psychosocial Outcomes..................................................26
      Framework Summary..............................................................29
   Review of Literature.................................................................................................30
Descriptive Findings.................................................................90  
Examination of the Research Questions..............................95  
Summary.......................................................................................98  

5 DISCUSSION AND IMPLICATIONS..........................................100  
Discussion of Findings and Conceptual Framework..............100  
Findings in Relation to Previous Research............................104  
  Chronic Illness.................................................................104  
  Chronic Illness and Emotional Distress..............................105  
  The Family and Epilepsy......................................................106  
  Epilepsy, Behavior, Underachievement, and Learning Problems.................................107  
  Adolescent Depression and Epilepsy.................................108  
Application to Nursing Practice.............................................110  
Limitations of This Study.......................................................113  
Suggestions for Future Research...........................................115  
Summary......................................................................................117  

APPENDICES...............................................................................119  
REFERENCES.............................................................................137
List of Tables

1  Years of Age and Education of Mother/Primary Care Givers.........................75
2  Age, Age at Diagnosis, and Years of Seizure Duration of Study Youths............76
3  Ethnic Backgrounds of Study Youth...............................................................77
4  Frequency of Ages at Diagnosis with Epilepsy.............................................79
5  Group Comparisons of Total Piers-Harris Self-Concept Scores.......................91
6  Group Comparisons of Children’s Depression Inventory Scores.......................93
7  Group Comparisons of Revised Family APGAR Scores...................................94
8  Mean Scores of Self-Concept, Depressive Symptoms, and Family Measures by Age Group and Gender.................................................................96
9  Multiple Analyses of Variance Between Subjects for Gender, Age, and Age and Gender .................................................................................................97
10 Pearson Correlation Coefficients for Psychological, Interpersonal, and Developmental Variables.................................................................98
List of Figures

1 A Developmental-Contextual Framework for Understanding and Researching Adolescent Adaptation and Adjustment.............................................................9

2 A Modified Version of the Developmental-Contextual Framework for Researching Understanding and Adolescent Adaptation and Adjustment.........................89

3 Numbers of Participants with CDI Scores in Major Diagnosis Categories, by Age and Gender...........................................................................................................92
List of Appendices

A  Permission for Use of Framework Figure ................................................................. 120
B  Permission to Utilize Data for Secondary Analysis.................................................. 122
C  IUPUI Informed Consent Statement......................................................................... 123
D  The Way I Feel About Myself, Piers-Harris Self Concept Questionnaire.............. 125
E  Child Depression Inventory Questionnaire............................................................... 130
F  Revised Family APGAR Questionnaire................................................................. 135
G  Human Research Committee Approval Letter......................................................... 136

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Adolescence is a life stage distinct from all others. Adolescents are neither children nor adults. This developmental stage, in the past described as one of stress and storm, is now heralded as the time of great change with opportunities for growth and development. In most Western cultures and the United States, adolescence begins around the age of 10 and continues through the late teens to early 20s (Feldman & Elliot, 1990). The changes can be separated into three distinct categories: biological, psychological, and social role changes.

Physical and sexual maturity comprise the biological changes. These are demonstrated by changes in hormone levels, attainment of secondary sexual characteristics, and adult height and body structure (Tanner, 1989). The rate of growth during adolescence is second only to the rapid growth rate seen in the first year of life.

Psychological and cognitive changes are also inherent to this developmental period. Erikson (1950) describes this stage of development as the phase of identity versus role confusion. Adolescents must develop a sense of self and how they perceive this self to fit in with the rest of society. According to Piaget (as cited by Singer & Revenson, 1996), during the transformation from childhood to adulthood, thought processes change from concrete to formal operational cognition. These changes include more sophisticated reasoning abilities, abstract thought processes, further development of coping mechanisms and broadened emotional depth in relationships, as well as
educational and occupational decisions that will affect the individual’s future and career choices.

As adolescents develop an independent sense of identity, relationships with parents and peers also undergo transformations. This stage is characterized by definition of self, separate from parents and family (Erikson, 1950). As roles change within the family structure, stressors are inherent to this transition (Elliot & Feldman, 1990). Often, adolescents form tighter bonds with their peers. This development of a peer group is often both a development of self and a finding of camaraderie with peers who share some of the same ideals and views of society (Elliot & Feldman). Peers and family can have great impact upon the development of the roles in life these teens take on, and will continue to further define throughout their lifetimes.

During adolescence, several developmental tasks need to be completed. In the United States today, adolescence is characterized by segregation from adults and is heavily focused on peer groups (Elliot & Feldman, 1990). To a certain extent this is a normal part of development. However, adolescents in American culture have an unequaled freedom for self-determination and decisions in many aspects of their lives (Elliot & Feldman). The adolescents are often making decisions for themselves with little or no parental input into issues such as friendships with both sexes, selection of peer groups, amount of attention directed toward educational objectives, the amount of involvement in risk-taking behavior, and long range educational, vocational and family planning. What is of concern is that developmentally, most early adolescents making these decisions are still focused on the present and devote insufficient regard to the long-range effects of these decisions (Elliot & Feldman). Because so much time and attention

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is placed within the peer group, it is having great developmental impact upon these young people and who they will become.

Throughout this stage of life, the above factors also greatly influence the adolescent experience of children with chronic illnesses, including how they interact within their peer group and the family. Although behavioral problems such as anxiety, depression, hyperactivity, peer conflict, and social withdrawal can and do occur in all adolescent groups, those with chronic illness deal with these issues more often than those without (Newacheck, McManus & Fox, 1991). Adolescents with a chronic condition are also more likely to have problems related to peer conflict and social withdrawal.

The overall incidence of chronic illness in children has not changed much in the past twenty years. However, the survival rates of children have greatly increased in all categories of chronic illness, while suicide and homicide survival rates have been unaffected (Jackson, 2000). The percentage of children affected by a chronic condition has increased to an estimated 31%; this includes common diagnoses such as allergies and chronic otitis media, as well as asthma, diabetes, and epilepsy (Newacheck & Taylor, 1992). Of these children, 66% can be classified as having a chronic condition but with little-to-no bother and no limitation on activity, 29% having conditions that cause some bother or limitation in activity, and 5% having severe conditions that cause frequent bother or limitation in activity. This last 5% account for 19% of all physician contacts and 33% of all hospital days related to chronic illness (Newacheck & Taylor).

The number of chronically ill adolescents is increasing due to decreasing morbidity and mortality rates of children with chronic disease states and genetic defects. The shifts in decreased morbidity and mortality are the result of several factors, including
advances in technology, improved treatment of infectious diseases, improved diagnosis and treatment of many diseases, and the implementation of many public and preventive health measures (Jackson, 2000). Many of these children are now surviving through adolescence, into early adulthood, and beyond. Early adolescents with chronic illnesses in many ways are the same as their peers without chronic illness. They are in the developmental stage of life where aspects of themselves and their environment are changing and developmental tasks need to be completed.

Chronic illness in children and adolescents is generally not static, but rather a series of exacerbations and remissions superimposed upon their growth and development process (Jackson, 2000). Chronically ill adolescents also have added challenges, changes and responsibilities related to their condition and state of wellness. The best outcomes for these young people are to control the effects of the chronic illness and to maintain as minimal impact of the illness as possible while providing the opportunity for these individuals to develop to their maximal potential. Kryngas and Rissanen (2001) found that support was a crucial predictor of good compliance of adolescents with chronic disease (asthma, epilepsy, juvenile rheumatoid arthritis and insulin dependent diabetes mellitus). In the 1200 adolescents they studied from Japan and Finland, the most powerful predictor of treatment compliance for adolescents was the support of nurses. Those who were adequately supported by nurses had a 7.28 fold increase in compliance with their health regimens.

Prevalence of chronic conditions related to disease and injury of the nervous system are second only to those related to the respiratory system (Jackson, 2000). The prevalence of epilepsy in children and adolescents seems consistent in all populations
studied worldwide ranging from 50-100 persons per 100,000 persons (Hauser, 1994). However, virtually all of the studies done to determine incidence have been done in Western or industrialized populations (Hauser). Based on these studies the annual incidence (rate of new cases per year) is 5-7 per 10,000 children from birth to 15 years of age; and in any given year 5 out of every 1000 children have epilepsy (Cowan, 2002).

Etiologic classification of seizure disorders has helped researchers to be able to study homogenous groups (Cowan, 2002). These disorders are divided into two groups: provoked-seizures, resulting from some insult to the central nervous system, or unprovoked, which occur without an identified insult to the system. Epilepsy can result with either type of seizure disorder, however, only about 20% of patients demonstrate a clear antecedent (Hauser, 1994). Cowan found many factors that increase the risk of epilepsy in children, such as congenital malformations of the central nervous system, moderate to severe head trauma, infections of the central nervous system, and some inherited metabolic and genetic factors. However, these were implicated in only 25-45% of all cases of childhood epilepsy. Understanding of the causes of epilepsy remains limited mainly due to methodological difficulties in examining cause and effect relationships (Cowan). Cumulative incidence of all classes of convulsive disorders combined is such that 4-10% of all children will experience a seizure at some point in life; however, by age 20, 1% of the population will carry the diagnosis of epilepsy (Hauser, 1994). When epilepsy is defined as recurrent, unprovoked seizures, the incidence rates remain steady across populations and range from 50-72 people per 100,000 (Cowan).
As adolescence progresses, management of the medical requirements and medication regimen is transferred from parents to the children with epilepsy. How these added burdens affect the development of the adolescent is yet to be fully determined, but the impact may range from continued dependence upon family to low self-esteem (Newacheck, et al., 1991). Adolescents with chronic conditions experience 35% more behavioral problems (including anxiety, depression, hyperactivity, peer conflict, social withdrawal, and antisocial tendencies) than their healthy counterparts, and behavior problems related to peer conflict and social withdrawal tend to be especially pronounced (Newacheck et al.).

In a study by Austin (1989) of 254 children aged 8-12, those with epilepsy were more likely to have more behavior problems and significantly lower self-esteem than the children in the sample who had asthma. Adolescents with epilepsy have consistently shown differences in their perception of quality of life than adolescents with other chronic illnesses. Adolescents with epilepsy must also contend with the social stigma of the disease, the nature of the seizures, the potential of having a seizure that may attract attention, and the lack of control over seizures. This results in increased anxiety, depression, social withdrawal and poor peer relations (Andelman, 2000).

Purpose

This research attempted to determine if there is a relationship between adolescents’ perception of their parenting as assessed by the Revised Family APGAR (Austin & Huberty, 1989), their self-concept as measured by the Piers-Harris Self-Concept Scale (Piers, 1984) and the scores on the Child Depression Inventory (CDI) Kovacs 1980/81) in two groups of young adolescents diagnosed with epilepsy. The
sample was divided so that 9-11.44 year-olds’ and 11.45 -14 year-olds’ perceptions could be compared. Differences in these variables by gender were also explored. Practitioners who possess increased awareness of potential relationships between self-concept, satisfaction with family relationships, and symptoms of depression may encourage early intervention, and potentially lessen the impact that these stressors may have on the adolescent’s psychosocial development. The ability to foster and promote well-being of adolescents will yield positive interactions with health care providers and parents to support this future generation during this difficult transitional period.
CHAPTER 2
CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

Adolescent development and adjustment are unique within various cultures, but universal in marking the transitions to becoming an adult as defined by the individual and the culture and society to which one belongs. Children with chronic health issues are on the same route as those without, but the path may be altered or abated because of illness and the restrictions and ramifications thereof. It is vitally important for both the individual and society to facilitate growth and development in adolescence to encourage maximal development of the potential afforded to each individual (Jackson, 2000).

Holmbeck and Shapera have developed a framework to assist in understanding adolescent development and adjustment (1999). This framework views the primary developmental changes of adolescence as: (a) biological/ puberty, (b) psychological/cognitive, and (c) social redefinition. These are felt to impact the developmental outcomes of adolescence—achievement, autonomy, identity, intimacy, psychosocial adjustment, and sexuality. The interpersonal contexts of adolescent development (family, peer, school and work) and the demographic and intrapersonal moderating variables (ethnicity, family structure, gender, individual response to developmental change, neighborhood/community factors and socioeconomic status) also impact this process of attainment of the developmental outcomes.

This model (see Figure 1) encompasses the biological, psychological, and social changes that are inherent in the adolescent period of development and can be utilized to study both the individual and the contextual effects seen during adolescence. At the very
At a general level, this framework depicts how the primary developmental changes during adolescence impact the developmental outcomes via the interpersonal contexts in which adolescents develop (Holmbeck & Shapera, 1999).

Figure 1. A developmental-contextual framework for understanding and researching adolescent adaptation and adjustment. (Arrows directed toward midpoints of other arrows are considered moderated effects).


An appreciation of the rapid nature of adolescent developmental changes and the context in which they occur is imperative to developmentally relevant research. This framework is contextual, incorporating multiple facets of the individual, how the world
influences that individual, and ultimately the developmental outcomes of the adolescent. Recently, research has attempted to move beyond the study of singular family variables associated with adolescent adjustment outcomes. For example, rather than looking at the family in isolation, adolescent research has made attempts to identify the contexts and circumstances in which family variables are most pronounced (Holmbeck & Shapera, 1999). Using this approach, Holmbeck and Shapera’s model provides a framework to assist the researcher to understand the interplay between many variables, such as family, peer group, ethnicity, and gender, within the developmental context of the adolescent. In this model, developmental changes have an impact upon the interpersonal context. Both directly and via their influence on interpersonal context, these developmental changes then influence the ways in which the adolescent resolves the major issues of adolescence, such as autonomy, identity, and sexuality (see Figure 1).

The interpersonal context (family, peers, school, work) can be said to mediate outcomes between pubertal changes and developmental outcomes. If A represents the primary developmental change of the adolescent, B represents the interpersonal contexts of that development, and C represents the developmental outcomes, in the model A→B→C, B is presumed to mediate the relationship between A and C. For this to be true, there must be a significant association between A and C and some of the association between A and C must “flow” or pass via the impact of B (Holmbeck, 1997). The influences of cause and mediation may vary due to the demographic and intrapersonal context in which they occur (see Figure 1). In sum, the mediator (interpersonal contexts) directly affects the outcomes, and the independent variable (primary developmental changes) achieves its impact on developmental outcomes at least partially through an
effect on the mediator; and the impact of developmental changes on outcomes may vary due to the intrapersonal context in which they occur (Holmbeck).

Associations between primary developmental changes and the developmental outcomes of adolescence can be *moderated* by the demographic and intrapersonal moderating variables (Holmbeck & Shapera, 1999). Thus, the nature of the relationship between the two variables (developmental changes and outcomes) is dependent on the effect of a moderator (Holmbeck, 1997). The moderator interacts with the independent variable to affect the direction and/or strength of the relationship between independent and dependent variable. An expectation is that the association between the primary developmental changes of the adolescent and the developmental outcomes of the adolescent may differ as a function of the moderator. For example, early puberty may be associated with improved identity formation for girls, but late puberty may be associated with improved identity for boys. In this secondary analysis, the relationship between family in the interpersonal context of adolescent development and identity, a developmental outcome (measured for this study by the Piers-Harris Self Concept score [Piers, 1984]) may vary as a function of gender (see Figure 1).

*Primary Developmental Changes of Adolescence*

This framework depicts three types of primary developmental changes that occur during adolescence. These categories include, *biological/pubertal changes*, *psychological/cognitive changes*, and *social role changes*. These were chosen as primary because they are universal across all cultures and they also occur temporally prior to the completion of this developmental stage (Holmbeck & Shapera, 1999).
Biological/Pubertal

Biological pubertal changes are different for males and females. In general, these changes affect facial characteristics, voice, genital maturation, body hair, strength, coordination, and proportion in males and breast growth, menarcheal status, changes in body hair, fat distribution, and body proportions in females. A further difference between males and females that is vital to understanding the framework is that the average peak for females in pubertal development occurs an average of 2 years before that of males (Tanner, 1989; Zelter, 1985). Early adolescence is the time period during which the initiation and accomplishment of many of the physiological changes within the body take place.

As a result, the focus of the adolescent’s attention changes as he/she becomes preoccupied with the body, body awareness, normalcy, the present, and peers (Zelter, 1985). As the adolescent becomes more independent from parents during this time, the peer group becomes more important, especially as a field in which to try many new roles and ways of thinking. This is experimentation that is necessary for the eventual formation of a stable identity (Feldman & Elliot, 1990; Zelter).

Differences occur within an individual (intraindividual) in the sequence of onset of developmental changes and between individuals (interindividual) in the age at onset, duration of time for changes, and age at completion of the physical change process (Holmbeck & Shapera, 1999). Holmbeck and Shapera assert that these differences in adolescents have social consequences and that pubertal status and timing have an impact upon the quality of relationships. Family relationships are also affected. Hence,
biological changes can influence psychosocial adjustment in part via their impact on family and peer relationships.

Psychological/Cognitive

Psychological/cognitive changes, though more difficult to overtly observe, are no less important than the physical changes during the adolescent period. Piaget (1950) identified the adolescent period with attainment of formal operational thought. This allows reasoning to occur at the level of an adult who has successfully attained the ability to reason logically. Holmbeck and Shapera (1999) indicate that adolescents who have developed this capability are able to think in a more complex, abstract and hypothetical way than those who have not. These authors assert that the attainment of the capability to think in this way enables the adolescent to explore several possibilities when making decisions, look at the future in a more realistic fashion, and demonstrate increased understanding of significant others and their behaviors. Further, the adolescent must acquire empathy and role taking skills, social information processing and behavior skills, and must develop prosocial behavioral skills to fully demonstrate healthy developmental outcomes.

Because adolescence is a developmental time of adjustment to a different level of understanding and participating in society, many aspects of life come together for the first time and yield many differing rates of growth within individuals and adolescents as a group. In the article entitled Clinical Adolescent Psychology: What It Is, and What It Needs to Be, Laurence Steinberg (2002) writes:

For centuries, the study of psychology maladjustment and the study of adolescent development have been inextricably linked, both conceptually and empirically.
Philosophers, clinicians, scientists, and virtually all observers of human behavior have long noted that adolescence is a period of special significance for the emergence or intensification of various forms of emotional and behavioral disorder, including many internalizing problems (e.g., depression, eating disorders), externalizing problems (e.g., delinquency, violence), and addictive disorders (e.g., alcohol abuse and dependency, drug abuse and dependency). Although scholars may disagree about why adolescence is so important to the study of clinical phenomena, there is little dispute over whether it is important. Indeed, the list of clinical phenomena that are not primarily associated with adolescence (e.g., bipolar illness, autism, dementia) is shorter than the list of clinical phenomena that are (p. 124).

Holmbeck and Shapera (1999) explicate that most researchers choose to focus on a single outcome to study and look at the many variables that could be considered predictors for that multidimensional outcome. Further, though many researchers choose to focus on a single outcome, many outcomes tend to co-occur within individuals. For example, behavioral outcomes form clusters known as internalizing behaviors (anxiety, depression, and social withdrawal) and externalizing behaviors (delinquency, aggression, and self-control disorders). Rates of psychiatric disorder change rapidly during adolescence; many disorders appear for the first time during adolescence and other disorders vary by gender in the adolescent age group (Holmbeck & Shapera).

Social Role Changes

Social role changes also occur in various ways during adolescence, comprising the last category of the primary developmental changes. Although social role redefinition
is universal, the specific changes in the social status of children during adolescence vary greatly across cultures (Holmbeck & Shapera, 1999). In American culture, roughly a decade, from approximately 10-20 years of age, is dedicated to allow for the change in role from child to adult. During this time the adolescent experiences social redefinition and this process has profound impact upon the adolescent’s behavior (Steinberg, 1999). Ability of the adolescent to adapt to these role changes has prompted many to study the late adolescent period.

**Interpersonal Context of Adolescent Development**

The interpersonal contexts of adolescent development included in the framework are *family, peers, school* and *work*. Each of these areas has profound impact and may act as a mediating factor, moderating factor, or both, to influence the developmental outcomes of adolescence. Holmbeck and Shapera (1999) review each of these contexts separately as they pertain to the framework.

*Family*

The family context has been a domain frequently studied, and is often regarded relative to predictors of adolescent adjustment difficulties (Holmbeck & Shapera 1999). Recent research suggests that adolescence is a growth period involving transformation of family relationships in which mundane issues may cause a moderate increase in stress levels within the family. Holmbeck and Shapera feel these issues may serve an adaptive role for the adolescent. One major task of parents during this developmental period is to balance the adolescent’s increased need for independence and responsibility, with the maintenance of family cohesion. According to these authors, parents unable to be flexible in their parenting style and to adapt to the changing needs of their children as
they mature may have adolescents who demonstrate less success in developmental outcomes.

*Peers*

Peer relationships become increasingly important for role development as the adolescent matures. Based on the research done by Parker and Asher (1987) and Schwartz, Dodge, and Coie (1993), Holmbeck and Shapera conclude that poor peer relationships during childhood and adolescence is one of the strongest predictors of future psychological difficulties during adulthood (1999). Further, they assert that abilities to develop and maintain peer relationships contribute to the development of positive cognitive, social, sexual, and moral development, and have positive effects on adolescent adjustment. These relationships continue to evolve as well as increase in maturity and meaning as the adolescent moves through this developmental period.

*School*

The school environment and transitions from one level to another (such as grade school to middle school and then to high school) provide both stressors and exposure to more complex environments. Holmbeck and Shapera (1999), based on the research done by Entwisle (1990), Felner, Ginter, and Primavera (1982), and Trickett and Schmid (1993), have concluded that school is an important environment for the development of the adolescent in areas beyond acquisition of knowledge. These environments provide an important element in the development of personality, values and social relationships. Further, Holmbeck and Shapera believe that curriculum, teacher expectations, interactions with other adolescents and philosophies of education also impact the developmental outcomes for the individual adolescent.
Many adolescents are exposed to the work force. To date, little research has been done regarding the effects of work, the work environment, and the work experience upon adolescent development, despite the knowledge that almost 80% of American high-school students work prior to graduation (Greenberger, Steinberg, Vaux, & McAuliffe, 1980; Holmbeck & Shapera, 1999; Steinberg, 1999). Steinberg found that work experience had both positive and negative effects on adolescents. Those who work tend to develop a greater sense of self-reliance. However, they are also more likely to develop a cynical attitude about work, spend less time with family and with peers, and spend less time in school. Working adolescents are also more likely to commit delinquent acts as well as to use drugs, and have less time for self discovery and development of identity (Greenberger, et al.; Holmbeck & Shapera; Steinberg). Work may also play an important role in the adolescent’s future goals, such as earning money to further educational goals.

Demographic and Intrapersonal Moderating Variables

Many societal challenges face the adolescents of today. Media is everywhere and all intrusive, and with the advent of the World Wide Web, the amount of information now at our fingertips is greater than ever in the history of mankind. These changes have made the world a smaller place from many perspectives; communication between every corner of the planet now exists and information can rapidly be shared with large numbers of people, much without face or voice accompanying the exchange. This great influx of information has also had an impact upon the adolescent. The average adolescent is exposed to mass media in one form or another for eight hours per day (Steinberg, 1999).
Demographic and intrapersonal moderating variables impact every aspect of the framework. Some are generally static, such as ethnicity and gender. Others such as neighborhood and community factors, socioeconomic status, family structure and the way the individual responds to developmental changes may change over time. All of these variables can influence how the primary developmental changes of adolescence affect the interpersonal contexts of adolescent development. They may also impact developmental outcomes directly, or they may moderate the associations between developmental changes and interpersonal contexts, or between interpersonal contexts and developmental outcomes (see Figure 1).

**Developmental Outcomes of Adolescence**

The developmental-contextual framework identifies achievement, autonomy, identity, intimacy, psychosocial adjustment, and sexuality as the developmental outcomes of adolescence (Holmbeck & Shapera, 1999). These are considered developmental goals and could be measured on a continuum of accomplishment by the adolescent. These outcomes are viewed by Holmbeck and Shapera as imperative for healthy adult life within our society. Each individual may attain varying levels of success within each goal, success in one not ensuring success in another. The attainment of these developmental goals comprises the uniqueness of the individual. The combination of the developmental outcomes for the adolescent yields their unique psychological makeup that will then impact how well the adolescent functions as an adult within society.

The attainment of these developmental outcomes, to whatever extent possible, is universal for all adolescents, including those with chronic health care concerns. Research using this model may be able to discern to what extent the developmental outcomes are
affected by chronic illness in the adolescent population. Further, it is also important to
determine how these differences would then affect the functionality and acceptance of the
adolescent within the culture and society in which he/she resides. This framework takes
into account the multiple factors and reciprocal impact of many of these influences,
which occur throughout adolescent development within the context of social relationships
in our society. The outcome goals of adolescence are on a continuum and affect the
overall adjustment of the individual within a society. Further discussion of the content
and observable demonstration of each goal follows in those areas relevant to this study.

Achievement

Achievement is linked closely with an adolescent's ability to make good decisions
regarding attainment of goals. Cognitive abilities, the individual's potential, the
individual's drive to succeed and well-planned, future-oriented decisions are also closely
linked to make a goal attainable. These abilities can be measured in a number of ways
including various tests and school grades. The decisions an adolescent makes have great
impact upon the future employment and educational options that will be available to
him/her. Adolescents who demonstrate growth in cognitive abilities, such as, future-
oriented and abstract thinking, and hypothetical reasoning, will have the advantage of
greater options for further educational and career advancement (Holmbeck & Shapera,
1999). An example of how adolescents can demonstrate achievement is through
performance in school and extracurricular activities where mastery can be demonstrated.
In many cases, self-concept is closely related to achievement as children and adolescents
will often judge themselves according to how well they perform in these activities. As
children with epilepsy often have difficulty in school and behavior problems, how these youth feel about themselves is important within the context of this secondary analysis.

One early study by Rutter, Graham, and Yule (1970) studied children with epilepsy in the Isle of Wight. They discovered that 28.6% of the children in that population with seizures but with no other neurological damage had behavioral problems. Further, the rate among children with other chronic diseases was only 10.3% and in the general childhood population 6.6% were affected. Since then, many research studies have found behavior problems, underachievement, and learning difficulties to be over-represented in the pediatric and adolescent epileptic populations (Austin, Risinger, & Beckett, 1992; Camfield, Camfield, Smith, Gordon, & Dooley, 1993b; Dunn, Austin, & Huster, 1997; Hartlage & Green, 1972; Hermann, 1982; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Matthews, Barabas, & Ferrari, 1983; Papero, Howe, & Reiss, 1992; Siebelink, Bakker, Binnie, & Trenite, 1988; Stumiolo & Galletti, 1994; Westbrook, Silver, Coupey, & Shinnar, 1991; Williams, Griebel, & Dykman, 1998). Even when compared to other children with chronic illness, usually diabetes or asthma, those with epilepsy have consistently lower scores in self-concept and perform academically below expected levels for intelligence (Austin, 1989; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Matthews, Barabas, & Ferrari, 1983; Papero, Howe, & Reiss, 1992; Westbrook, Silver, Coupey, & Shinnar, 1991). These differences affect the developmental outcomes of both children and adolescents in many ways.

For example, the school achievement of 20 boys and 21 girls aged 6-10.8 years with epilepsy, was examined by Stumiolo and Galletti (1994). School underachievement occurred in 61 percent of the sample based on expected performance related to IQ scores.
Sex of the child, social background, age at onset of epilepsy, seizure type, duration of illness, treatment, or features in the EEGs were not influential; however, social skill impairment, depression, poor motivation, and low self-esteem were associated with poor school performance. They also experienced visual-motor impairment. Twelve children with poor school performance had a mean IQ score of 94.6 (average for the general population being 100) and had difficulties related to almost all academic areas. The 13 children in the average school achievement group had a mean IQ score of 105.5, but functioned mentally 2 years below their chronological age.

The sample included sixteen children with epilepsy who demonstrated good performance in school. These children had a higher mean IQ score of 108.8, and less visual-motor impairment. This group did not differ in performance from their healthy peers, and did not demonstrate emotional maladjustment (Sturniolo & Galletti, 1994).

**Autonomy**

Autonomy is considered a multidimensional construct, as it is a need of adolescents that impacts many aspects of their lives. Many life skill areas allow the adolescent to demonstrate different types of autonomy. Adolescents demonstrating emotional autonomy will not continue the childlike dependencies upon parents as they come to see their parents in an objective way, and depend on them less for immediate emotional support (Holmbeck & Shapera 1999). Further, behavioral autonomy is evident as the adolescent becomes able to make his/her own decisions and is less influenced by others, thereby becoming both self-governed and self-reliant.

Adolescents and children are often faced with information that involves the everyday exposure of media coverage of events around the world and in their
neighborhood. As adults and children spend more leisure time with these media, less
time is spent in 2-way communication. Children are left to discern more complicated
information without parental or adult input. Rather, they often spend more time with
their peers to explore and develop their identities (Feldman & Elliot, 1990).

An adolescent’s decision to behave in a violent manner is a reflection of
autonomy. Violence has increased in both the world and our society, from multiple
shootings in high schools like Columbine, to the attack on the World Trade Center in
September of 2001. The amount of violence among young people has become a major
public health problem/concern and the results of violent acts by young people have
become more lethal (Yung, Hammond, Sampson, & Warfield, 1998). While rates of
accidental deaths of adolescents have decreased dramatically over the past 50 years,
suicide rates have significantly increased (Garland & Zigler, 1993; Mohler & Felton,
2001). While self-expression is vital to developing one’s identity, appropriate boundaries
and parameters must be defined through consistent and clear communication within the
family system.

While the use of illicit drugs in the adolescent population has decreased
somewhat, the use and abuse of alcohol continues at alarming rates and at increasingly
younger ages (Coker & Borders, 2001). Much research has been done demonstrating the
links between problem drinking and serious health, social and behavioral problems for
the adolescent. A recent study examining alcohol use found that 70% of adolescents
reported that they had used alcohol by 12 years of age (Peterson, Hawkins, Abbot, &
Catalano, 1994). The use of alcohol also greatly impacts the adolescent’s safety in a
wide range of activities from driving to sexual activity, and increased risk-taking
behaviors (Alcohol Alert No. 37 United States Department of Health and Human Services, 1997). The ability to make appropriate decisions, especially in light of peer pressure, is of concern for all adolescents. However, the foundation is built much earlier to enable young people to make wise decisions. The ability to make autonomous decisions about risk-taking behavior begins earlier in life with the acquisition of a skill set for learning how to solve problems.

Adolescents with epilepsy are exposed to the same society, communities, school environments, and peer pressure. They, like their healthy peers, must achieve success in the adolescent developmental outcome of autonomy. However, whether they have the needed tools to assist them is in question. Lothman and Pianta (1993) studied fifty-nine 7-13 year olds (M = 9.6 years) with epilepsy and their mothers to assess the children’s psychosocial adjustment in school, and problem-solving ability. In videotaped tasks involving sorting and building, assistance and guidance provided by the mothers and needed by the children were evaluated for the quality of interactive behaviors such as mother’s support for task completion, the child’s self-reliance, and the coordinated expression of emotion in the mother-child dyad. Tasks were then videotaped of each child, without the mother, to assess problem-solving skills.

Lothman and Pianta’s (1993) ratings of the videotaped mother-child interactions and child adjustment as seen in the problem-solving scenario were significantly correlated (r = 0.37, p < 0.01). Additionally, teacher ratings of the child’s school adjustment (assessed with Harter’s Teacher Rating Scale) were related to the ratings of the behaviors in the scenarios (r = 0.15-0.25, p < 0.01 for boys, and r = 0.19-0.17, p < 0.01 for girls). For all in the sample, maternal support, availability, and the child self-reliance
ratings were significantly related to the child’s confidence and involvement seen in the independent problem solving tasks. The children who received greater maternal support were also rated higher by their teachers on scholastic competence. Those who rated poorly on the mother-child dyad interaction and maternal availability were those whose teachers reported difficulties with conduct problems in school. The data indicate that the relationship between maternal support and availability and child adjustment was greater for boys ($r = 0.60-0.71, p < 0.01$) and child self-reliance showed a stronger relationship for the girls ($r = 0.65, p < 0.01; r = 0.32, p < 0.05$).

Many issues of autonomy related to both the individual and the family become relevant in the adolescent period. The adolescent and parents must determine whether the expectations of the level of autonomy of the adolescent are realistic, determine the amount of autonomy granted, determine the amount of autonomy accepted, agree regarding the degree to which the adolescent is able to manage the autonomy granted, manage discrepancy between the amount of autonomy granted and ability to manage autonomy, respond to attempts at autonomy, and demonstrate flexibility within the family system (Holmbeck & Shapera, 1999). How well the parents and adolescent negotiate the increased responsibility demonstrated by the adolescent and need for autonomy can affect psychosocial outcomes. Holmbeck and Shapera assert that predictors of psychosocial outcomes can be obtained through measurement and examination of the discrepancies between the parental and adolescent perceptions of autonomy.

*Identity*

Identity is also multidimensional and includes multiple self-perceptions and commitments gained in a variety of domains through role exploration. Across many
aspects of the human social condition, identities within each of those domains blend to form an adult identity. The ranges of domain specific identities that contribute to a global sense of identity include academic, interpersonal, occupational, political, religious, and sexual aspects of identity. After multiple role explorations, often various levels of commitment begin to occur within the multiple dimensions of these adolescents’ lives. Further, Holmbeck and Shapera (1999) purport that identity can vary from least adaptive, usually obtained without role exploration or commitment, to identity achievement, attained after extensive role exploration and commitment is made. An adolescent’s identity status can vary depending on which domain is considered, and can change over time as a result of maturation or regression to a more or less adaptive identity status.

For example, during the developmental stage of adolescence, sexual identity is often defined due to physical, emotional, and social role changes. In the United States, national surveys show the majority of people initiate sexual activity, including intercourse, during the adolescent years (Chapin, 2000; Jadack & Keller, 1998; Ross, 2002). Exploration of sexuality may have repercussions beyond the adolescents’ expectations, often altering many other aspects of their identity as well as relationships with family and friends. The adolescent pregnancies and health related issues of sexually transmitted diseases, such as AIDS (Chapin; Lehr, Dilorio, Dudley, & Lipana, 2000; Ross) also affect the community and society.

During the adolescent developmental period humans develop the ability to have intimate relationships with one another. Although relationships within the family are changing and sometimes exhibit substantial increases in stress within this developmental period, family relationships are vitally important (Feldman & Elliot, 1990). The
characteristics of the family relationships change and develop in accordance with changes experienced by the adolescent within the framework of his/her attainment of goals and developmental outcomes. Specifically key are those characteristics relating identity and autonomy. The capability to establish and maintain relationships characterized by trust, mutual self-disclosure, a sense of loyalty, and helpfulness is not fully comprehensible to the adolescent prior to this time in development (Holmbeck & Shapera, 1999). Girls are more likely to have more intimate same sex relationships than boys. These authors explain that the ability to have intimate friendships is adaptive and therefore those adolescents with such relationships are more likely to have positive adjustment outcomes. Further, the capacity to have empathy and view social situations from multiple perspectives enables an increased likelihood that friendships will become more mature, complex and intimate in nature.

Relationships are to adolescents, including those with epilepsy, an important aspect of the development of identity. How some of these youth feel about relationships will be assessed, for the purpose of this secondary analysis, through their perceptions of parenting with the Revised Family APGAR (Austin & Huberty, 1989). These relationships and how they feel about themselves also affect their evolving identity. The Piers-Harris Self-Concept Scale (Piers, 1984) is the tool used in this secondary analysis to assess the self-concept of these young people.

Psychosocial Outcomes

Psychosocial outcomes have been often of interest to researchers who study the adolescent period. Holmbeck and Shapera (1999) note that most researchers focus on a single outcome (ideally, measured with multiple methods) and that predictors tend to
vary from outcome to outcome. In considering psychological outcomes, it is clear that many tend to co-occur. This has led researchers to identify two global types of psychosocial outcomes: internalizing problems (which include anxiety, depression, and social withdrawal) and externalizing problems (which include delinquency, aggression, and self-control disorders). Rates of psychiatric disorder change rapidly during adolescence; many disorders appear for the first time during adolescence and other disorders vary by gender in the adolescent age group (Holmbeck & Shapera).

The continuum of mental health problems experienced by adolescents ranges from isolated incidences of psychological distress associated with individual traits such as loneliness and low self esteem to clinical diagnostic disorders such as depression and conduct disorders (Kools, 1998). An estimated 20% of American adolescents suffer from a significant mental health problem. This reflects the fact that problems encountered in childhood such as autism, attention deficit/hyperactivity, and behavioral disorders persist, in addition to the fact that adolescence is often the catalyst for development of depression, eating disorders and schizophrenia (Kools). The psychosocial genesis of the adolescent’s vulnerability for mental health problems is multifactorial including individual characteristics like personality and cognitive abilities, as well as the social context of the adolescent (Kools).

According to Holmbeck and Shapera (1999), most adolescents have mixed reactions about becoming sexually mature, and parental responses to this phenomenon are also often conflicting. Stice and Whitenton (2002) when studying risk factors for body dissatisfaction in adolescent girls, found that a quarter of the girls in the early adolescent sample reported dissatisfaction with their bodies. Eating disorders and
unhealthy eating behaviors are common among adolescents, especially girls. In a study of 9th graders published in 2002 by Croll, Neumark-Sztainer, Story, and Ireland, 56% of the girls and 28% of the boys reported disordered eating behaviors as defined as one or more of the following to either lose or control weight: fasting, skipping meals, using diet pills, binge eating, vomiting, using laxatives, or smoking cigarettes. While the current estimated prevalence of anorexia nervosa or bulimia is 0.5-4.8%, these numbers do not include marginal cases that are under-reported (Graber, Brooks-Gunn, Paikoff, & Warren 1994). Body image and eating disturbances may prospectively predict some of the increase in depressive symptoms in adolescent girls (Stice & Bearman, 2001).

Research on prediction of major depression has identified several psychosocial childhood risk factors. These factors include parental mental illness, socioeconomic position, family composition, marital disruption, family size, parental age, loss of a parent (particularly the mother), gender, substance abuse, neonatal and childhood health, childhood illness, childhood injury, and health problems (Achenbach, Howell, & McConaughy, 1998; Lewinsohn, Roberts, Seeley, Rohde, Gotlib, & Hops 1994; Reinherz, Giaconia, & Hauf, 2000; Reinherz, Giaconia, Hauf, Wasserman, & Silverman, 1999). Although these risk factors are helpful to alert providers to assess for depressive disorder potential, single risk factors can rarely be conceived to result in depressive outcomes (Cicchetti & Toth, 1998). The evolving adolescent should be considered within the organization of a developmental framework so all aspects of the individual can be integrated into treatment, and further social implications can be identified (Cicchetti & Toth).
Framework Summary

The advent of puberty has a direct effect on the primary developmental changes of adolescence. Biological changes are due to hormonal input altering the cognitive processes and the physical body. These in turn affect the psychosocial maturation processes changing during this same developmental time. Further, society has deemed that this stage includes many social role changes to enable the individual to become a contributing member of society. As epilepsy has a direct effect upon the adolescent from a biologic/physiologic, psychosocial/cognitive and a social redefinition, all developmental changes of adolescence are affected. Demographic and intrapersonal variables (ethnicity, family structure, gender, individual responses to change, neighborhood factors, community factors, and socioeconomic status) as well as interpersonal variables (family, peers, school and work) play an important role in the development of the adolescent.

This framework is primarily a multidimensional path to allow the conceptualization of all potential influences and their impact upon the individual throughout this developmental period. As this framework is based upon the individual, the important role of the family and the family environment in which the individual functions may not be clearly demonstrated. While these factors are almost inextricably linked within the family, to demonstrate the multifactorial interplay in a framework would be difficult at best. Since epilepsy impacts all dimensions within this framework, all developmental changes and outcomes may be affected. Utilization of this framework delineates the potential relationships of these factors of adolescent development visually,
thereby increasing the ease of understanding of discerning variables and their potential relationships.

As in the case of their peers, adolescents with epilepsy must also proceed through this developmental process and accomplish developmental goals and outcomes to become functional adults within our society. Consideration of the impact of epilepsy upon the individual’s identity (perception of self), psychosocial adjustment (potential for increased risk of depressive characteristics), and the effect of their perceptions in the context of family circumstances (perceptions and satisfaction with family relationships), is to be accomplished within the developmental-contextual framework. Because gender differences are usual in many aspects of the developmental process, in this study males and females with epilepsy will be compared. Examination of the potential relationship between frequency of depressive symptoms and perception of parenting may provide insight into potential factors associated with increased risk for depression for epilepsy patients.

Review of Literature

Much has been written about adolescence in both the professional and popular literature within the past decade. Books like Reviving Ophelia (Pipher, 1994) and Raising Cain (Kindlon & Thompson, 1999) are on bestseller lists and as a result, they are raising popular awareness of the experiences of adolescents in the United States. The volume of current literature pertaining to adolescents is beyond the scope of this paper, however, a brief overview of pertinent current literature will be discussed. As our society changes and advances are made in technology, science, and communication, so too have these influenced our culture, child rearing practices and transition to adulthood. The
tremendous changes within our world, culture, workplace, workforce, the family and individuals have also affected adolescents in this rapid growth period. The cumulative effects of these changes on society, our culture and the individual have yet to be determined.

The amount of scientific research pertaining to adolescence has also grown rapidly over the past decade, though many aspects are yet in need of further exploration. Greater understanding of this developmental period has been accomplished, but yet the transition from youth to adulthood has not become easier to navigate. As the overall body of scientific and psychological knowledge has increased, there has been an overall decrease in the health status and well-being of adolescents (Compas, Hinden, & Gerhardt 1995).

This review will briefly explore research concerned with depression and chronic illness as they relate to the adolescent population. A discussion of epilepsy in general and how the biologic factors apply to this disease will be followed by how this disorder affects the family and the adolescent. Epilepsy impacts behavior, underachievement, and learning, and these may in turn be factors in the development of both low self-concept, and increased symptoms of depression that are often seen. Following this discussion of the interaction of epilepsy and depression, a summary of the literature and the research questions will be presented.

**Adolescent Depression**

Lewinsohn, Hops, Seeley, and Andrews (1993) did an epidemiological study of incidence and prevalence of depression and other disorders in 10,200 Oregon adolescents from both rural and metropolitan areas. Through information obtained from the students,
they found substantial increases in incidence of adolescent psychopathology rates for many DSM-III-R diagnoses. Depression rates were high at all levels, including first incidence, total incidence, and relapse rate. When these rates were projected onto a high school with 1000 students during a one year period, it could be expected that 42 students would become depressed for the first time, and 32 with a previous history of depression but not included in the initial 42 would become depressed again, for a total of 74 students suffering from depression at some time during that one-year period.

Overall lifetime distributions of mental disorders revealed more females (42.3%) than males (31.8%) would have at least one disorder. Female students were more likely than male students to be diagnosed with unipolar depression, anxiety disorders, eating disorders, and adjustment disorders while males were twice as likely as females to have disruptive behavior disorders (Lewinsohn et al.). Research has consistently shown differences in the prevalence of certain disorders in adolescence as a function of gender. For example, the prevalence of depression is greater in females while substance disorders are more common in males (Burke, Burke, Regier & Rae, 1990). These findings may demonstrate a gender differentiation in the manifestations of expression of the same response in adolescence, yielding variation in characteristic behaviors for males and females.

Major depressive disorder is present in the adolescent population with an estimated lifetime prevalence of between 15-20%, approximately the same lifelong rate as adults. This is suggestive that adult depression may originate during adolescence (Harrington, Rutter, & Fombonne 1996). The consequences of adolescent depression are significant, as the disorder is not short lived, does not dissipate with time, and is not a
normal developmental occurrence (Cicchetti & Toth, 1998). Comorbidity is also an issue, as 40-70% of depressed children and adolescents develop additional diagnoses. Twenty to fifty percent of these have two or more comorbid diagnoses (Cicchetti & Toth). Frequently seen comorbid diagnoses are depressive disorder, anxiety disorder, disruptive disorder, and substance abuse (Harrington et al.).

Allgood-Merten, Lewinsohn, and Hops (1990), investigated psychosocial variables as they related to depression in adolescents in Oregon. The variables studied included sex, age, body image/self-esteem, self-consciousness, stressful life events, and the degree to which the adolescent identified with the cultural stereotype of masculinity. Six hundred and eighty-six mostly white, upper-middle to middle class public high school students in 9th to 12th grade were twice given a battery of self-report assessments with one month between data collections. The testing battery included assessments for major life events, personal attributes, self-consciousness, body satisfaction, depression recent life events, self-esteem, anxiety, and anti-social behavior.

In each group of high school students, females demonstrated more symptoms of depression. The rate of symptoms, for females, did not increase with each age level, but rather remained high throughout the high school age groups. This sample also demonstrated a higher prevalence of depressive symptoms than typically seen in the adult population. The female adolescents reported more negative body image, lower self-esteem, more depressive symptoms, increased self-consciousness, more recent stressful events, and increased feminine attributes compared to males.

Allgood-Merten et al. (1990) found that as expected, recent life events and depression correlated for both girls ($r = .28, n = 278, p = < .001$) and boys ($r = .50, n =$
When these researchers compared Pearson Correlation Coefficients for boys and girls, they found that body image was strongly related to self-esteem, especially for females in the sample. These researchers also felt that body image is an important correlate for depression in adolescents. Multiple regressions were done to assess the effect of body image at two separate times for both girls (T1 $R = .44$, T2 $R = .49$) and boys (T1 $R = .34$, T2 $R = .36$). When self-esteem was controlled for in the regression analysis, the sex difference was eliminated, further body image variables and depression were no longer correlated. These data indicate that self-esteem was the critical mediating variable for increased risk of depressive symptoms in this sample. These researchers state:

When the variables on which there was a significant sex difference were forced into a hierarchical multiple regression with sex entered last, the relation between sex and CES-D (Center for Epidemiological Studies-Depression Scale) was greatly reduced. This suggests that if boys and girls had equal levels of these psychosocial variables, the sex difference would largely be eliminated (p.61).

Allgood-Merten et al. (1990) feel these results may demonstrate there is something unique about the effect of gender and adolescent depression. They also questioned whether this was a result of over-reporting by the adolescents, genuinely more depressive symptoms present, or a result of developmental turmoil. Female responders did not report more anxiety, masculine attributes or antisocial items, diminishing the possibility of sex-bias reporting.
Although the sample was neither sufficiently diverse nor large enough to enable generalization to the whole of society, the results are interesting and give merit to further investigation especially with regard to sex differences and body image as these relate to self-esteem in the adolescent population. The correlation coefficients and the size of the samples used for computation were not listed for all relationships claimed to be significant. Statistics were given for the multiple regressions and some of the individual analysis of covariance (ANCOVA) series. These results determined that the effects of gender would largely be eliminated when some variables were controlled for, such as body image and self-esteem. This study would be stronger if more statistical data on correlational results had been printed and sample size had been larger and most importantly, more diverse.

The emotional well-being of adolescents should be of utmost concern to our society. There is a demonstrated need for further study, and such research could have important implications for detection, referral, and treatment of the adolescent population. Emotional well-being is the key factor to prevention of many potentially dangerous risk behaviors with the adolescent population. Several studies list illness as an additional risk factor for the development of depression during adolescence or later in adulthood (Cadman, Boyle, Szatmari, & Offord, 1987; Suris, Parera, & Puig 1996; Wolman, Resnick, Harris, & Blum, 1993).

**Chronic Illness**

Cadman, Boyle, Szatmari and Offord (1987) reported the findings of the Ontario Child Health Study, an epidemiologic survey of 3294 children aged 4-16 from a general community. They studied the relationship of chronic illness and disability to the
manifestations of psychiatric and social adjustment disorders of children and young adolescents. To enable Cadman et al. to control for the confounding effects of age and sex, which they felt could alter the magnitude of any relationships found, they calculated odd ratios using Woolf's procedure to obtain a weighted ratio. The children who had both chronic illness and disability were found to have a threefold risk to develop psychiatric disorders and were significantly at risk to develop social adjustment problems. The children who had chronic illness but who were without disability were found to have a twofold increased risk of developing psychiatric disorders. Their risk of social adjustment problems was increased as compared to healthy peers, but to a lesser degree. Cadman et al. conclude that health care providers in the community, when working with children with chronic illness, need to develop skills in recognizing mental health and social problems. Additionally, they need to become familiar with prevention and treatment approaches appropriate for psychosocial issues of children with chronic illness.

Epidemiological studies can give important information regarding the scope of many health issues affecting children and adolescents. As increased risk has been demonstrated in the population with chronic illness, assessment for early intervention is imperative. Once issues are exposed it is the responsibility of the health care community to provide accurate and expedient assistance to all children and youth in need to prevent further complications and promote health potential to the fullest.

Zelter (1985) interpreted research regarding chronic illness and disability and found an additional way that chronic illnesses differentiate adolescents with these conditions from their peers. The timing of puberty may be altered, either due to the
disease process itself, or due to medications used in treatment. He further explains that progressing through developmental tasks is a challenge for adolescents with chronic illness because of potential limitations causing alterations in timing of physical changes, difficulties in having independent and peer-related experiences, and time and privacy for sexual exploration. Self-esteem is often dependent upon how adolescents perceive others see them. They often assume that others are as focused on them as they are upon themselves (Feldman & Elliot, 1990; Zelter, 1985). Adolescents with chronic illness often display an increase in self-consciousness and question the motives of others attempting to befriend them, imagining that others, too, must have the same negative evaluations they have of themselves. These beliefs can lead to depression and social withdrawal (Zelter).

Wolman, Resnick, Harris, and Blum (1993) used the Adolescent Health Survey to compare 7th-12th grade adolescents in the areas of emotional well-being, worries and concerns and body image. Their sample, selected from 36,254 public school students who participated in the Minnesota Adolescent Health Survey, was comprised of 1683 adolescents with chronic health conditions and 1650 adolescents without chronic health conditions. This sample was demographically representative of the general population of Minnesota with regard to race and socioeconomic status. Among the students with chronic conditions 57% (n = 950) were female and 42.6% (n = 706) were male. Just over 48% (n = 795) of the students without chronic conditions were female while 51.8% (n = 855) students were male.

As no significant differences were found by illness type among the adolescents with various chronic illnesses (cerebral palsy or muscular dystrophy [n = 90], arthritis
that limited daily activities \([n = 129]\), scoliosis that limits daily activities \([n = 134]\), diabetes \([n = 188]\), asthma that limits daily activities \([n = 789]\), and seizure disorders \([n = 291]\)) these young people were combined into one group to compare with those without a chronic condition. Adolescent males \((F \ [1,1416] = 30.65, p < .001)\) and females \((F \ [1,1597] = 30.60, p < .001)\) with chronic health conditions had lower emotional well-being scores than those without. However, students with chronic illnesses who perceived higher levels of family connectedness had significantly higher well-being scores, whether male \((F \ [1,1416] = 19.87, p < .001)\) or female \((F \ [2,1597] = 38.12, p < .001)\), than those with chronic illnesses without those perceptions. Adolescents with chronic conditions also worried more about dying soon \((males \chi^2 = 16.2, p < 0.001, females \chi^2 = 6.20, p < 0.05)\), school and future work \((males \chi^2 = 15.6, p < 0.001, females \chi^2 = 16.69, p < 0.001)\), and had poorer body image \((males \chi^2 = 5.96, p < 0.05, females \chi^2 = 24.59, p < 0.001)\). Males with a chronic condition worried more about peer relations \((\chi^2 = 21.32, p < 0.001)\), while this was not significant with the females with chronic conditions. An encouraging finding, however, among the variables studied to predict emotional well-being, was that having a chronic condition was ranked fourth in importance, with body image \((R^2 = 0.18)\), family connectedness \((R^2 \text{ change} = 0.08)\), and concern about peer relations \((R^2 \text{ change} = 0.05)\) accounting for approximately 32% of the variance related to emotional well-being for the adolescents with chronic conditions (Wolman, et al. 1993).

This research study had sufficient sample size for the statistical analysis as well as a sample diverse in proportion to Minnesota. As European-Americans accounted for 88.2% of the students with chronic conditions sample and 90.6% of the control group, these results will not necessarily apply to a generally more ethnically diverse society.
These researchers explored the impact of increased family connectedness and found that all adolescents in the study, both those with and those without chronic health conditions, demonstrated higher well-being scores than those whose families were less connected. These findings reinforce how important the family is to all youth, but especially those with a chronic illness. Although more males with chronic conditions than without such conditions worried significantly about peer relationships, no differences were found in this parameter in the female students. This difference invites further research to be done in this area. As male friendships tend to focus around activities and female friendships focus on a close relationship, this may account for this gender difference in concern.

**Chronic Illness and Emotional Distress**

Chronic illness affects many aspects of an individual’s life. To what extent and how individuals are affected is important to assess. Suris, Parera, and Puig (1996) studied emotional distress and suicidal ideation in adolescents with and without chronic illness. The sample groups were drawn from the *Barcelona Adolescent Health Survey* of 3129 students between the ages of 14-19. From this group an index group of 100 females and 62 males with chronic conditions including asthma [that limited daily activity] \( n = 86 \), diabetes \( n = 13 \), seizures \( n = 30 \) and cancer \( n = 39 \) were selected. The control group included 383 females and 482 males who answered negatively all questions about having chronic illnesses.

This study found no differences in prevalence of either emotional distress or suicidal ideation among the four categories of disease diagnoses studied. The females with chronic illnesses differed significantly from their healthy peers with regard to increased incidence of emotional problems (30.0% vs. 15.4% for healthy peers), and
suicidal ideation (23.5% vs. 8.9% for healthy peers). More males with chronic illnesses suffered with emotional problems (16.1% vs. 7.3% for healthy peers) but had no greater incidence of suicidal ideation than healthy peers. However, even though greater numbers of adolescents with chronic illnesses experienced emotional problems, they were no more likely to seek assistance from a mental health care professional than their healthy peers (Suris et al., 1996).

Whether emotional distress is present in the same way to the same degree, and has similar intensity in all disease states is readily debated. Hoare (1984) compared children with chronic epilepsy (n = 29) and newly diagnosed epilepsy (n = 29), and with chronic diabetes (n = 36) and newly diagnosed diabetes (n = 29), to children from the general population. He chose these groups to study to determine if the increase in psychiatric disorders seen in epileptic children were present at the onset of the condition, or were the result of treatments. Diabetic children were chosen as a comparison group due to similarities of the diseases in regards to the abrupt onset of these illnesses in children, the close and continual medical attention required for treatment of each, and the stressful effects of the new health problem. Diabetes differed in its lack of involvement of the central nervous system. The newly diagnosed groups for both the children with epilepsy and diabetes were diagnosed within 3 months of the onset of the study. Hoare assessed for psychological disturbance using the Rutter Scales for parents and teachers (Rutter, Tizard, & Whitmore, 1970b), which were completed by both parents and teachers for all children.

In this study, Hoare (1984) found no significant differences between the groups with respect to sex, age range, and mean age of the children, except between the newly
diagnosed diabetic group and the chronic diabetic group with regard to mean age ($t = 2.90, p < 0.005$). No significant differences were found among the groups with regard to demographic variables (social class, parental marital status, family size and number of children within the family). Mean duration of illness for the two chronic groups was also compared and found to be 5 years, 5 months for the epileptic groups and 4 years, 11 months for the diabetic group ($t = 0.86, p < 0.05$). A significant difference was found in the IQ between the chronic ($M = 101$) and newly diagnosed epileptic ($M = 109$) group ($t = 2.51, p < 0.01$).

In Hoare’s (1986) sample, children with epilepsy had significantly more psychiatric disorders than did the children with diabetes, and children in the general population. When children with chronic epilepsy and chronic diabetes were compared, according to both the parent ratings ($t = 2.92, p < 0.005$) and the teacher ratings ($t = 3.41, p < 0.001$) the children with chronic epilepsy had more problems. When children with newly diagnosed epilepsy and diabetes were compared, those with epilepsy were more disturbed on the parents’ assessments ($X^2 = 3.94, p < 0.046$), and likewise on the teachers’ assessments ($X^2 = 3.94, p < 0.046$). Interestingly, both groups of epileptic children had similar rates of disturbance (45%), whether newly diagnosed or dealing with long-standing disease. Psychiatric illness was also present in both diabetes groups (17%), compared to the general population (7%). The rate of disturbance within the diabetic groups was more similar to that seen in children with chronic physical illness found in the Isle of Wight study by Rutter (1970) of 11.6%. It appeared that these disturbances are present from the beginning of the disorder rather than developing subsequently.
Though larger sample sizes would have been helpful to give strength to both the relationships between the groups of children with epilepsy and diabetes and to provide increased confidence within the rates of disturbance, the data are sufficiently different to demonstrate trends within these groups. Also, to have found similar trends with both parent and teacher assessments is reassuring, especially when measuring observed behaviors. When these behaviors are observed in more than one setting, specific family environmental issues are less likely to be the causative agent for these behaviors.

Children with epilepsy have higher risk of psychosocial challenges than healthy children or those with other chronic illnesses. Therefore, children and adolescents with epilepsy should be assessed and monitored on a regular basis for early detection and intervention of these difficulties. Whether they have an increased risk over a child with another chronic illness is less important than that the assessment needs must be met for all children with chronic illnesses. However, because epilepsy involves the central nervous system, the stigma is different as well as some restrictions placed upon adolescents with seizure disorders, especially if seizures are not under control. For example, the impact upon work, social life and family can be great as these young people may not be able to drive or operate machinery as a result of seizures or the medications required to control the seizures. Therefore, health care providers must be diligent in their efforts for early intervention with this population.

*The Family and Epilepsy*

Whenever a child or adolescent is involved with a health problem, the family is also involved. Because a child is also a part of a family system, whatever affects one member invariably alters the system, further affecting all members and how the family
functions. Family variables have been explored in a number of studies concerned with the experiences of those with epilepsy. The success of the family in coping or failure to cope, will in turn impact the family’s ability to adjust to the diagnosis, of epilepsy thereby affecting the way in which the family deals with the disease, and the child who has the disease, for better or worse. The ability to cope will impact the family as a system to the same end.

Ferrari, Mathews, and Barabas (1983) studied the family and child with and without epilepsy, and the disease impact upon the family. Families of 15 children with epilepsy, 15 with diabetes, and 15 with no chronic illness were compared. These groups were matched as closely as possible with the following variables: chronological age, age at onset of chronic illness-except control group, sex of child, socioeconomic status, and academic standing. The Rochester Adaptive Behavior Inventory ([RABI] as cited by Ferrari et al.) and the Piers-Harris children’s Self Concept Scale (as cited by Ferrari et al.) were administered in the family homes by a researcher blind to the group the child belonged to.

Data collected by Ferrari et al. (1983) in this study suggests that illness-specific adjustment problems extended beyond the affected child and into the family and their interactions. These researchers used a 3x2x2 (group x sex x age) analysis of variance (ANOVA) to examine the individual items constituting the RABI to assess differences between the responses of the families. The families of children with epilepsy reported that the children with epilepsy expressed complaints of personal rejection more frequently ($p < 0.003$), had more frequent periods of emotional distress ($p < 0.05$), were more immature ($p < 0.03$), and were more likely to have a history of assaultive behavior
toward parents ($p < 0.05$). These families reported decreased family cohesion ($p < 0.02$) and increased difficulty with family communication, compared to either the diabetic or nonchronically ill groups. Parents of epileptic children reported their communications with the affected child ($p < 0.0003$) were often centered upon specific concerns or problems, such as complaints about siblings, rather than the general discussions such as the events of the child’s day. The parents of epileptic children more commonly reported this latter pattern of communication than parents of either diabetic or healthy children.

Scores on the overall Piers-Harris Children’s Self Concept Scale were also significantly different ($F [2, 39] = 11.92, p = .0001$) between the children with epilepsy and those with diabetes or who were not chronically ill. Ten of the eighty items on this scale also pertain to the family. Five of these were significantly different for the children with epilepsy (all $X^2 [2] > 5.7, p < 0.05$). The children with epilepsy responded ‘yes’ to the following items more frequently, demonstrating that the children perceived themselves as being problematic within the family. The items were (a) I cause trouble to my family, (b) I pick on my brothers and sisters, (c) I am disobedient at home, (d) My parents expect too much of me, and (e) My family is disappointed in me. All of these pertained to diminished self-concept for the children with epilepsy.

The overall mean self-concept score of the epileptic group was 53.2, compared to the children with diabetes, whose mean score was 60.3, and the healthy peers, whose mean score was 67.1. Ferrari et al. (1983) summarize epilepsy as a chronic illness with characteristics that affect children yielding decreased self-concept and affecting families in a unique way that is different than other chronic conditions. Further, it has a negative effect on family communication, cohesion, and integration.
Hoare and Kerley (1991) examined the psychosocial adjustment of families with children who have chronic epilepsy and those with difficult to control epilepsy, to identify problems that could be addressed in treatment plans. The sample was recruited from the children (and their families) who attended the pediatric neurology clinic at the Royal Hospital for Sick Children in Edinburgh, Scotland. Although this was not an epidemiological study, the authors felt it to be a representative sample of children with more severe or long-standing epilepsy, because this is the only facility capable of treating this patient population in the region. All children aged 5 – 15 years, and their families, were recruited for a 15-month period.

Sixty boys and 48 girls with a mean age of 10.4 years (SD = 3.0 years) and their families were included in the study. All economic classes were represented and mean marital satisfaction ratings were similar to the general population in the region. In this sample, 36% of the children had additional health problems, 69% had normal intelligence, 14% had mild retardation, and 17% were severely retarded. For 50% of this sample, the age of onset for epilepsy was 3 years or younger. The mean duration of treatment for this sample was 5 years, 10 months. Sixty-two percent of the children studied attended a regular school.

Within the Hoare and Kerley (1991) sample, many seizure types were represented. Children with mixed seizures comprised 29% of the sample, 28% were diagnosed with complex partial seizures, 23% with tonic-clonic seizures, 8% and 7% with complex and simple absence respectively. The final 5% had simple partial and simple motor seizures. Mean duration of treatment time for the sample group was 5 years, 10 months. Electroencephalograms (EEG) were done to reveal 42% with
generalized spike and wave abnormalities, 21% without abnormalities, 17% with right-sided abnormalities, 16% with left sided abnormalities, and 4% with 3 per second spike and wave abnormalities. Sixty percent of the children in the sample were receiving carbamazepine either alone or in combination with other drugs and 16 subjects were involved in trials with newer anticonvulsants such as vigabatrin. While 75% had less than one seizure per month, the remaining 25% had frequent seizures.

Maternal knowledge and attitudes about epilepsy were assessed using the Edinburgh Parental Attitude Scale to Epilepsy (EPASE) [Hoare, 1986]. In the sample of 108 mothers, this scale revealed 31% felt that death during a seizure was probable. With regard to school, 37% thought their child with seizures was less intelligent than they would have been without epilepsy, 41% and 30% felt their child with epilepsy had trouble with reading and math, respectively. In this group, 33% felt the epileptic child was more moody and 38% reported behavioral problems. Thirty percent of the mothers reported that the child with epilepsy had fewer friends than siblings or peers and 32% felt the behavior of child with epilepsy was more difficult to control. Of the mothers, 27% felt their child had adverse effects from anti-epileptic drugs and 32% felt the epileptic child required more supervision. Long-term goals were also of concern; 54% felt their child was less likely to obtain employment. Mothers were also affected. They were 22% less likely to work outside the home and 16% felt that epilepsy caused increased problems for the family. Further, Hoare and Kerley (1991) concluded from their data that an association existed between increased maternal scores for anxiety on the EPASE and behavioral disturbances measured by both the parents and teachers using the Rutter Scale for the assessment of the epileptic child. Again in this sample, approximately 50% of the
children with epilepsy showed disturbance assessed by both parents and teachers using the Rutter Scales (Rutter et al., 1970b).

Hoare and Kerley (1991) also compared 35 families of children with epilepsy and 35 control families (without children with epilepsy) to ascertain some of the effects of epilepsy on family life. Families with children with epilepsy scored significantly higher using Wilcoxon matched pairs signed ranks test \((p < 0.05)\) than families without children with epilepsy in overall family stress, dependency, cognitive impairment, restrictions for the family, long-term care concerns, anxiety about life expectancy, and increased burden for parents. These data reveal that the parents of children with epilepsy perceive that epilepsy imposes increased burden on both the child and the family.

From the results of this study, Hoare and Kerley (1991) have demonstrated that families with epileptic children have more concerns and anxiety than families without. Although Hoare tested each questionnaire used for normal distribution, it is difficult to make generalizations by seizure type and relate this factor to the responses of families and children. The sample size was not sufficient for each seizure type to make generalizations about behavior based on seizure type.

This literature demonstrates the common themes reported in research studies and seen clinically in families that have a child with epilepsy. Families have increased difficulty with communication, increased emotional distress and anxiety, and decreased family cohesion. Further, they demonstrate decreased knowledge of epilepsy leading to increased anxiety, such as fear of death of the child during a seizure.

These families tend to communicate with the child with epilepsy about specific tasks and situations rather than demonstrating a vested interest in the child with epilepsy.
as an individual. The children with epilepsy demonstrate decreased self-concept, self-esteem and verbalize decreased sense of self-worth and importance as an integral family member. Parents report that the child with epilepsy is more difficult to control behaviorally, and emotionally immature. As the family has the greatest impact upon the potential outcome for the child with epilepsy, much education, attention, assessment and support needs be given to these families to promote positive outcomes for the family and child.

_Epilepsy_

In a population-based study by Camfield, Camfield, Gordon, Smith and Dooley (1993a) children in Nova Scotia who were diagnosed with epilepsy from 1977 through 1985 were studied in order to develop a predictive scoring system for remission. As a first step in identifying the study sample, the physicians in Nova Scotia all agreed to order an electroencephalogram (EEG) on every child with first seizure. Then the study group reviewed all EEGs of the children aged 28 days to 16 years. If greater than one non-febrile, unprovoked seizure occurred between January 1, 1977 and December 31, 1985, the child was retained for the sample. All types of seizures were included except myoclonus, akinetic, atonic, and infantile spasms because of the likelihood of a poor prognosis. A sample of 504 eligible patients met criteria for the study.

Of this sample, 304 children were considered both neurologically and intellectually normal. Neurologic studies were done at the time of diagnosis and 393 children were considered normal, 55 with mild abnormality, and 56 with severe abnormality. Intelligence was also estimated for the children at that time, 316 were estimated to have normal intelligence, 57 estimated to have mild to severe retardation,
another 57 estimated to have learning disorder(s) and 18 with both learning disorder(s) and behavior disorder(s).

Sixteen of the 504 children received no medication for treatment. Of the 488 children treated with medication, 336 had remissions to allow for at least one trial off antiepileptic medication, 150 had a complicated course without remission, and 2 were lost to follow-up. Of the children in remission who were taken off medication, 72% remained off to the end of follow-up. For the 28% that had recurrent seizures, 50% became seizure free a second time and discontinuation of medication was attempted. Seventy percent of these children were able to remain off medication. Therefore, upon completion of their study, Camfield et al. (1993a) found that 55% of the children became seizure free during the study without the aid of medication. Although the majority of children become seizure free without needing medication, the rates of behavior problems and psychosocial distress were often high, despite remission of epilepsy.

Many authors have indicated that adolescents with neurologic chronic conditions have more problems with adjustment and behavior problems than adolescents with chronic conditions that are not neurologic in nature (Austin, 1989; Austin, Risinger, & Beckett, 1992; Howe, Feinstein, Reiss, Molock, & Berger, 1992; Papiro, Howe, & Reiss, 1992). Prognosis is good for most children and adolescents with epilepsy for seizure control. Usually the seizure control pattern is established within the first 2 years after diagnosis, and this is especially true for late onset and idiopathic seizures in people without neurologic dysfunction (Hauser, Freilinger, Seidl, & Groh 1995). However, as Camfield et al. (1993b) discovered, remission of epilepsy and attainment of seizure control does not always prove to be a positive predictor of good social outcome.
Howe, Feinstein, Reiss, Molock, and Berger (1993) compared adolescent adjustments to chronic neurologic and non-neurologic disorders. A sample of 214 adolescents aged 12-18 years (M = 14.3), consisting of 80 with neurologic conditions, 85 with other chronic medical conditions, and 49 healthy controls and their families, were recruited. The mean IQ score for the entire sample was 99.4. Forty-seven percent of the sample were females and 53% were males. The majority of the participants, 62%, were white, 35% were black, and 3% were other. No group differences emerged for either age or gender, but black adolescents were slightly over represented in the healthy control group.

The diagnoses present in the neurologic group were cerebral palsy 11%, epilepsy 9%, hydrocephalus 8%, and spina bifida 9%. Howe et al. (1993) found that the adolescents with neurologic conditions had more behavior problems, functioned less autonomously and had poorer achievement in school than either the non-neurologic conditions or healthy peers groups. Non-neurologic diagnoses included vision impairment, 7%, cystic fibrosis, 12%, diabetes, 12%, and arthritis, 10%. The adolescents with non-neurologic conditions differed from their healthy peers by reporting lower math achievement scores and having less work experience. This study supports the findings of others demonstrating that adolescents with neurologic involvement demonstrate both general effects from having a chronic disease and also factors that are seemingly specific and impact them more extensively due to neurologic involvement.

Westbrook, Silver, Coupy and Shinnar (1991) compared 34 adolescents with uncomplicated, mild, idiopathic epilepsy, 32 adolescents with other chronic illnesses defined as a serious medical condition requiring ongoing medical care for at least 3 years

50

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(such as asthma, diabetes, and sickle cell anemia), and 50 adolescents without illness in their school and social characteristics. These were 13 to 19 year old adolescents participating in an ongoing research program at a metropolitan teaching hospital.

Westbrook et al. (1991) found that although their sample involved adolescents with mild epilepsy, the epilepsy group was more likely than the other chronic illness group to attend special classes and to have learning disabilities. Although these students had uncomplicated and well-controlled epilepsy, the disease appeared to negatively impact at least some aspects of academic functioning. In the social aspects of their lives, those in the epilepsy group were also less likely to disclose their disorder to their peers than the chronically ill group.

**Behavior, Underachievement, and Learning Problems**

The experience of having epilepsy reaches beyond the impact of living with a physical problem and affects many aspects of an individual’s life. Even though when no seizure is occurring epilepsy is not visible, this disease has a negative stigma attached to it that impacts the individual beyond the disease process itself. It may affect the child’s self esteem, and in turn, affect behavior, achievement and learning. In 1986, DeVellis and DeVellis published the first phases of a psychosocial model of epilepsy. They felt that up to that point, the role of psychological and social factors had largely been ignored. They hoped through the development of a model incorporating the psychological and social aspects along with the physical realm, a more holistic approach would encourage research into the psychosocial impact of epilepsy. Over time, these issues have had greater attention. One area of consistent concern for children and adolescents with epilepsy is scholastic endeavors.
Hermann (1982), as a part of a larger study, utilized neuropsychological function test results to place 50 children with epilepsy aged 8-12 into two matched groups of 25, based on their performance on standardized neuropsychological functioning. Those children with a medial split of the Luria-Nebraska Battery (Golden, Hammeke, & Purisch, 1980, as cited by Hermann) scale scores exceeding a $T$ value of 70 were placed into the good category and those below into the poor. These children compared to children in the areas of overall behavioral pathology, aggression, and overall social competence. The groups of children with both good and poor scores contained children with temporal lobe epilepsy (good, 14, poor, 12) generalized epilepsy (good, 7, poor 10) and focal epilepsy (good, 4 and poor, 3). The group of children with poor neuropsychological functioning was significantly more aggressive ($F = 22.3; df = 1,48; p < 0.001$), had higher scores on the Total Behavioral Scale indicating overall behavioral dysfunction ($F = 18.1; df = 1,48; p = 0.001$), and also significantly lower scores on the Total Social Competence scale ($F = 25.2; df = 1,48; p = 0.001$).

Hermann’s study (1982) investigates the relationships between aggression, behavior problems, and social incompetence with neuropsychological functioning. The results are consistent with logical expectations that children with poorer function may experience increased difficulty and frustration. However, although types of epilepsy were considered, how well epilepsy was controlled, and the medications used, were not discussed in light of the results. More variables may be present to account for some of the differences between the groups. More research should be done with larger study groups of each seizure type and specific areas of epileptic foci to discern if there are differences in the behavior problems seen. As to date, no differences have been found.
However, these are smaller studies, whereas some studies done with adults who have epilepsy have demonstrated increased aggression and psychopathology in persons with temporal lobe epilepsy (Hermann, Trenerry, & Collian, 1996).

Behavior problems are common among children diagnosed with epilepsy; however, it is not known when these problems begin or whether they are caused by the same neurologic condition that elicits the seizure activity. Dunn, Austin, and Huster (1997) studied 42 youths, (23 girls and 19 boys) within 6 weeks (average of 2.4 weeks) of their first non-febrile seizure and again 4 months from the initial data collection point. These children, recruited from private practices, a university-based child neurology clinic, hospital emergency rooms, and hospital-based EEG laboratories, were 4-15 years old (M = 8.4 years); 57% of these children experienced partial seizures and 43% experienced generalized seizures. Ultimately, 71% of the sample was diagnosed with epilepsy.

The parents of these children were asked to complete the Child Behavior Checklist ([CBCL] Achenbach, 1991a) to rate the child’s behavior immediately prior to the first seizure and then again were asked to complete the CBCL 4 months after the first seizure. The prevalence of behavior problems detected by the CBCL prior to initial seizure activity was 24 %, based on parental recall, and when reassessed 4 months after initializing seizure treatment decreased to 12 %, demonstrating an improvement in child behavior. Additionally, it was found that children with high seizure severity scores also had higher internalizing and social behavior problems at both data collection intervals.

Six to 15 year old children treated for epilepsy in the outpatient clinics at Arkansas Children’s Hospital between 1990-1995 were studied by Williams, Griebel, and
Dykman (1998) in regards to school achievement, memory, attention, language, fine motor, executive function, visual motor integration and behavior. This sample of 79 children, limited to those who did not have neurological conditions (such as seizures resultant from head injury), neurodegenerative disorders, motor handicaps, or a history of neurosurgery, completed comprehensive neuropsychological evaluations. Thirty-seven female and 42 male children completed the evaluations.

These researchers found the full-scale mean intelligence score for this sample group was 86.6, (SD = 10.4) with a range of 70-121, placing the majority of the group in the low-average to average range of intelligence as compared to the general population. When comparing the performance on neurocognitive tests for these children according to the overall cognitive ability that would be expected based on IQ scores, no significant differences were found except that basic reading scores and the Trail Making Test (Reitan & Davison, 1974, as cited by Williams, Griebel & Dykman, 1998) standard scores were higher than expected. However, a reduction in attention skills as related to measured ability for verbal attention factors \((t = 2.42; \text{df.} = 73; p < 0.018)\) and visual attention factors \((t = 4.44; \text{df.} = 73; p < 0.0001)\) was consistently found among all the children regardless of seizure type or area of epileptic foci. Given the mean IQ of the sample group, specific measures on subtests for verbal and visual memory skills were within the expected range except for two activities highly sensitive to attention. The results of these tests suggested that this sample of children had difficulty with the initial encoding of information.

Williams et al. (1998) concluded that the scores relating to both verbal and visual attention factors, based on ability level, were significantly lower than expected for the
sample group. These findings indicated a more generalized pattern of inattention that impacted cognitive performance, which was not related to seizure type or hemisphere-specific foci. They further concluded that the reduced ability of the epileptic children in this sample to attend to and encode information from the environment might be the cause of the decreased achievement seen within this group.

Austin, Risinger, and Beckett (1992) studied 118 epileptic children between 8 to 12 years of age (M = 10.5 years), and their mothers. This group was also participating in a larger longitudinal study. This portion of the study was aimed to attempt prediction of behavior problems found in children with epilepsy. All children included in this sample had been diagnosed with epilepsy for at least one year, and most much longer (M = 5.1 years). They were currently taking prescribed anti-epileptic drugs (84% on monotherapy), had no other chronic conditions, and had an IQ of at least 70. Children who were classified as mildly mentally handicapped and required special classes were excluded from the study. The sample represented four different types of epilepsy, primary generalized (28%), secondary generalized (8%), primary partial (14%) and secondary partial (50%). Thirty-three percent of the sample had been seizure-free for one year or more and less than 5% had 20 or more seizures in the month prior to the study.

Seventy-two percent of the children were from two-parent homes. The socioeconomic standing score (M = 59.7) indicated most of the children came from upper-middle class families. The sample was recruited from two large medical facilities four outpatient clinics as well as private patients from the private offices of pediatric neurologists connected with the clinics.
Achenbach’s Child Behavior Checklist (CBCL) was used to determine frequency of behavior problems. The mean score for this sample was 63.4. The clinical cutoff as determined by Achenbach and Edelbrock (as cited by Austin et al., 1992) is 63, which is the 90th percentile for the general population, while a score of > 70 is the 98th percentile. In this sample, 50% scored > than 63 and 27% had total scores > than 70.

The family stress variables were assessed using the Family Inventory of Life Events and Changes ([FILE] McCubbin & Thompson, 1987) and the Family Inventory of Resources Management ([FIRM] McCubbin & Thompson, 1987). The families in the Austin et al. (1992) sample reported a mean score of 9.9. This score indicated that most families had experienced approximately 10 stressful events in the year preceding the study. The mastery resource variable reported by these families (M = 38.9) indicated they perceived minimal to low levels of mastery for both events and outcomes affecting the family. Austin et al. (1992) also reported that these families further perceived a moderate amount of support from relatives and the community, indicated by a reported mean value of 8.7 for the extended family social support variable.

Austin et al. (1992) utilized backward and forward stepwise elimination of variables and they found five significant variables including (a) family stress (p < 0.012), (b) female gender (p < 0.010), (c) seizure frequency (p < 0.020), (d) family mastery (p < 0.013), and (e) extended family social support (p < 0.019) were found to account for 29% (p < 0.001) of the variance in behavior problems as assessed by the Child Behavior Checklist. Because the multidimensional family stress variable is often a strong predictor for behavior problems, Austin et al. did further analyses to assess specific aspects within the variable of family stress. These researchers assessed nine specific aspects of family
stress and found two of these correlated highly with behavior problems, intrafamily strain 
($r = 0.43$) and marital strain ($r = 0.28$). Austin et al. conclude from the results of this study, 
that the family variables may have stronger influence on the child than the severity of the illness itself.

This study yields potentially helpful data for healthcare providers, especially with regard to the family factors and behavior problems. Austin et al. (1992) did isolate from their sample many potentially confounding variables, such as severe mental deficiency by IQ requirements and also attend regular classrooms. Also, because most of the children came from 2-parent homes and similar socioeconomic backgrounds, it is not likely that the differences found are due to extraneous variables. However, as most of the children in this study came from two parent homes, further research should be done to determine if these variables are also significant with other types of families. The majority of these families were also upper-middle class, whether the stress levels in other socioeconomic classifications increase, decrease, or are equivalent would also be beneficial.

Further information regarding the frequency of seizures (divided into 8 frequency groups for this study) as they relate to family stress would provide valuable information for the healthcare provider. This study demonstrates that increased stress relate to increased behavioral problems. However, whether the increase in family stress is related to seizures, such as frequency and severity of seizure activity affecting marital stress, or whether the stress was present within the marriage prior to the child demonstrating seizure activity. Regardless, due to the affect upon the child, the results from Austin’s study show the need for the assessment of stress in families. Self-concept and symptoms of depression expressed in this sample would also be of interest. Further research in
these areas could potentially impact the ability for healthcare providers to give appropriate support and referrals for these young people and their families.

Self-concept and symptoms of depression would affect the adolescent greatly in how he/she perceives his/her quality of life. Because this concept refers to the adolescent’s own perceptions of how the illness and symptoms affect him or herself, the adolescent’s responses to these effects may not be as the healthcare provider expects. For many adolescents with epilepsy, quality of life may be closely related to depression, anxiety, and locus of control (Andelman, 2000). The perceptions of the adolescent play an important role for the treatment and service that health care provides these individuals.

Austin, Huster, Dunn and Risinger (1996) compared the quality of life (QOL) of 228 adolescents with active and inactive epilepsy (n = 117) and active and inactive asthma (n = 111). At the baseline measurement, the subjects were between 8 and 12 years old (M = 10.5). Eligibility was restricted to those who had an IQ of ≥ 70. Both the epilepsy and asthma groups had been treated with medication for at least one year. Most in the study groups were Caucasian and from middle-class families.

Within the epilepsy sample group, scores were given to establish level of severity of the disease in relationship to the type of seizures experienced (generalized tonic-clonic seizures being considered most severe), frequency of seizures, and number of anti-epileptic medications and/or side effects from these medications. In the epilepsy sample: 46.2% (n = 54) had inactive epilepsy, having no seizures and taking no anti-epileptic medications; 28.2% (n = 33) were not having seizures and were taking an anti-epileptic medication; 25.6% (n = 30) were having a high frequency of seizures and/or were taking two anti-epileptic medications and/or experiencing side effects from their medication.
The asthma sample was also given scores to establish level of severity for study purposes, based upon number of asthmatic episodes, side effects from medications, hospital admissions, missed days from school, and visits to the emergency room for treatment. Of the asthma sample, 19.8% (n = 22) were considered inactive, having had no episodes in the past 6 months and no hospital visits for the past year; 52.3% (n = 58) were considered low severity, most having had one episode in the past month and 2 subjects had experienced a hospitalization within the past year; and 27.9% (n = 31) were considered high severity, and had multiple episodes within the past month, 16 having had ≥10 episodes and 13 subjects having had ≥one hospital visit over the past year.

To assess QOL in this study, a battery of instruments was used. These included the Piers-Harris Self-Concept Scale ([PH] Piers, 1984), Child Behavior Checklist- Parent and Teacher Reports ([CBCL] Achenbach, 1991), Child Attitude Toward Illness Scale ([CATIS] Austin & Huberty, 1993), and the Family APGAR ([APGAR] Smilkstein, 1978). Scores obtained using the CBCL and APGAR were standardized to T-scores normed for sex and age (M = 50, SD = 10). Within the QOL domains of psychological, social, and school, these researchers measured 19 variables.

Multivariate analysis of covariance (MANCOVA) indicated a difference (F = 3.36, p = 0.0001) between the total epilepsy and total asthma groups when covariates of age and age of onset were used. These covariates were also used for univariate analysis of covariance (ANCOVA) to examine group differences for individual variables. Psychological variables found to be significantly more troublesome for the children with epilepsy were internalizing problems (p = 0.0004), externalizing problems (p = 0.037), attitude, thought problems (p = 0.010), and attention problems (p = 0.0001). Both
mothers and teachers reported more social problems \((p = 0.0002\) and \(p = 0.0001,\) respectively) in the children with epilepsy. Peer relations \((p = 0.001)\) were also more problematic for the children with epilepsy. When school variables were compared between the two groups, the children with epilepsy had more difficulty in school progress \((p = 0.0001)\), school achievement \((p = 0.0001)\), internalizing \((p = 0.0001)\) and externalizing problems \((p = 0.0052)\), thought and attention problems \((p = 0.0001)\), and intellectual self-concept \((p = 0.0027)\). These were studied for covariance, with illness, epilepsy and asthma as the independent variables and age at onset and follow-up accounted for within the analysis.

All variables revealed significantly more disturbance for the epilepsy group, except self-anxiety, self-happiness, child attitude, family relationships, activities and thought problems at school. Scores on 6 of the 7 school variables also indicated significantly greater problems for the children with epilepsy, reaffirming findings of other researchers who have examined these issues. Therefore, school challenges are continuing during adolescence.

When all four groups were compared, those with active epilepsy had the greatest number of difficulties. This group demonstrated significantly lower scores in 10 of the 19 quality of life variables assessed including variables in all three domains. Significant variables were:

1. increased internalizing \((p = 0.0001)\) and attention problems \((p =0.0001)\) in the psychological domain;

2. peer relations \((p = 0.0001)\) and social problems, documented by both mother \((p = 0.0001)\) and teacher \((p = 0.0001)\), in the social domain, and
3. school progress \( (p = 0.001) \), intellectual self-concept \( (p = 0.0008) \), and internalizing \( (p = 0.0001) \), externalizing \( (p = 0.0146) \), and attention problems \( (p = 0.0001) \) in the school domain.

Adolescents with inactive asthma fared best with only the internalizing problems variable showing significance. Adolescents most significantly impacted according to quality of life variables measured in this study are epileptic females with high illness severity (multivariate \( F = 1.68, p = 0.014 \)) demonstrated by severe seizures.

The findings of this study are vital to practitioners working with chronically ill adolescents, and especially those working with those who have epilepsy. Internalizing, attention problems, peer relations, social problems, school difficulties and low self-concept continue to be problematic issues for adolescents, and do not appear to diminish with age nor abate with remission of epilepsy. However, these issues are often more problematic as the severity of epilepsy increases. Adolescents with asthma should also be assessed for internalizing problems. The ability to generalize these findings to the general population must be done with care due to the fairly homogenous sample assessed.

_Epilepsy and Depression_

In the population of adults who have epilepsy, mood disorders are common. Rutter (1981) discusses several studies that raise questions about an increased incidence for children with brain damage and neuroepileptic conditions of both behavioral and psychiatric disorders. He studied adults and children after brain injury and noted that although most psychiatric problems could not be connected with lesions in any specific location, depression was more prevalent when lesions were located in either the right frontal or left parieto-occipital regions of the brain. Hoare (1984) studied children
specifically, and found an increase in rates of psychopathology in children with epilepsy but did not delineate any one specific disorder. Questions arise as to whether these differences with epileptic children are due to the effects of epilepsy itself, the treatment (such as side-effects from anticonvulsants) or from dealing with a chronic disease.

Individuals with epilepsy often ignore depressive symptoms. Kanner and Nieto (1999) discuss three reasons for this. First, they suggest that epileptics often minimize their psychological symptoms for fear of further stigmatization. Second, many times the clinical manifestations of depression in epileptics are atypical, and third, clinicians often fail to ask or assess for depression in epileptic patients.

An interesting concept relating to epilepsy and depression is that these are often comorbid diagnoses regardless of whether the epilepsy is well-controlled or not. In a chapter entitled “An Evolving Psychosocial Model of Epilepsy” in Psychopathology in Epilepsy: Social Dimensions, DeVellis and DeVellis (1986) drew comparisons between epilepsy and laboratory operations often used to induce learned helplessness, stating:

Epilepsy shares many characteristics with other disorders. Among these characteristics is a degree of uncertainty regarding the disorder. A sense of uncertainty may be especially acute in epilepsy, however, because of the dramatic, unpleasant, and unpredictable nature of seizures. Individuals with severe and poorly regulated convulsive disorders may subjectively experience seizures as largely independent of their voluntary behavior. Complying with a prescribed treatment regimen may seem not to reduce substantially the likelihood of seizures whereas deviating from the regimen may seem not to increase seizures. When convulsive episodes occur, they do so without warning, often
having physically, psychologically, and socially unpleasant consequences. Other individuals whose epilepsy is more tractable may similarly perceive their disorder to be highly uncontrollable and unpredictable, even though their seizures occur less randomly. In both cases, the inevitability and unpredictability of seizures may sap the individual’s motivation to respond to life’s changes, leading to a sense of futility and state of depression (p. 124).

Learned helplessness and attributional style were studied by Hermann, Trenerry, Colligan and the Brozeman Epilepsy Surgery Consortium (1996) to examine their relevance to depression in epileptic patients. Their sample consisted of 73 patients with intractable right temporal lobe epilepsy (RTLE) and 70 patients with left temporal lobe epilepsy (LTLE) who were early adolescents (M = 13.3 years) and late school-age (M = 11.2 years) respectively at onset of epilepsy. This study group consisted of candidates for temporal lobectomy. At the time of data collection, the mean ages for these groups were 25.9 years for the RTLE group and 25.2 years for the LTLE group. The IQ scores (RTLE m = 88.9; LTLE M = 89.9) and education completed in years was quite similar for both groups (RTLE M =12.4 years; LTLE M = 12.9 years). The study groups were assessed using two self-report inventories for depression, the Beck Depression Inventory (BDI) and the Center for Epidemiological Studies Depression Scale (CES-D). Scores from these inventories were examined related to the Optimism/Pessimism Scale to reflect key components of the learned helplessness theory attributional style.

From this study, Hermann et al. (1996) discovered an attributional style of thinking often results from repeated exposure to uncontrollable, unpredictable aversive
events, (like seizures) and was associated with higher scores on the BDI and CES-D self-report scales in both groups, indicating increased traits of depression. This association remained consistent even after the effects of age, age at onset, laterality of lobe of epilepsy, sex, and method variance were controlled for through regression analysis.

The effects of laterality in the seizure focus were found not significant using ANOVA analyses ($F[1,139] = 0.01, p = 0.97$) for both genders, or by sex ($F[1,139] = 0.42, p = 0.52$) or the interaction of laterality and sex ($F[1,139] = 1.18, p = 0.28$). Correlations were run to determine if a relationship existed between attributional style and scores of self reported depression. These were found to be significant for both left and right temporal laterality groups combined ($r = 0.58$ [BDI], $r = 0.67$ [CES-D], $p < 0.0001$); as well as separate, left temporal focus ($r = 0.64$ [BDI], $r = 0.66$ [CES-D], $p < 0.001$) and right temporal focus ($r = 0.55$ [BDI], $r = 0.70$ [CES-D], $p < 0.001$). Using a multiple regression ($p < 0.0001$), increased depression, demonstrated by higher scores on the BDI (partial correlation = 0.43, $p < 0.0001$) and CES-D (partial correlation = 0.61, $p < 0.0001$), was associated in both groups with a pessimistic explanatory style.

The results of this study indicate that attributional style and learned helplessness are related to the genesis of depression in patients with epilepsy, as they are in the general population. Because techniques of prevention and intervention are available to address attributional style and learned helplessness, greater consideration should be given to the utilization of such interventions with the epileptic population. However, these results are based on the study above with a sample made up exclusively of adults, therefore more study must be done using adolescents and children before these results should be extrapolated to them. Further, nothing is disclosed related to ethnicity of this sample.
For most biologic explanations of depression in epilepsy patients, seizure type and the location of the seizure foci, especially lateralization, have been studied. In children, these have been, at best, weak predictors for behavior problems, and have not been associated with rates of depression. No studies could be found relating children's perceptions of epilepsy and how these correlate to the increased incidence of depression in this population.

Dunn, Austin, and Huster (1999) continued study with a sample they followed earlier as part of a longitudinal study from 1994 and 1996. This sample of adolescents with epilepsy was chosen to try to identify factors associated with symptoms of depression. The sample for this study consisted of 115 adolescents (55 females and 60 males) aged 12-16 years who had been diagnosed with epilepsy for a mean of 4.9 years. All subjects were currently taking antiepileptic medications and none had another chronic condition or were considered by either school or medical records to be mentally retarded.

Instruments used to assess the adolescents in this study included variables related to attitude toward illness, coping, locus of control, and depression; a portion of the Family Inventory of Life Events (FILE) McCubbin, Thompson, & McCubbin, 1996) entitled Family Stressors, the Family Inventory of Resources for Management (FIRM) McCubbin et al.1996), the Family APGAR (Smilkstein, 1978), Child Attitude Toward Illness Scale (CATIS) Austin & Huberty, 1993) the Coping Health Inventory for Children (CHIC) Austin, Patterson, & Huberty, 1991), the Multidimensional Measure of Children's Perceptions of Control by Connell (as cited by Dunn et al., 1999), the Children's Depression Inventory (CDI Kovacs, 1980/81), and the Child Behavior Checklist-Youth Self-Report (YSR Achenbach, 1991) to measure behavior and the
anxiety/depression subscale, normed for age and gender. In analyses, these authors included demographic variables, family variables, including family adaptive resources, and family functioning. Maternal perceptions about epilepsy and stigma, measured by the Stigma Scale by Ryan, Kempner, & Emlen (as cited by Dunn et al., 1999) and maternal symptoms of depression measured by the Center for Epidemiologic Studies Depression Scale (CES-D by RadlofT (as cited by Dunn et al., 1999) were also assessed.

Depression scores for the adolescents were not related to the demographic or biologic variables for age of seizure onset, seizure severity, or gender. While the mean score for this sample was 7.8, many of the sample assessed by Dunn, Austin, and Huster (1999) demonstrated elevated scores on the CDI self-report questionnaires related to depression. Those that scored ≥ to 12, 22.6% of the adolescent sample, were considered by Dunn et al. to warrant clinical follow-up and were considered to have elevated scores. The YSR subscale results were similar, with 21 % scoring above the clinical cutoff of ≥ to 60 (M = 55.07). Dunn et al. found no significant differences in the CDI depression scores by gender, severity or the interaction of gender and severity. They also compared the CDI and YSR anxiety and depression subscale (r ≥ 0.30, p ≤ 0.001) for this sample. Pairwise correlations were performed by Dunn et al. relating the adolescent’s attitude toward epilepsy, whether or not they were satisfied with family relationships, negative coping, and an external or unknown locus of control. When compared, the variables of gender, age, age at onset of epilepsy, and the seizure severity calculated score accounted for 7 % of the variance in the CDI and 6 % in the subscale of YSR. When other test scores were added (Child’s Attitude Toward Epilepsy, Child’s Satisfaction with Family Functioning, and Locus of Control-General Unknown) $R^2 = 0.53$ for the CDI and $R^2 =$
0.44 for the YSR subscale. Adolescents in the sample, who demonstrated an unknown or external locus of control during social interactions, also had increased self-assessment scores for symptoms of depression. These findings are consistent with studies that demonstrated the learned helplessness model as one etiological contributor for depression in adults with epilepsy (Hermann et al. 1996).

Dunn et al. (1999) hypothesize that because epilepsy is a disorder with an unpredictable course, they presume this factor to contribute to the adolescents’ unknown or external locus of control. Further, they purport that negative attitudes about epilepsy, a perceived lack of family support, and an external or unknown locus of control may provide one explanation for the increased incidence of depression among individuals with epilepsy. The use of the CDI and YSR within the same sample, administered at the same time with consistent results between the two tests, provides affirmation that this sample consistently demonstrates symptoms of depression in approximately one fifth of the respondents. The comprehensive battery used with this sample by Dunn et al. further confirms the validity of the findings within the adolescent sample with epilepsy.

Dunn and Austin (1999) question if some of the behavior problems seen in children and adolescents with epilepsy, such as irritability, may indeed be signs of depression that are misinterpreted. Other symptoms such as lethargy and poor concentration that have been attributed to either epilepsy or antiepileptic therapies may also be due to depression. Through the experience of epilepsy, adolescents may be less able to successfully adjust to developmental changes (Dean & Austin, 1996).
Summary and Implications for Study

Adolescence is a time during which many changes, both physical and developmental, are occurring within both the individual and the family. Literature of previous studies suggests children and adolescents with epilepsy demonstrate increased risk for many psychosocial problems. How these young people and their families navigate through this developmental period will have impact upon all aspects of life. Some studies reveal more externalizing problems seen in behavior for boys and more internalizing behavior problems, such as depressive symptoms, for girls.

A seeming unwillingness to attempt to excel during this developmental period may, for many, be related to having already experienced difficulty in many other aspects of their lives, beyond the seizures themselves. Due to the pervasive nature of epilepsy’s effects, some of these adolescents may have ceased trying, especially with regard to school. Many children and adolescents would benefit from early psychological assessments to allow for intervention designed to potentially improve their quality of life. If critical relationships can be determined to impact these youth and their families, screening tools might be utilized during routine office visits for early detection of potential problems. This information could be used to identify patients that would benefit from early intervention, and potentially reduce the negative impact of this disease. If appropriate support for these adolescents and their families could be made available, improved developmental outcomes may be achieved. The study reported here explored the possible relationships of self-concept, perceptions of parenting, and presence of depressive symptoms in adolescent boys and girls with epilepsy.
Research Questions

The following research questions were asked:

1. Is there a relationship between perception of parenting, self-concept, scores on depression self-assessment data, and length of time since diagnosis of epilepsy in adolescent girls aged 9-11.44 and those aged 11.45-14?

2. Is there a relationship between perception of parenting, self-concept, scores on depression self-assessment data, and length of time since diagnosis of epilepsy in adolescent boys aged 9-11.44 and those aged 11.45-14?

3. Is there a difference between male and female adolescents aged 9-11.44 and 11.45-14 with epilepsy in perception of parenting, self-concept, scores on depression self-assessment data, and length of time since diagnosis of epilepsy?

Definition of Terms

In this study, the following definitions were used. Early adolescence was defined as the period of life from the beginning of puberty through 14 years of life, inclusive of those in this sample. Youths refer to both children and adolescents within a given group or subgroup. Perception of parenting refers to the participants' perceptions of parenting and family satisfaction as measured by the Revised Family APGAR (Austin & Huberty, 1989). Self-Concept refers to the mean scores of study participants on the Piers-Harris Self-Concept questionnaire, entitled How I Feel About Myself (Piers, 1987). Scores on depression self-assessment data refers to the Children's Depression Inventory (Kovacs 1980/81) score. The length of time since diagnosis refers to that time calculated in years, from diagnosis of epilepsy to entrance into the study.
CHAPTER 3

METHODS

Research Design

The design for this study was a secondary analysis of data collected by Joan Kessner Austin, DNS, RN, FAAN during the years 1997 to 2001 at the University of Indiana (see Appendix B). A cohort of children with new onset epilepsy was selected and data collected longitudinally at 3 study periods. The criteria for inclusion at baseline was defined as being diagnosed with epilepsy for at least 6 months at initiation of data collection. Exclusion criteria were having an IQ below 70, and presence of a progressive brain disorder such as brain tumor or major medical condition that is progressive, incapacitating, or life threatening. Data were then collected for the second and third time at intervals of 12 and 24 months after baseline data collection.

For this analysis, the baseline data were used to identify the adolescents’ perceptions of mood, self-concept, family stressors and satisfaction with family functioning. To accomplish this and answer the research questions, the data from the Piers-Harris Self-Concept Scale (Piers, 1984), the Child Depression Inventory (Kovacs 1980/81) and the Revised Family APGAR (Austin & Huberty, 1989) were used. Data were available to this researcher from a downloaded computer file sent from Indianapolis in SAS format. The data were stored on floppy disc and in a locked desk when not in use by this investigator. In this data set, no identifying information was present to allow anyone, including this investigator, to know any personal health, demographic or other
data of any individual in the study, providing complete anonymity to all adolescents and family members.

This study represents a secondary analysis of data provided by the primary research team as a part of a much larger study. The difficulties encountered with secondary analysis are that the assessment tools were selected and the data set was created without the input of the secondary researcher. Therefore, the secondary researcher’s questions could only be answered through analysis of data already in existence and it is possible that other assessment tools or questionnaires may have been more helpful or comprehensive to answer specific questions regarding the adolescents’ perception of parenting and family functioning.

The advantages to using a secondary analysis are many. Specifically for this study, a more homogenous sample of adolescents could be identified because of the extensive testing for the baseline profile. This testing allowed for a sample with similar diagnoses of epilepsy and intelligence, and without other diagnoses that could further compound variables. The broad Pediatric Neurology population base used in this larger study allowed a larger sample size than would have been possible on a smaller scale with fewer resources. Also, because data of the larger study were collected using multiple sites and expert examiners, there were more resources available for obtaining data and to monitor respondents. Secondary analysis was more cost effective and utilized research dollars for multiple questions simultaneously. Utilization of the data by more researchers, and answering more questions without duplication of the original research questions, decreases responder fatigue while providing complete anonymity to responders.
Several potential problems are inherent in research based upon the perceptions of subjects. First, perceptions are difficult to measure. To address this difficulty, standardized tests were utilized. Second, because the data were not completed at exactly the same time interval after diagnosis with each adolescent, the change in perceptions over time since diagnosis could not be readily accounted for within this data set. The mean time from diagnosis to onset of the study was 5.25 years (SD = 3.836). The minimum amount of time from diagnosis to inclusion in this study was 6 months. With this time frame, the adjustment time from diagnosis to entrance into the study is considered to be as constant as possible. However, the differing amounts of time may affect the perceptions and responses of the respondents. For example, whether self-concept is relatively static or inherently labile due to developmental factors or the chronic disease has yet to be determined.

Population and Sample

A non-probability convenience sample was utilized for the longitudinal study of 169 youths (85 girls and 84 boys) aged 9-14 years who had epilepsy for at least 6 months. The data collection was initiated upon entry into the study and then completed again at 12 and 24 months after baseline. In the current investigation, only data collected upon entrance into the study was used.

Eligibility for inclusion in the study was determined based upon entrance criteria. For the current study, no attempts were made to represent a larger epidemiological sample of the population in which those with epilepsy would be a group within the sample. This research is focused to the specific responses of participants aged 9-14 years with the solitary diagnosis of epilepsy. Use of a general epidemiological design, though
ideal, would decrease sample size because screening of the general population for a
sample within age and diagnostic criteria would deplete funds and manpower needed to
gather specific data. Thus, the main advantage for selecting for the population to be
studied is that it yields a larger sample size of like diagnoses.

Frequently, children with seizures have co-morbid diagnoses. Multiple diagnoses
have impact on both the subjects and their families, making it much more difficult to
delineate the effects of specific singular diagnoses. The effects arising from different
diagnoses could potentially alter the responses to specific questionnaires. Although
random selection from an epidemiological sample would be ideal, this method of
selection would not be cost effective for a study of this size and would result in selection
of subjects who either vary greatly within the scope of symptoms/diagnoses or lead to
very small sample sizes that are statistically unreliable.

All children in this study were screened for mental health and academic variables.
The neurologic variables studied include brain structure, intelligence, and
neuropsychological functioning measures. These were collected only in baseline data
because in other studies they have been shown to remain constant. Repetition would
increase fatigue and add to respondent burden, potentially altering responses. The age of
the child at the onset of epilepsy is also included as a variable in the baseline data. Both
family and child variables were taken into account at all data collection intervals to
maintain constancy and relationships to all other variables.

Because of the age of the sample group, many developmental changes are also
occurring. No control sample was available to assist this researcher to determine if
responses to the questionnaires are due to developmental stage or the presence of
epilepsy. Children of this age group must concomitantly cope with the developmental tasks associated with early adolescence and those associated with a chronic or episodic condition like epilepsy.

Youths and their parents were recruited for participation in the study from two large outpatient pediatric neurology clinics and two large pediatric neurology private practices in the greater Indianapolis area. All participation was voluntary. The mother/primary caregiver gave informed consent and the child gave assent to be in the study (see Appendix C).

Characteristics of the Subjects

Parents/primary caretakers

Mothers/primary caregivers were contacted in person, by mail, or via telephone to inform them about the study and to invite their participation. To encourage participation, every effort was made to accommodate the families’ schedules, and incentive fees for participation were offered to parents and children. Concerted efforts were made to recruit an ethnically diverse sample. Racial/ethnic distribution was fairly representative of the Indianapolis area. Based on Austin’s (1992) earlier research in this geographical area, the sample was expected to be comprised of approximately 10% Black, not of Hispanic origin, 89% White, not of Hispanic origin, and 1%, other for each gender. Recruitment occurred in a wide range of settings, including those that serve economically deprived families. All economic levels were included, because epilepsy occurs among all levels of economic striation. When recruited, the overwhelming majority of the sample was Caucasian (91.1%) with African Americans (5.9%) and other ethnicities (3%) comprising
the rest. The ages and educational level of the Mothers/Primary caregivers are summarized in Table 1.

Table 1

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>39.15 (5.570)</td>
<td>38</td>
<td>27 - 54</td>
</tr>
<tr>
<td>(n = 164)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>13.55 (2.298)</td>
<td>13</td>
<td>8-20</td>
</tr>
<tr>
<td>(n = 166)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adolescents with epilepsy

Eighty-five female and 88 male early adolescents with epilepsy, aged 9-14 years (M = 11.78 years, SD = 1.78), were recruited. The age group of 9-14 years was selected because prior research by Austin and her colleagues indicated that this is a critical period in the development of a child, which may be altered in a child with a chronic condition. Four males of the original 88 included within this data set were excluded from the sample after discovering that these individuals had not completed two of the three questionnaires, (RAPGAR, PH, and CDI) used in this study.

The mean age and age at diagnosis were similar in males and females, but females had experienced seizures for a slightly longer period of time (see Table 2). Length of time between diagnosis and entrance into the study was at least 6 months, but in many
cases this time was longer. As expected, older adolescents (aged 11.45 to 14 years) had experienced seizures for a longer time period than younger children (aged 9 to 11.44 years), but the mean age at diagnosis was also higher.

Table 2

*Age, Age at Diagnosis, and Years of Seizure Duration of Study Youth*

<table>
<thead>
<tr>
<th>Sub group</th>
<th>Mean Age (n)</th>
<th>Age at Diagnosis (SD)</th>
<th>Seizure Duration (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>11.925 (85)</td>
<td>6.340 (3.842)</td>
<td>5.558 (3.920)</td>
</tr>
<tr>
<td>Males</td>
<td>11.609 (84)</td>
<td>6.724 (3.655)</td>
<td>4.882 (3.743)</td>
</tr>
<tr>
<td>Younger*</td>
<td>10.235 (38)</td>
<td>5.923 (3.74)</td>
<td>4.302 (2.530)</td>
</tr>
<tr>
<td>Older^b</td>
<td>13.320 (37)</td>
<td>7.161 (4.259)</td>
<td>6.176 (4.256)</td>
</tr>
</tbody>
</table>

* Ages 9 to 11.44 represented.  
^ Ages 11.45 to 14 represented.
Similar numbers of males and females were distributed across the major ethnic groups represented in the study, except in the African American group where males outnumbered females (see Table 3).

Table 3

*Ethnic Backgrounds of Study Youth*

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>African American</th>
<th>Caucasian</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>$n$</td>
<td>$n$</td>
</tr>
<tr>
<td></td>
<td>($%$)</td>
<td>($%$)</td>
<td>($%$)</td>
</tr>
<tr>
<td>Females</td>
<td>3</td>
<td>79</td>
<td>3</td>
</tr>
<tr>
<td>($%$ of all females)</td>
<td>(3.5)</td>
<td>(93)</td>
<td>(3.5)</td>
</tr>
<tr>
<td>Males</td>
<td>7</td>
<td>75</td>
<td>2</td>
</tr>
<tr>
<td>($%$ of all males)</td>
<td>(8.33)</td>
<td>(89.3)</td>
<td>(2.4)</td>
</tr>
<tr>
<td>Younger$^a$</td>
<td>6</td>
<td>75</td>
<td>4</td>
</tr>
<tr>
<td>($%$ of all younger$^a$)</td>
<td>(7)</td>
<td>(88.2)</td>
<td>(4.8)</td>
</tr>
<tr>
<td>Older$^b$</td>
<td>4</td>
<td>79</td>
<td>1</td>
</tr>
<tr>
<td>($%$ of all older$^b$)</td>
<td>(4.8)</td>
<td>(94)</td>
<td>(1.2)</td>
</tr>
<tr>
<td>Total Sample</td>
<td>10</td>
<td>154</td>
<td>5</td>
</tr>
<tr>
<td>($%$ of total sample)</td>
<td>(5.9)</td>
<td>(91.1)</td>
<td>(3)</td>
</tr>
</tbody>
</table>

$^a$ Ages 9 to 11.44 represented. $^b$ Ages 11.45 to 14 represented.
There were also more African American and non-Caucasian adolescents in the group of younger adolescents than in the older. This sample consisted of predominantly Caucasian respondents.

The age at diagnosis has the potential to affect the adolescents' time for adjustment and understanding of the disease, and also the psychosocial aspects of both the adolescent and the family. Therefore, the age at diagnosis may possibly affect how both the adolescent and the family member answer some of the questionnaires, especially with regard to family. Also, the longer a family deals with the care of a child with chronic illness could affect the responses to questions. The mean age at diagnosis for children of this study was 6.53 years (SD = 3.74). Table 4 reveals the number of children diagnosed during each stage of childhood development (see Table 4).

Instruments

**Mental Health and Academic Testing Profile**

Austin, Dunn, Perkins and Fastenau (1997) administered a number of tests to the children and their mothers at baseline. In addition to the Child Behavior Checklist ([CBCL] Achenbach, 1991a) completed by the mothers, the following instruments were completed by the youth:

2. Piers-Harris Self-Concept Scale (Piers, 1984), and
3. Child Depression Inventory (Kovacs 1980/81).

Lay interviewers trained to use the Diagnostic Interview Schedule for Children ([DISC] Shaffer, Fisher, Dulcan, Davies, Piacenti, Schwab-Stone et al., 1996) also assisted the
Table 4

*Frequency of Ages at Diagnosis with Epilepsy*

<table>
<thead>
<tr>
<th>Stage of Development</th>
<th>Infancy</th>
<th>Toddler</th>
<th>Preschool</th>
<th>School-aged</th>
<th>Pre-teen</th>
<th>Adolescent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≤ 12</td>
<td>12.1 - 36</td>
<td>36.1 - 60</td>
<td>5 - 10.99</td>
<td>11 - 12.99</td>
<td>13 - 14</td>
</tr>
</tbody>
</table>

**Entire Sample**

| N = 165 | 14 | 23 | 23 | 85 | 11 | 8 |

**Females**

| n = 83 | 9 | 10 | 14 | 41 | 4 | 5 |

**Males**

| n = 82 | 5 | 13 | 9 | 45 | 7 | 3 |

**Younger**

| n = 84 | 7 | 11 | 14 | 52 |

**Older**

| n = 81 | 7 | 12 | 9 | 34 | 11 | 8 |

* Ages 9 to 11.44 represented.  
* Ages 11.45 to 14 represented.
research team in assessment of the psychiatric profiles of the children. The current study utilized data obtained with the Piers-Harris Self-Concept Scale and the Child Depression Inventory.

**Neurological variables**

A thorough assessment of neurological status was performed as a part of the baseline profile and to determine eligibility for participation in the investigation. Although not pertinent to the questions of this secondary analysis, it is of note that the following were used in the baseline assessment.

*Brain structure* information was designated as normal or abnormal. This information was gathered from chart review and records of neurological examinations, EEGs, and neuroimagining. These results were tabulated on the *Neurologic Status Form* (See Appendix A) developed by Austin. The ratings on this form include brain structural integrity such as malformation, presence of structural damage and/or lesions.

*Intelligence* was measured by the *Kaufman Brief Intelligence Test* ([K-BIT] Kaufman & Kaufman, 1983). This test utilizes vocabulary and visual-spatial testing to estimate IQ. The authors of the test indicate that its scores correlated highly with the test results obtained from the more comprehensive standard IQ test with a national sample. The K-BIT was deemed more appropriate for use in the investigation because again, the score was utilized for inclusion purposes only. The more comprehensive IQ tests would have increased testing fatigue of the participants.

*Neuropsychological Functioning* was determined through use of a standardized testing battery. The following measures were used.
1. Wide Range Assessment of Memory and Learning ([WRAML] Adams & Sheslow, 1990),
3. Conner’s Continuous Performance Test v3.0 ([CPT] Conners, 1995),
4. Grooved Pegboard (Knights & Moule, 1968),
5. Tokens Test for Children (DiSimoni, 1978),
6. Woodcock Johnson-Revised Picture Vocabulary (Woodcock & Johnson, 1989),
7. Stroop Color and Word Test (Golden, 1978),
8. Trail Making Test ([TM] Reitan & Wolfson, 1993), and

The tests enumerated above were completed at baseline. All were age appropriate for the target population of children used in this study.

Data analyzed for this secondary analysis were obtained using (a) a demographic questionnaire for primary caregivers, (b) the Piers-Harris Self Concept Scale completed by the adolescents, (c) the Child Depression Inventory completed by the adolescents, and (d) the Revised Family APGAR also completed by the adolescents. All data used for this study were collected at baseline.

Piers-Harris Self-Concept Scale

The Piers-Harris Self Concept scale (Piers, 1984) is a self-report inventory of 80 first-person declarative statements, 44 negative and 36 positive, to which the respondent circles “Yes”, if in agreement with the statement, or “No” if not in agreement with the statement for how he/she feels about him/herself (see Appendix D). One point is awarded to each question answered in the direction of high self-esteem with a range of 0
to 80. It is intended for use with children in the 4th through 12th grade. This scale is to be considered a general screening device, an adjunct aid to clinical assessment, and a research tool (Epstein, 1985).

The scale takes approximately 20-25 minutes to complete. The raw scores can be converted to percentiles, stanines and t-scores and may be reported as an overall score or as a profile of each of the 6 cluster scores of the following: behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction. For the purpose of this secondary analysis, the overall total score will be considered.

Reliability and validity are very good in several separate studies (Saylor, Finch, Furey, Baskin, & Kelly, 1984). Epstein (1985) reports test-retest reliabilities to be 0.42-0.96 (M = 0.73), and the internal consistency coefficient for the total score was 0.90. The Piers-Harris was found to be the most reliable for clinical use with older children aged 9-16 for self-concept (Hughes, 1984). In the current sample, Austin, et al. (1997) found the reliability to be acceptable and a Cronbach’s alpha of 0.92 was obtained.

In an Australian study by Collins, Kafer and Shea (1985), 800 children from both rural and urban areas completed the Piers-Harris Self Concept Scale. For each age, 50 boys and 50 girls aged 8 through 15 were studied for comparative factor analysis using the data obtained from the scale. The results of this study were congruent with those done earlier by Piers using children from schools in Pennsylvania (as cited by Collins et al.). The minor differences obtained were attributable to age and sex and did not warrant the development of different age/grade norms. Collins et al. (1985) obtained a mean Piers-Harris score of $52.48 \pm 12.43$ in their sample. Further, they found that clusters of
behavior, intellectual and school status, physical appearance and attributes, anxiety, and popularity hold the most promise for use as diagnostic tools for clinical and counseling settings.

**Children’s Depression Inventory**

The Children’s Depression Inventory ([CDI] Kovacs 1980/81) is a 27-item self-report instrument that is patterned after the Beck Depression Inventory (Beck, Ward, Mendelsohn, Mock & Erlaugh, 1961) used for adults. The CDI is designed for use with children and adolescents from 8-17 years old (see Appendix E). The internal consistency coefficient has been found to be 0.71-0.87 (Kavin, 1992). Scores of the CDI were found to correlate well when tested against two self-rating instruments that assess constructs related to depression (Smith, Mitchell, McCauley, & Calderon, 1990). The CDI scores were found to correlate positively with the Revised Children’s Manifest Anxiety Scale (Kavin, 1992, Reynolds & Richmond, 1978) and negatively with the Coopersmith Self-Esteem Inventory (Kavin, 1992) thereby demonstrating validity.

Some studies have reported concern over the use of a self-report instrument for screening children and adolescents for depression. Saylor et al. (1984) reported that use of structured interviews would reduce the amount of variability in the information obtained to form more sound diagnostic assignments. These researchers felt that the interview of parents and teachers should also be used in these assessments. They concluded that depression in children needed to be further defined. Saylor et al. further state “although children’s accounts of their depressive symptomatology may not coincide with the behaviors observed or reported by others, they are consistently reported by the children themselves across self-report measures and should be respected” (p. 984).
Diagnostic interviews by trained professionals are used for the diagnosis of depression, as no self-report measure by itself is considered diagnostic. Because clinician-completed interviews rely substantially upon training and judgment, it was not practical for common use in this type of research study. Rather, rating scales can attempt to quantify clinical phenomena or symptoms to ease scientific research (Kovacs, 1980/81). The CDI is an appropriate screening tool to look for the common responses found in children with depression.

Strauss, Forehand, Frame, and Smith (1984) examined characteristics of children with extreme scores on the CDI. They compared the self-report measures with those reported by teachers and peers by utilizing the Revised Children’s Manifest Anxiety Scale (Reynolds & Richmond, 1978), the Piers-Harris Self Concept Scale (Piers, 1984) and the Children’s Action Tendency Scale (as cited by Strauss, Forehand, Frame, & Smith). The study group of children with high CDI scores and another group with low CDI scores were then scored using the other measures completed by the teacher and the peers. These scores were then contrasted to reveal the children with the high CDI scores rated themselves as more anxious and having lower self-concept than the control group. The teachers also rated the high CDI group as more anxious, socially withdrawn, doing less well academically, and having attention problems in the classroom. The peers rated the high CDI group as less smart, less popular, less athletic, less attractive and socially withdrawn. The teachers and the peer groups did not perceive the high CDI group as either aggressive or having conduct problems. Strauss et al. (1984) concluded that children with high CDI scores were similar to those identified as depressed in other investigations that use alternative methods of assessment.
The use of the CDI as a self-assessment tool has been shown to be consistent with others’ assessments of those individuals with extreme scores. As the scores increase for the individual, other observers often see increased symptoms. Even though the CDI is non-diagnostic, it provides a reliable measure of depressive symptoms for children and adolescents. In the current sample, Austin, et al. (1997) found the reliability to be acceptable and a Cronbach’s alpha of 0.83 was obtained.

Revised Family APGAR

In 1989, Austin and Huberty revised the Family APGAR (Smilkstein, 1978) for use with 8 year-old children and those with learning problems able to read at a second grade level. The Family APGAR is a brief screening tool of 5 closed-ended questions to which the responder is to reply one of three responses, (a) Almost always, (b) Some of the time, or (c) Hardly ever (see Appendix F). The responses are then assigned points, 2, 1, and 0, respectively, to be used to assess the responder’s view of the functional state of his/her family. The revised version follows this same format.

The Revised Family APGAR (Austin & Huberty, 1989) is meant to assess the perception of the respondents’ view of his/her family in the realm of: (a) Adaptability-defined as the utilization of the intra and extra-familial resources for problem solving when family equilibrium is stressed during crisis, (b) Partnership-defined as the sharing of decision making and nurturing responsibilities, (c) Growth-defined as the physical and emotional maturation as well as self-fulfillment achieved by family members as a result of mutual support and guidance, (d) Affection-defined as the caring and loving relationships that exist among the family members, and (e) Resolve-defined as commitment of time and devotion to family members to provide physical and emotional...
nurturing that usually involves sharing wealth and space (Smilkstein, 1978). During the
development of the revised scale, Austin and Huberty (1989) tested for internal
consistency and reliability using test and re-test procedures. The coefficient alphas were
found to be 0.71 (test 1) and 0.68 (test 2) and the Pearson correlation coefficient
computed for the scores of both time periods was 0.73. The correlations between the
original scale and the revised version of the Family APGAR were found to be 0.74-0.79
demonstrating the acceptability of the revised version for research purposes. In the
current sample, Austin, et al. (1997) found the reliability to be acceptable and a
Cronbach’s alpha of 0.92 was obtained for the revised version of the Family APGAR.

Procedure

Austin, Dunn, Perkins, and Fastenau (1997) determined eligible participants for
this study by examining neurological variables of children treated at participating offices
and clinics in the greater Indianapolis area. Following written consent (see Appendix C),
clinical records, including neuroimaging reports, electroencephalogram reports, seizure
condition, and medication variables were assessed. The descriptions of seizures, seizure
frequency, side effects of medication(s), and seizure severity were obtained during
structured parent interviews. Nursing or rehabilitation psychology graduate students
trained under the direction of Joan Austin, DNS, RN, FAAN, and Dr. David Dunn, M.D.,
conducted these interviews. With the consent of the parents, the interviews were audio
taped.

Neuropsychological functioning and academic achievement data were obtained
from individual testing sessions conducted by a graduate student in psychology under the
direction of Phil Fastenau, Ph.D. After obtaining written consent from primary
caregivers and assent of the youth, the primary research team contacted the family and scheduled testing time at their convenience. The entire neuropsychological battery took approximately two hours. Two instruments, the Piers-Harris Self-Concept scale, and the CDI, part of the data set for this secondary analysis, were included within this battery. Trained examiners administered the tests and monitored the children for signs of fatigue. Scheduled breaks were included, and if needed, further breaks were added. Multiple test sessions were arranged for children unable to complete the battery in one session. The results of the individualized testing batteries were discussed and made available to parents for their use to assist with educational planning if they so desired.

Data for child and family variables, including demographic data, were collected either face to face or via the telephone by trained interviewers under the direction of Dr. Joan Austin. The data were entered directly into a computer using the relational database program FOXPRO. Dr. Austin monitored these interviews to assure accuracy and consistency over time.

After research questions for the current study were agreed upon, the research team at Indiana University assembled the specific demographic and questionnaire data required to answer these questions from the larger study, *Epilepsy Outcomes in Youth: Neurological and Family Factors* (Austin, et al. 1997). Data were sent to this investigator in the form of a computer file. After receiving exemption from the Human Research Review Committee at Grand Valley State University (see Appendix G), the file was opened and the statistical analysis was completed.
Risks to Subjects

In the original data collection procedure, risks to participants were minimal to none. All participants were monitored for fatigue. Breaks or another session were added to accommodate participants when needed. All responses were treated with utmost confidentiality. All participants were monitored for potential discomfort from disclosure, and trained personal were present to assist any participant who demonstrated such need. If psychological discomfort occurred, data collectors were trained to talk to the adolescent or parent until the discomfort was reduced. Drs. Austin and Dunn were also available if needed to assist any participant. Dr. Austin has doctoral training in psychiatric nursing and Dr. Dunn is a child psychiatrist.

As some of the assessment tools may provide information regarding potential mental health problems, the instruments were scored immediately upon completion. If any score yielded an area of concern, such as a score of 9 or greater on the CDI, the participant was asked if he/she has someone with whom they could discuss their feelings. These participants were encouraged to talk with their family and counselors about feelings and problems. At risk participants were also monitored on an ongoing basis as needed. Dr. Dunn was consulted regarding any participant at risk for suicide.

All identifying information was removed from the data set prior to acquisition by this researcher. The data, when not in use, has been in a secured file within a locked office. No information was discovered during analysis for the current study to demonstrate any concern regarding any participants that Dr. Austin was not already aware of, and monitoring.
The purpose of this research was to determine if there is a relationship between adolescents’ perceptions of parenting, self-concept, scores on the depression self-assessment and the number of years since diagnosis with epilepsy for boys and girls aged 9-11.44 years and 11.45-14 years. A modification of Holmbeck and Shapera’s (1999) model will aid in understanding the potential variable relationships (see Figure 2).

Figure 2. A modified version of Holmbeck and Shapera’s (1999) developmental-contextual framework for understanding and researching adolescent adaptation and adjustment specific to this study. (Arrow directed toward midpoint of another arrow is considered to be a moderated effect).

In Figure 2, the development and adjustment variables of adolescents with epilepsy examined in this study are depicted and transposed into a modification of the developmental-contextual framework for understanding adolescent adaptation and adjustment by Holmbeck and Shapera (see Figure 1). Various statistical techniques were used to determine if relationships existed in this sample of adolescents with epilepsy. This study examined potential differences between groups of adolescents with epilepsy both by age, (younger and older), and sex (see Figure 2).

Techniques

Data analysis was accomplished using the Statistical Package for the Social Sciences (SPSS) program for Windows version 11.5. Descriptive statistics were obtained for demographic variables (reported in Chapter 3) and for scores on the Piers-Harris (PH), the Child Depression Inventory (CDI), and Revised Family APGAR (RAPGAR).

Descriptive findings

The Piers-Harris (PH) total score was used for this study as a measure of self-concept. Within the framework, self-concept is a developmental outcome component of the adolescent’s identity. A maximum score of 80 indicates a strong positive self-esteem and as the scores decrease, the strength of the individuals’ self-esteem also decreases. Ferrari, Matthews, and Barabas (1983) used the PH to compare the measured self-concept of children with epilepsy, diabetes and healthy children. The children with epilepsy were found to have total PH self-concept scores significantly lower (M = 53.3) than children with diabetes (M = 60.3) and the children who were healthy (M = 67.1). Austin (1989) compared the self-concept scores of boys and girls with epilepsy and asthma. The mean score of the PH for boys was 54.8 for the children with epilepsy and 61.8 for the children...
with asthma. The girls’ scores were 55.8 for epileptics and 58.5 for asthmatics. Currently, for this secondary analysis, the PH total mean score was 59.029 (SD = 11.828), and ranged from 25.32 to 78. See Table 5 for further comparisons within this study with participants divided into younger, older, male and female subgroups.

Table 5

*Group Comparisons of Total Piers-Harris Self-Concept Scores*

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Median</th>
<th>Range for this sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger&lt;sup&gt;a&lt;/sup&gt;</td>
<td>58.711</td>
<td>59.487</td>
<td>25.32 - 77.00</td>
</tr>
<tr>
<td>n = 83</td>
<td>(11.822)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older&lt;sup&gt;b&lt;/sup&gt;</td>
<td>59.347</td>
<td>62.000</td>
<td>26.00 - 78.00</td>
</tr>
<tr>
<td>n = 83</td>
<td>(11.896)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>57.301</td>
<td>59.000</td>
<td>25.32 - 78.00</td>
</tr>
<tr>
<td>n = 84</td>
<td>(12.128)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>60.800</td>
<td>64.000</td>
<td>26.00 - 77.00</td>
</tr>
<tr>
<td>n = 82</td>
<td>(11.312)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Ages 9 to 11.4 represented.  <sup>b</sup> Ages 11.45 to 14 represented.
The mean scores of this group were slightly better than the scores of the epileptics in other studies and were comparable to those with other chronic illnesses.

The Children's Depression Inventory (CDI), another developmental outcome for the psychosocial adjustment of the sample group, has possible scores from 0 to 54. Scores greater than 12 indicate an increased potential for depression. Although the scale is not diagnostic, scores greater than 12 warrant clinical follow-up (Dunn, Austin, & Huster, 1999). Scores less than 12 (which can reach a minimum of 0) indicate decreased expression and self-recognition of depressive symptoms. The likelihood of the respondent being depressed with a score less than 12 is less. In this sample, 43 subjects (25.75%) had a score ≥ to 12. Further, 30 subjects (17.96%) had a score ≥ to 16, indicative of increased potential for meeting diagnostic criteria for depressive disorders. The figure 3 depicts the numbers of participants within the study sample that fall in categories of < 12, 12 – 16, and over 16.

![Frequencies of CDI Scores in Sample Groups](image.png)

<table>
<thead>
<tr>
<th>Number of participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDI less than 12</td>
</tr>
</tbody>
</table>

Figure 3. Numbers of participants with CDI scores in major diagnosis categories By age and gender.
Table 6

*Group Comparisons of Children’s Depression Inventory Scores*

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Median</th>
<th>Range for this sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger⁠¹</td>
<td>9.094</td>
<td>7.0</td>
<td>0 – 30.0</td>
</tr>
<tr>
<td>n = 83</td>
<td>(7.561)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older⁠²</td>
<td>7.885</td>
<td>7.0</td>
<td>0 – 25.0</td>
</tr>
<tr>
<td>n = 84</td>
<td>(5.928)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>8.872</td>
<td>7.0</td>
<td>0 – 29.0</td>
</tr>
<tr>
<td>n = 85</td>
<td>(7.059)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>8.085</td>
<td>7.0</td>
<td>0 – 30.0</td>
</tr>
<tr>
<td>n = 82</td>
<td>(7.059)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

⁠¹ Ages 9 to 11.4 represented. ⁠² Ages 11.45 to 14 represented.

The CDI mean score for the total group was 8.486 (SD = 6.795). Scores ranged from 0 to 30. These scores are comparable to 8 – 12 year olds with epilepsy studied by Dunn, Austin, and Huster (1999) whose mean CDI score was found to be 7.8 and 22.6% of those children scored ≥ 12.
The Revised Family APGAR (RAPGAR) as viewed in the framework in the interpersonal context of adolescent development was hypothesized to be related to the developmental outcomes of both the PH and CDI scores (see Figure 2). As the score rises, the individual is expressing an increase in satisfaction with his/her family. For this sample, the mean score for the RAPGAR was 2.994 (SD = 0.765) and the range was 0-4.0. See Table 8 to compare mean RAPGAR among the subgroups of the sample.

Table 7

*Group Comparisons of Revised Family APGAR Scores*

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Range for this sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger(^a)</td>
<td>3.128 (0.753)</td>
<td>3.4</td>
<td>0.2 - 4.0</td>
</tr>
<tr>
<td>Older(^b)</td>
<td>2.860 (0.759)</td>
<td>3.0</td>
<td>0 - 4.0</td>
</tr>
<tr>
<td>Females</td>
<td>2.967 (0.809)</td>
<td>3.0</td>
<td>0 - 4.0</td>
</tr>
<tr>
<td>Males</td>
<td>3.022 (0.721)</td>
<td>3.0</td>
<td>0.2 - 4.0</td>
</tr>
</tbody>
</table>

\(^a\) Ages 9 to 11.4 represented.  \(^b\) Ages 11.45 to 14 represented.
One hundred of those studied scored above 3.0, with 15 participants scoring 4.0, expressing strong satisfaction with their family relationships at this time. These scores are comparable to those obtained in the study of children with epilepsy by Dunn et al. (1999). The mean for that study was 2.94 (SD 0.686).

**Examination of the Research Questions**

Gender was considered within this sample to be a potential moderating variable (see Figure 2). It was further considered that gender and age could interact in their effects on self-concept (PH) and depressive symptoms (CDI). Table 8 summarizes scores of the family (RAPGAR), psychosocial (CDI) and identity (PH) variables when age and gender were considered simultaneously. None of the groups' mean scores differed significantly.

A Multivariate analysis of variance (MANOVA) was used to determine whether there were any statistically significant relationships of the different groups to the dependent variables. Specifically, neither gender nor age group was related to increased report of symptoms of depression on the CDI, or to decreased self-concept score. The results of the MANOVA also determined there were no differences by gender or age group in perceptions of parenting as demonstrated by the RAPGAR (see Table 8). Wilk's Lambda was chosen as recommended by Portney and Watkins (2000) to test these hypotheses, and was not significant for any of the relationships tested (see Table 9). Although no relationships were proven significant, the results must be considered with respect to the insufficient power found, therefore the stability of the statistical tests is affected and also these conclusions.
Table 8

Mean Scores of Self-Concept, Depressive Symptoms and Family Measures by Age Group and Gender

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Younger&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Younger&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Older&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Older&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Females</td>
<td>Males</td>
<td>Females</td>
<td>Males</td>
</tr>
<tr>
<td></td>
<td>(SD)</td>
<td>(SD)</td>
<td>(SD)</td>
<td>(SD)</td>
</tr>
<tr>
<td></td>
<td>n = 37</td>
<td>n = 42</td>
<td>n = 47</td>
<td>n = 35</td>
</tr>
<tr>
<td>PH</td>
<td>58.190</td>
<td>59.416</td>
<td>56.601</td>
<td>63.360</td>
</tr>
<tr>
<td></td>
<td>(11.671)</td>
<td>(11.830)</td>
<td>(12.556)</td>
<td>(9.860)</td>
</tr>
<tr>
<td>CDI</td>
<td>9.270</td>
<td>9.003</td>
<td>8.620</td>
<td>6.720</td>
</tr>
<tr>
<td></td>
<td>(7.837)</td>
<td>(7.594)</td>
<td>(6.524)</td>
<td>(4.661)</td>
</tr>
<tr>
<td>RAPGAR</td>
<td>3.195</td>
<td>3.081</td>
<td>2.775</td>
<td>2.970</td>
</tr>
<tr>
<td></td>
<td>(0.713)</td>
<td>(0.809)</td>
<td>(0.842)</td>
<td>(0.638)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Ages 9 to 11.4 represented. <sup>b</sup> Ages 11.45 to 14 represented.

Bivariate correlations were run to determine whether variables of the model were correlated. Table 10 includes the coefficients obtained in this analysis. As expected, the Piers Harris Self-Concept total score (PHTS) and the Children’s Depression Inventory (CDI) score were negatively correlated (see Table 9). Age at diagnosis (ADX) and the seizure duration from diagnosis date (SZD) to baseline data collection were also negatively correlated, as would be expected. Interestingly, the revised family APGAR
(RAPGAR) did not correlate with either the Piers-Harris Self-Concept Scale or the Children’s Depression Inventory scores for this sample (see Table 9).

Table 9

*Multiple Analyses of Variance Between Subjects for Gender, Age, and Age and Gender*

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>$F$</th>
<th>$\eta$</th>
<th>$p$</th>
<th>$\lambda$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>3</td>
<td>1.981</td>
<td>.503</td>
<td>.119</td>
<td>.963</td>
</tr>
<tr>
<td>Age</td>
<td>3</td>
<td>2.443</td>
<td>.600</td>
<td>.066</td>
<td>.955</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>3</td>
<td>1.319</td>
<td>.347</td>
<td>.270</td>
<td>.975</td>
</tr>
</tbody>
</table>

*Note. $\alpha = .05$, error df = 155.0.*

Correlations were used to determine if number of years of epilepsy, self-concept (PH) scores, depression scores (CDI), and perceptions of parenting (RAPGAR) were associated when girls and boys were considered separately, and also when the sample was subdivided into groups containing older (11.45 – 14 year-old) and younger (9 – 11.44 year-old). Further, the relationships were examined with the group subdivided into older boys, younger boys, older girls and younger girls. No significant relationships were found among the variables within these groups.
Table 10

*Pearson Correlation Coefficients for Psychosocial, Interpersonal, and Developmental Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>SZD</th>
<th>PHTS</th>
<th>RAPGAR</th>
<th>CDI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( r )</td>
<td>( r )</td>
<td>( r )</td>
<td>( r )</td>
</tr>
<tr>
<td></td>
<td>( (n) )</td>
<td>( (n) )</td>
<td>( (n) )</td>
<td>( (n) )</td>
</tr>
<tr>
<td>PHTS</td>
<td>-.073</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>( (162) )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RAPGAR</td>
<td>-.021</td>
<td>.107</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>( (162) )</td>
<td>( (163) )</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDI</td>
<td>.026</td>
<td>-.789*</td>
<td>-.071</td>
<td></td>
</tr>
<tr>
<td></td>
<td>( (163) )</td>
<td>( (164) )</td>
<td>( (164) )</td>
<td></td>
</tr>
<tr>
<td>ADX</td>
<td>-.888*</td>
<td>.106</td>
<td>-.045</td>
<td>-.078</td>
</tr>
<tr>
<td></td>
<td>( (165) )</td>
<td>( (162) )</td>
<td>( (162) )</td>
<td>( (163) )</td>
</tr>
</tbody>
</table>

* \( p < .0001 \).

**Summary**

The descriptive statistics did yield some interesting data. The mean score for the Piers-Harris for this group of young adolescents (59.029) was greater than in children with epilepsy studied in previous research, where a range of 53.3 to 55.8 has been found. The mean score of the Children’s Depression Inventory for this group was below the
clinical cutoff of 12, which indicates most did not demonstrate a need for further follow-up. However, 43 (25.75%) of the 167 within this sample scored 12 or above and required follow-up. Finally, the scores on the Revised Family APGAR indicate that most of these young people are currently satisfied with their family relationships.

Neither gender nor ages were related to the scores on the questionnaires utilized in this study at this point of development of these adolescents. Length of time from diagnosis to entrance into the study was not significant. The MANOVA did not yield any significant relationships within the sample group for either age or gender. However, the decreased power seen in the statistical analysis demonstrates the need for caution with regard to the stability and the accuracy of the findings.
Discussion of Findings and Conceptual Framework

Adolescence is a very dynamic time in children's lives as they transition to adulthood. Youth have many goals to accomplish during this time in order to fulfill their desires to be treated as adults, transform relationships with family and friends, enable achievement of intimacy to begin the development of their own families, and become productive and responsible members of society. Adolescents with chronic diseases have additional goals to accomplish including the management of their health care decisions and practices.

Young people with epilepsy must also deal with the uncertainty of seizure disorders and the stigma linked to these diseases while developing their identity and independence. About half of these adolescents must address the challenges encountered as a result of learning and behavior problems. This secondary analysis examined relationships among the variables identified in the developmental framework for understanding adolescent adaptation and adjustment (Holmbeck & Shapera, 1999). Specifically, perceptions held by young adolescents engaged with the challenges of epilepsy were explored. The visualization of the potential relationships of variables demonstrated the organization necessary to more easily determine means by which to answer the research questions.

The research questions examined involved many of the areas described in the framework by Holmbeck and Shapera (1999). In this sample, as expected, the
relationship between the Piers-Harris ([PH] Piers, 1984) Self-Concept and the Children's Depression Inventory ([CDI] Kovacs, 1080/81) was found, demonstrated by the PH score decreasing as the CDI score increased. The framework was helpful to delineate how the variables studied might impact other aspects affecting the adolescent through mediating and moderating variables.

Reflecting the ideas in the model, the Biological/Puberty category of the Primary Developmental Changes of Adolescents dimension was represented by the variables of (a) the diagnosis of epilepsy and (b) the age of the participants in the study. The Psychosocial/Cognitive category involved the variables of (a) age at diagnosis, and (b) length of time from diagnosis to the beginning of the study. The amount of time between diagnosis (age at which diagnosis occurred) and beginning this study might influence how the variables measured by the questionnaires are perceived and responded to by both the adolescent and the family. The effects of having a member with epilepsy may alter the family, and in turn affect the adolescent. The second dimension of the model, Demographic and Intrapersonal Moderating Variables, was represented in this secondary analysis by use of gender. The third dimension in the model, Interpersonal Context of Adolescent Development, was represented by the adolescents' perceptions of their families. The final dimension depicted in this model represent outcomes of the adolescents' development.

The Developmental Outcomes of Adolescents examined within this study were Identity and Psychosocial Adjustment. The Piers-Harris Self-Concept (Piers, 1984) score represented Identity, and its relationship to the variables of age, age at diagnosis, length of time diagnosed with seizures prior to the onset of study, gender, and responses to the
Revised Family APGAR (Austin & Huberty, 1989) were examined. The mean PH score for the sample and subgroups, along with the previously mentioned variables of age, age at onset of epilepsy, duration of epilepsy from diagnosis to the entrance into the study, and gender, were then used to determine if there was a relationship to the Psychosocial Adjustment of the this group as measured by the Children’s Depression Inventory (Kovacs, 1980/81).

At this time in the lives of these young people, no significant relationships were found. As these were the baseline data from a longitudinal study it is noteworthy that further follow-up with these variables was done by primary investigators of the larger study to determine if, over time, any such relationships develop. Follow-up of the self-concept, symptoms of depression and satisfaction with the family may be of great benefit to these young people, because if any issues were to arise, early detection might allow for intervention on the part of the health care and family systems.

The adolescents within this sample were found to be very similar in their perceptions of parenting, self-concept, and depression self-assessment scores regardless of age, age at diagnosis, duration of time since diagnosis, or gender. However, variables within the framework that were not assessed, such as peers, school, and family structure may be affecting the developmental outcomes of the early adolescents with epilepsy. Furthermore, although no differences were found between these groups, this group of young people with epilepsy may exhibit differences from their healthy peers in the general population.

There is no evidence, at the time of this secondary analysis, that diagnosis with epilepsy had differentially impacted biological changes, or the adolescents’ views of their
families. The mean scores demonstrate this lack of difference for both the total sample and within the subgroups (males, females, younger and older) as the Revised Family APGAR demonstrated a high level of satisfaction with family relationships.

Furthermore, most of the scores on RAPGAR in the data collected from this group demonstrated that mediation by the family is either successful in assisting the adolescents' achievements in psychosocial adjustment and identity as assessed by the PH and the CDI, or these youth are not yet struggling with issues in their family relationships. Because previous research has shown that puberty affects the family relationships, it is unlikely that diagnosis with epilepsy will have no impact upon or relationship to the developmental outcomes of adolescents in the long term.

As these youth further develop, and the peer group becomes an integral part of their lives, age and gender may have an increasing impact on relationships as the family roles change. At this time, no significant differences in gender have been found within this group of young people with epilepsy; therefore, within the framework no moderation of Developmental Outcomes of Adolescence according to gender is detectable. It appears that in this group of pre-adolescent and early adolescent youth, most of the changes and differentiation that often are seen among genders during the developmental process have not changed the total scores of the PH. It was not explored whether gender differentiation was present in these data for the dimensions of the PH. For example, popularity and physical appearance PH dimension scores may have been different between males and females. Differences by gender are not yet large enough in any one dimension to affect the overall mean PH score.
In light of the work done by Wolman, Resnick, Harris, and Blum (1993), more information in the sub-scores of the PH may have been helpful to assess the potential differences by gender. Wolman et al. found females to be more concerned about body image and males about peer relations. Although the current sample was younger than the participants in Wolman’s study, differences may have been found in the PH sub-scores of physical appearance and body image, although self-concept as a holistic characteristic may not differ.

Findings in Relation to Previous Research

Chronic Illness

Based upon previous research, the timing of puberty and psychosocial changes may be altered due to either the illness or treatment (Zelter, 1985). All individuals within this sample had a chronic illness, which may explain why no significant differences were seen between the groups. The timing of the data collection with regard to the age of participants and the time since diagnosis may also be critical. There should be a lag between biological changes and the psychosocial impact of those changes. The timing of this baseline data may not have captured the psychosocial changes. If biological and psychosocial developmental changes begin and proceed along a later course than expected, these differences may impact the relevant outcome factors assessed by the RAPGAR, PH, and the CDI. For example, changes in satisfaction with family functioning often correspond with adolescent development, with satisfaction decreasing as stress from adolescent role changes, independence, and peer influence increase (Feldman & Elliot, 1990; Lerner, Lerner, von Eye, Ostrom, Nitz, Talwar-Soni, & Tubman, 1996).
In this study, the mean score for the Revised Family APGAR (RAPGAR) for the group was 2.994 on a 4.0 scale. This value, compared to the mean score of 2.94 on a 4.0 scale found in a sample of slightly older adolescents with epilepsy (M = 14.4 years) by Dunn, Austin, and Huster (1999), was comparable. While differences in the RAPGAR were tested for between the younger group (M = 3.127), the males (M = 3.022), the females (M = 2.967) and the older group (M = 2.860), these differences were not significant.

Chronic Illness and Emotional Distress

For healthcare providers working with adolescents with chronic illness, emotional distress is common as demonstrated by the CDI scores greater or equal to (≥)12 within this secondary analysis. Though known that chronic illness increases the rate and prevalence of emotional distress (Hoare, 1986), these young people are no more likely to obtain professional help for these issues than their healthy peers (Sures et al., 1996). The rates of psychosocial distress remained fairly constant according to Hoare, whether this disease is newly diagnosed or chronic. Because of the epilepsy diagnosis, a healthcare provider should assess and follow these adolescents for psychosocial distress.

To appropriately manage a seizure disorder, the healthcare provider and the young person with epilepsy should be able to readily discuss feelings and frustrations to allow both appropriate medication side effect management and psychosocial support. Providers must possess a comfort level that enables discussion of alteration in mood, depressive symptoms, and other feelings and concerns. As a good number of the CDI and PH scores assessed within this sample of pre-adolescents and early adolescents were borderline showing increased symptoms of depression and lower self-concept, this group was
monitored for signs and symptoms of psychosocial and identity concerns in the longitudinal study (Austin, et al., 1997).

**The Family and Epilepsy**

As these adolescents are monitored for difficulties, as a part of holistic care, so their families should be as well. Many changes are occurring within these families that may cause increased stress and challenges. Although the scores incurred on the Revised Family APGAR ([RAPGAR] Austin & Huberty, 1989) by this sample demonstrates all subgroups (younger, older, males and females) have relatively the same levels of satisfaction with their families, as they continue through adolescence, reassessment should occur.

When children approach adolescence, this is often a difficult time for parents. With the added importance and responsibility of epilepsy, usual adolescent lifestyle, such as sleep deprivation and irregular meals, can take on new ramifications with regard to seizure threshold and medication management. How these families handle these changes will affect independence issues for the adolescent within the family system.

Hoare and Kerley (1991) found that families with epileptic children have increased levels of stress compared to those without. Austin, Risinger, and Beckett (1992) further ascertained that the children are very affected by the amount of intrafamilial and marital stress within the family to the point that these may have greater impact than the epilepsy itself. Ensuring a high level of understanding of epilepsy and its management can assist the family with diminishing the levels of anxiety related to lack of knowledge about seizures and other health care concerns.
Even though research demonstrates that most people with epilepsy achieve remission of seizures (Camfield, Camfield, Gordon, Smith, & Dooley, 1993a) the potential for further seizures and the side effects of the antiepileptic medications needed to control the seizures, continue to affect the individual. Over two-thirds of the children studied by Camfield et al. were able to trial off medications, while one-third continued without remission necessitating continued treatment with medications. However, despite the high rate of remission, it appears that no decreases in behavior problems occur (Austin, Huster, Dunn, & Risinger, 1996; Camfield et al., 1993b; Westbrook, Silver, Coupy, & Shinnar, 1991).

Parent and teacher assessments of behavior (Child Behavior Checklist, Parent and Teacher Reports, as cited by Austin et al., 1997) of these young people were not addressed in this study to determine the level of behavior problems, underachievement, and learning disorders within the sample. However, prior research has shown that often 50% of children with epilepsy have problems with behavior and/or learning disorders (Austin, Risinger, & Beckett, 1992; Camfield, Camfield, Smith, Gordon, & Dooley, 1993b; Sturniolo & Galletti, 1994; & Williams, Griebel & Dykman, 1998). Certainly, it should be assumed that these issues are present to some extent within this sample. These differences in behavior and learning may also potentially alter the sequence of events in the developmental period of adolescence. This alteration may affect or delay achievement in school that could greatly impact both self-concept (PH) and how one feels (CDI) as demonstrated by decreased PH scores and increased CDI scores.
The mean PH self-concept score for this sample was 59.03, which is better than the mean score of 53.2 for the sample of children with epilepsy studied by Ferrari, Matthews, and Barabas (1983). Although the scores for the current study are comparable to the scores reported by these authors for children with diabetes (M = 60.3), they are not as strong as scores reported for healthy children (M = 67.1). It appears the scores for this sample of children with epilepsy are improved, but they still lag behind when compared to healthy children.

McNelis, Huster, Michel, Hollingsworth, Eigen and Austin (2000) reported mean PH self-concept scores from a longitudinal study of children with asthma to be 62.2 (age M = 10.2 years) and 62.8 (age M = 14.29 years) for first and second assessments collected 4 years apart. When comparing the scores of the subgroups of the current sample, the mean PH score of the younger (58.71) and older (59.35) subgroups have comparable scores to the earlier sample of children with asthma. However, note should be made that the females’ mean score was 57.30 (SD = 12.13) compared to the males’ mean score of 60.80 (SD = 11.31). Because Allgood-Merten, Lewinsohn, and Hops (1990) found differences between genders relating to body image and recent stressful event subscales in the Piers-Harris Self-Concept Scale, it is recommended that further testing of subscale scores is warranted.

Adolescent Depression and Epilepsy

As several studies of adolescents have found an increase rate of depressive symptoms present in females (Allgood-Merten, et al., 1990; Austin, Risinger, & Beckett, 1992; Burke, Burke, Reiger, & Rae, 1990; Lewinsohn, Hops, Seeley, & Andrews, 1993; Wolman, Resnick, Harris, & Blum, 1993) it is surprising that no significant gender
difference was found with regard to CDI scores within this group of adolescents with epilepsy. However, Burke, et al. reported the highest hazard rates for development of unipolar depression and bipolar illness within their samples as between the ages of 15-19 and 25-29, with a significantly higher prevalence in females than males ($\chi^2 = 70.41$, 1 df, $p < 0.0001$). If the findings of Burke et al. are robust, it can be assumed that the current sample, with ages from 9 to 14 years has not yet reached the age of highest hazard rate.

The mean CDI score for this sample was 8.49. In the study by Howe, Feinstein, Reiss, Molock, and Berger (1993) CDI scores were compared in a sample of adolescents, aged 12-18 (M = 14.3), with neurologic, non-neurologic conditions and healthy peers. The mean CDI scores for those with neurologic medical conditions, non-neurologic medical conditions and healthy peers were 8.05, 6.56, and 6.77 respectively. Interestingly, the group of adolescents with non-neurologic health conditions had a lower CDI score, indicating fewer depressive symptoms, than the control group of healthy peers. The mean CDI score for the current study was higher than the group studied by Howe, et al. This demonstrates reasons for concern for this study group. As the participants of the current study are younger than those studied by Howe, et al., needs for follow-up may be demonstrated later in adolescence, as they have yet to reach the age in which these difficulties are most common.

Scores greater than or equal to ($\geq$) 12 on the CDI are held to be indicative of a need for follow-up. Although, 27.01% of the females had a score $\geq$ 12 on the CDI and 24.40% of the males also reported a score of $\geq$ 12, this was not significantly different within this sample. Percentages of respondents with CDI scores $\geq$ 12 were similar between the younger and older children of the sample, 26.51% and 25.00% respectively.
Further, when older and younger females and older and younger males were compared, no significant differences were found. All youths in this study with CDI scores $\geq 12$ were assessed and followed as needed by Austin et al. (1997) as this longitudinal study progressed.

The rates of symptoms of depression in patients with epilepsy are increased compared to the general public and others with chronic illnesses (Hoare, 1984; Kanner & Nieto, 1999; Rutter, 1981). Theories set forth to explain this finding include suggestions that this increase is due to a biological connection with differences in brain function, or a psychological connection due to development of external locus of control (Harden, 2000; Kanner & Balabanov 2000). Also, as most research indicates that depression rates increase at some point during adolescence, especially for females, whether this increase in incidence is due to biological or psychosocial underpinnings has yet to be determined (Burke, Burke, Regier, & Rae, 1990; Cicchetti & Toth, 1998; Nolen-Hoeksema, 1990). Within the current sample, CDI scores were reassessed by Austin et al. as their study progressed. The final status of these adolescents has not yet been reported.

Application to Nursing Practice

Adolescence is a unique and dynamic time in a young person’s life. While all the changes are occurring psychologically, socially, and biologically, a positive relationship with their healthcare provider can be a valuable resource. Great assistance for the healthcare provider can be found through the use of a framework, such as Holmbeck and Shapera’s (1999) *Developmental-Contextual framework for Understanding and Researching Adolescent Adaptation and Adjustment* to be aware of variables that may influence developmental outcomes for adolescents.
All practitioners who work with adolescents, and especially those with chronic conditions, such as epilepsy, need to be aware of the role of family, self-concept and symptoms of depression during this vulnerable period of psychosocial development. A good rapport is important to allow the healthcare provider to ask and elicit the information necessary from the adolescent to provide support. To assist in this process, the Revised Family APGAR (Austin & Huberty, 1989) is a quick assessment tool designed for use in healthcare settings to obtain the most pertinent information to allow rapid assessment of family satisfaction. This information allows for the healthcare provider to encourage communication and development of family resources to cope with the developmental challenges facing adolescents with epilepsy.

The self-concept of the adolescent also plays a large role in the capability these young people feel in accomplishing goals and planning for the future. Although the Piers-Harris Self-Concept Scale (Piers, 1987) is often used for research, the results of this study indicate that the self-concept of individuals with epilepsy is often not as strong as it is for healthy youth of the same age. The healthcare provider must use this knowledge to support and assist the family and children with epilepsy at an earlier age than adolescence. As many children with epilepsy have difficulty with behavior and being successful in school, parents, teachers and healthcare providers must provide many interventions to promote the success of these children both academically and socially. Frequent and consistent communication with the child and family with regard to school progress and early intervention is vital for these children to develop positive self-concepts and healthy self-esteem. Supporting the child through close monitoring of academic progress is imperative for early intervention to attain maximal academic success. Further
assistance to the child and family can be offered to work with the school system to
decrease the stigma of epilepsy. Healthcare professionals can answer questions, provide
appropriate seizure first aid information to staff, and explain the disorder in terms
appropriate for different age groups.

By providing support and a close relationship with these young people prior to
adolescence, the issues that begin to emerge once developmental changes occur will
promote open communication. Changes in body image and capacity for reproduction
occur, and often affect the medication regimens of adolescents. Further, epilepsy
impacts the adolescent’s eligibility for a driving license, which is a symbol of autonomy
very important to this age group. The ability to complete these changes often depends
upon the foundation laid earlier in childhood.

Use of the Child Depression Inventory is appropriate to guide the need for
intervention within the primary care office (Smith, Mitchell, McCauley, & Calderon,
1990). When the young person reaches scores \( \geq 16 \), further intervention, such as
psychosocial support provided by the primary care provider, is appropriate. Often,
having someone to talk to may be all the intervention needed and can easily be
accomplished within the therapeutic relationship with the healthcare provider. If the
score is greater than 16, further assessment should be sought with the primary care
provider facilitating any immediate care needed, assessment of the young person for the
potential to harm themselves, and referral to the appropriate resource for further
assessment and intervention. The responsibility of the primary healthcare provider to
remain the coordinator of healthcare requirements and case management continue with
the increased services that may be needed to support the individual.
Young people with epilepsy have demonstrated an increase in difficulty with many aspects of their lives, which may hinder their successful completion of the developmental goals before them. Research has shown that children and adolescents with epilepsy have increased difficulty with learning and behavior and are greatly impacted by the stressors within their families. An increase in awareness of these factors on the part of the healthcare provider may well provide opportunity for early detection, intervention and support to potentially diminish problems to attain psychosocial adjustment and identity goals.

Limitations of this Study

The ability to generalize the findings of this study to the general population of adolescents with epilepsy is limited by a number of critical issues. First, the majority of the sample was Caucasian. As the world and the United States are ethnically diverse, further study inclusive of these other groups is important. Building upon this research worldwide would potentially enable both larger and more diverse samples and allow greater confidence in the conclusions drawn.

A second limitation of this study is that these individuals are from the small geographic area of greater Indianapolis. In the United States, cultures often change with the geographic region, as various ethnic and cultural groups tend to live in close proximity as they emigrated from other countries. How different cultures respond to health and illness varies, therefore affecting how adolescents and family systems are altered by chronic illness.

A third limitation is that the sample was not large enough to enable all statistical tests to be performed with sufficient power. This increases the possibility of type II
errors. In the population of adolescents with epilepsy differences within the age groups regarding length of time since diagnosis, or seizure duration from diagnosis to study entrance, may actually exist, but are not exhibited by this specific sample. Risk of this type of error decreases as sample size increases, but is a function of the strength of the relationships among variables (Portney & Watkins, 2000). The logistics and financial resources for obtaining large and diverse samples, however, can prove insurmountable.

A fourth limitation was that no control groups of either healthy peers or children who have another chronic illness were available to compare with this sample of youths with epilepsy. Other researchers have previously compared groups of children with both diabetes and asthma, revealing that those with epilepsy have more problems with learning, behavior, lower self-concept and increased rates of depressive symptoms. However, as current events, culture, and children’s environments impact all areas of life, whether control groups from previous studies can truly be compared to this sample is of uncertain value.

Fifth, it is possible that other questionnaires may have been more specific and superior to answer the research questions asked. In particular, the Revised Family APGAR, which is a very quick assessment, is not as thorough as others regarding family function and satisfaction. Other assessment tools, such as the Family Inventory of Recent Events and Changes (FILE), the Family Inventory of Resource Management (FIRM) and the Family Orientated Personal Scales F-COPES by McCubbin and Thompson (1987) would have provided more specific data with regard to family stressors, resources, and communication.
Finally, to continue this study utilizing more than the baseline assessments would have provided important data. The ability to determine if responses were stable over time or whether other trends would be demonstrated as this sample ages would be helpful to compare with past research. In particular, the question of whether or not additional symptoms of depression would appear between 15 and 19 years of age could be examined. Successive assessments of this sample may demonstrate differences in rates of depressive symptoms for those with epilepsy compared to other chronic illnesses, as well as between genders. Other research findings for rates of depression among youth with epilepsy suggest these differences exist.

Suggestions for Future Research

Additional research should be done with this sample in a longitudinal study, as was planned. The relationships and development of these adolescents and their families may provide insight to assist future adolescents with epilepsy. As these individuals encounter more developmental changes, both biological and psychosocial, further valuable data may be gained to allow insight into relationships of variables affecting the developmental outcomes of these adolescents.

Determining whether epilepsy is different from other chronic illnesses due to the involvement of the central nervous system would be valuable information. Diseases involving the central nervous system are pervasive and may affect the brain structure, altering both function and potential. If more can be learned about how the brain is affected and the types of interventions that could alter that course, the fear of the unknown may be diminished for these adolescents. The course of epilepsy is unpredictable; no guarantees can be made as to when and if seizures will occur. Often, it
is impossible to avoid potential subtle triggers that may not be recognized. Contrast this for example, to those who are asthmatic and allergic to cats. Those with cat allergies can either avoid or, more importantly, if unexpectedly exposed, can intervene quickly with medication to diminish the ensuing asthmatic reaction to the trigger. No such rapid intervention is available to those with seizures without becoming incapacitated by the medications that prevent these occurrences.

Further research regarding family and child psychosocial responses to epilepsy would be helpful to assess which seizure types are most problematic for adolescents and their families, and the resources that would best support the family system in these circumstances. Though studies done to date enable practitioners to examine trends (such as increased behavior problems and learning difficulties often seen in children with epilepsy and increased rates of depression in adults) more specific data for those at greater risk of developing psychosocial problems and to provide early intervention that can diminish or eradicate these problems would benefit this population greatly, across the lifespan.

Rates of depression are high in adults with epilepsy, especially females. Further study of adolescents may enlighten health professionals as to when those changes occur and what alters the ability of young people to continue to cope while avoiding development of depressive symptoms. Depression will affect the attainment of developmental outcomes of adolescence. If it can be determined that origination of adult depression begins during adolescence, further study could determine predictive variables and allow for early assessment, prevention and detection.
Summary

Adolescents with epilepsy must complete a number of developmental tasks to successfully pass into adulthood. Adjustments and alterations are required in all areas of life—biological, psychosocial, cognitive, and in redefining social roles. How smoothly this course is traveled depends upon many interpersonal factors such as family, peers, school, and work as well as demographic and intrapersonal factors such as ethnicity, family structure, gender, individualistic responses to change, neighborhood, community, and socioeconomic factors. Ultimately, developmental outcomes will be determined, to a greater or lesser degree, by the success of the individual in attaining adult functional capability in areas of achievement, autonomy, identity, intimacy, sexuality, and psychosocial adjustment.

This secondary analysis demonstrates that this group of younger (9 to 11.44 years) and older early adolescents (11.45 to 14 years) does not differ in self-concept, perceptions of parenting, and self-assessment of symptoms of depression. The variables of age, age at diagnosis, and length of time from diagnosis to study were also incorporated in the analysis and not found significant between these groups. At the time of data collection, age, age at onset, length of time from diagnosis to study, perception of parenting, and gender, had no significant relationship to self-concept and symptoms of depression for this sample. However, all of the groups had a clinically significant number of persons with a CDI score of greater than 12, which implies that follow-up with these individuals, is warranted. The primary healthcare provider can and should provide the initial assessment and intervention for these individuals. In many cases, a therapeutic relationship with the primary care provider may be the only intervention the family and
adolescent require. For those instances requiring further psychological intervention, for example those with a CDI score of > than 16, the appropriate referrals must be facilitated and collaboration of the healthcare team maintained.

Currently, standards are not set within the medical community to assess young people with epilepsy for learning, behavior, and psychosocial difficulties. It is the responsibility of the healthcare provider to be mindful of the increased prevalence of these disorders within this population. As routine office visits occur, both the child and family should be assessed for difficulties at home, school and mood as well as seizure control, medication efficacy, and side effects. Through diligent assessment, a good working rapport, and knowledge of family strengths and community resources, support can be given to these young people and their families to assist in the attainment of the adolescents' developmental goals. For those with mild depressive symptoms, a therapeutic relationship with a healthcare provider may be all that is necessary and for those with serious difficulties beyond the primary healthcare providers' expertise, timely referral to appropriate resources would greatly improve the developmental outcomes of adolescents with epilepsy.
Appendix A

Permission Request

From: PGoldweb@wiley.com <PGoldweb@wiley.com>
To: hofheina@student.gvsu.edu
CC: 
Received: 02/04/03 01:11 pm
Subject: Permission Request
Attachments:
February 4, 2003

Alison Hofheinz
Grand Valley State University
7605 Aspenwood Dr. SE
Ada, MI 49301

Dear Ms. Hofheinz:

RE: Your January 31, 2003 request for permission to republish Figure 25.1 on page 638 from Kendall/HANDBOOK OF RESEARCH METHODS IN CLINICAL PSYCHOLOGY (ISBN: 0471295094). This material will appear in your forthcoming dissertation, to be published by Grand Valley State University in April 2003.

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Senior Permissions Asst.

Paulette Goldweber  
Senior Permissions Assistant  
John Wiley & Sons, Inc.

Phone: 201-748-8765  
Fax: 201-748-6008
January 17, 2001

Cynthia P. Coviak, PhD, RN
Grand Valley State University
352C DeVos Center
Grand Rapids, MI 49504

Dear Cynthia,

It was good to talk with you on the telephone about Allison’s plans for her masters study. I am pleased that she is interested in analyzing some data from our NINR-funded study, “Epilepsy Outcomes in Youth: Neurological and Family Factors.”

Enclosed is a copy of the research plan from the grant application, copies of the psychosocial care needs questions, and copies of three articles on the psychosocial care needs scales that were published in the Journal of Neuroscience Nursing. The data for those articles are from another sample. The data that Allison will be using has not been analyzed to date.

Once you have read the materials and have decided what information you will need, please contact me via e-mail <joausti@ipui.edu> and let me know the exact variables that you will need. I will then have data management extract those variables. I look forward to hearing from you.

Sincerely,

Joan K. Austin, DNS, RN, FAAN
Distinguished Professor

Enclosures

JKA/jc
IUPUI INFORMED CONSENT STATEMENT

for

**Project Title:** Epilepsy Outcomes in Youth: Neurological & Family Factors

You are invited to participate in a research study, entitled Epilepsy Outcomes in Youth: Neurological and Family Factors. The purpose of this study is to describe factors that are related to how well a child deals with a seizure condition. If you agree to participate, you and your child will be one of approximately 160 families who will be participating in this research.

To learn about your experience we would like to interview you in person or over the telephone about your child and your experience with the seizure condition. The interviews should last about 2 hours and will be audio-taped, for the description of the seizure condition and for quality assurance. We will also ask you to sign forms granting us permission to obtain information from your child’s medical records, from your child’s teacher, and from your child’s school records. We also would want to interview your child about him/herself and your family. We would be contacting you and your child two more times (1 year and 2 years later) to repeat these interviews. We would also want to contact your child’s current teacher two more times (1 year and 2 years later) to obtain information on your child at school. We also would want to bring your child to the medical center for individualized testing. Your child’s academic achievement will be tested at each of three data collection times, which should take about 45 minutes. In addition, your child’s mental or thinking ability would also be tested at the first and last data collection times, which should take about 3 hours at the first data collection and about 45 minutes at the last data collection.

We do not expect that completing the interviews or the individualized testing to be uncomfortable for you or your child, but they could be. We believe that the slight risk of discomfort is reasonable compared to the important information you are providing about your experience. If either of you should find the interview to make you uncomfortable, you should tell the interviewer immediately and she/he will talk to you about your discomfort. You or your child also may call either Joan Austin or David Dunn at 317-278-2073 (collect) to talk about your discomfort or any questions either of you may have about the study at any time.

The information in the study records 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. Results of your child’s individualized testing of mental or thinking ability and academic achievement will be made available to you free of charge.

Subject’s Initials

123
Consent:

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

In consideration of all of 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 $50 and my child will be paid $25 for each completed data collection. I will be paid a total of $150 and my child will be paid a total of $75 for the three completed data collections. In addition, each year I will be eligible to win an additional $100 in a lottery held for families who keep all appointments without canceling or rescheduling. A lottery for $100 will be held each time we have 10 families with perfect attendance.

I acknowledge receipt of a copy of this informed consent statement.

PARENT SIGNATURE

PARENT SIGNATURE

WITNESS SIGNATURE

DATE ________________

Child Consent:

I have been able to ask questions about this study and the questions have been answered. I am willing to participate in the interviews and in the individualized testing. I know my answers will be kept secret. If the results of this study are published, I will not be named. I know that the results from the testing will be made available to my parent. I will be paid $25 each time I complete the interview and the testing. I will be paid a total of $75 for the three times.

CHILD SIGNATURE ____________________________________________

DATE ________________
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)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>1. My classmates make fun of me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>2. I am a happy person.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>3. It is hard for me to make friends.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>4. I am often sad.</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>5. I am smart.</td>
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<td>Yes</td>
<td>No</td>
<td>6. I am shy.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>7. I get nervous when the teacher calls on me.</td>
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<td>Yes</td>
<td>No</td>
<td>8. My looks bother me.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>9. When I grow up, I will be an important person.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>10. I get worried when we have tests in school.</td>
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<td>Yes</td>
<td>No</td>
<td>11. I am unpopular.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>12. I am well behaved in school.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>13. It is usually my fault when something goes wrong.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>14. I cause trouble to my family.</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td></td>
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<td></td>
<td></td>
<td>15. I am strong.</td>
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<td></td>
<td>16. I have good ideas.</td>
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<td></td>
<td></td>
<td>17. I am an important member of my family.</td>
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<td></td>
<td></td>
<td>18. I usually want my own way.</td>
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<td>19. I am good at making things with my hands.</td>
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<td>20. I give up easily.</td>
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<td></td>
<td></td>
<td>21. I am good in my school work.</td>
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<td></td>
<td></td>
<td>22. I do many bad things.</td>
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<td></td>
<td></td>
<td>23. I can draw well.</td>
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<td></td>
<td></td>
<td>24. I am good in music.</td>
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<td></td>
<td>25. I behave badly at home.</td>
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<td></td>
<td></td>
<td>26. I am slow in finishing my school work.</td>
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<td></td>
<td></td>
<td>27. I am an important member of my class.</td>
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<td></td>
<td></td>
<td>28. I am nervous.</td>
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<td></td>
<td></td>
<td>29. I have pretty eyes.</td>
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<td></td>
<td></td>
<td>30. I can give a good report in front of the class.</td>
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<td></td>
<td></td>
<td>31. In school, I am a dreamer.</td>
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<td>32. I pick on my brother(s) and sister(s).</td>
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<td></td>
<td></td>
<td>33. My friends like my ideas.</td>
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<td>34. I often get into trouble.</td>
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<td></td>
<td></td>
<td>35. I am obedient at home.</td>
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<tr>
<td></td>
<td></td>
<td>36. I am lucky.</td>
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<tr>
<td></td>
<td></td>
<td>37. I worry a lot.</td>
</tr>
</tbody>
</table>
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  86.  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.
Yes  No  90.  I don't do well at new outdoor games.
Appendix E

Date: / / Interviewer’s Initials: 

Family No:________ Family Member:____C____ Visit: B 12 24

**CHILD DEPRESSION INVENTORY (CDI)**

I will now be reading to you sentences which are listed together in groups. After I read one group of sentences, pick out ONE in the group that best describes your feelings and ideas during the past 2 weeks. I will do the same thing for each of the groups of sentences. Remember - - pick out the sentence that describes your feelings and ideas in the past 2 weeks.

1. _____ I am sad once in awhile.  
   _____ I am sad many times.  
   _____ I am sad all the time.

2. _____ Nothing will ever work out for me.  
   _____ I am not sure if things will work out for me.  
   _____ Things will work out for me O.K.

3. _____ I do most things O.K.  
   _____ I do many things wrong.  
   _____ I do everything wrong.

4. _____ I have fun in many things.  
   _____ I have fun in some things.  
   _____ Nothing is fun at all.

5. _____ I am bad all the time.
I am bad many times.
I am bad once in awhile.

6. I think about bad things happening to me once in awhile.
I worry that bad things will happen to me.
I am sure that terrible things will happen to me.

7. I hate myself.
I do not like myself.
I like myself.

8. All bad things are my fault.
Many bad things are my fault.
Bad things are not usually my fault.

9. I do not think about killing myself.
I think about killing myself, but I would not do it.
I want to kill myself.

10. I feel like crying everyday.
I feel like crying many days.
I feel like crying once in awhile.

11. Things bother me all the time.
12. _____ I like being with other people.
      _____ I do not like being with people many times.
      _____ I do not want to be with people at all.

13. _____ I cannot make up my mind about things.
      _____ It is hard to make up my mind about things.
      _____ I make up my mind about things easily.

14. _____ I look O.K.
      _____ There are some bad things about my looks.
      _____ I look ugly.

15. _____ I have to push myself all the time to do my schoolwork.
      _____ I have to push myself many times to do my schoolwork.
      _____ Doing schoolwork is not a big problem.

16. _____ I have trouble sleeping every night.
      _____ I have trouble sleeping many nights.
      _____ I sleep pretty well.

17. _____ I am tired once in a while.
      _____ I am tired many days.
I am tired all the time.

18. ______ Most days I do not feel like eating.
    ____ Many days I do not feel like eating.
    ____ I eat pretty well.

19. ____ I do not worry about aches and pains.
    ____ I worry about aches and pains many times.
    ____ I worry about aches and pains all the time.

20. ____ I do not feel alone.
    ____ I feel alone many times.
    ____ I feel alone all the time.

21. ____ I never have fun at school.
    ____ I have fun at school only once in awhile.
    ____ I have fun at school many times.

22. ____ I have plenty of friends.
    ____ I have some friends, but I wish I had more.
    ____ I do not have any friends.

23. ____ My schoolwork is all right.
    ____ My schoolwork is not as good as before.
24. I can never be as good as other kids.
   I can be as good as other kids if I want to.
   I am just as good as other kids.

25. Nobody really loves me.
   I am not sure if anybody loves me.
   I am sure that somebody loves me.

26. I usually do what I am told.
   I do not do what I am told many times.
   I never do what I am told.

27. I get along with people.
   I get into fights many times.
   I get into fights all the time.
Appendix F

Date: ___ / ___ / ___  Interviewer’s Initials: ___

Family No: _______  Family Member: ___  Visit: B 12 24

REVISED FAMILY APGAR

These 5 questions are to help us learn about you and your family. "Family" is the people you live with. For each question, choose only ONE answer that best describes how you felt about your family for the past year. Feel free to ask any questions.

Your answers will be based on the following responses:
1 = Never
2 = Hardly Ever
3 = Some of the Time
4 = Almost Always
5 = Always

1. When something is bothering me, I can ask my family for help.

2. I like the way my family talks over things and shares problems with me.

3. I like how my family lets me try new things I want to do.

4. I like what my family does when I feel mad, happy, or loving.

5. I like how my family and I share time together.
May 8, 2003

Alison Z.D. Hofheinz
7605 Aspenwood Dr. SE
Ada, MI 49301

RE: Proposal #03-208-H

Dear Alison:

Your proposed project entitled Adolescents with Epilepsy: The Relationship Between Perceptions of Parenting, Self-Concept, and Self-Assessment Scores of Depression has been reviewed. It is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

Robert Hendersen, Ph.D., Acting Chair
Human Research Review Committee

136
REFERENCES
References


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