1993

A study of subjective symptoms associated with seizure disorders in adolescents

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Order Number 9414206

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The College of William and Mary, 1993

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A STUDY OF SUBJECTIVE SYMPTOMS ASSOCIATED WITH SEIZURE DISORDERS IN ADOLESCENTS

A Dissertation

Presented to

The Faculty of the School of Education

The College of William and Mary in Virginia

In Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

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by

Elaine Fletcher-Janzen

November, 1993

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DEDICATION

I would like to dedicate this dissertation to the children and adolescents with whom I have had the privilege of working with over the years. In particular, I dedicate this work to the children, and their families, who have lived the consequences of Epilepsy.

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ACKNOWLEDGMENTS

There are many people to acknowledge at the end of this project. Wonderful individuals have supported my efforts, and I am grateful to all of them. I would like to thank my committee members Dr. Ries, Dr. Ward, and Dr. Lavach for their guidance and humor. Dr. Lori Korinek's assistance in the syntax, organization, humor, and the kindness departments was invaluable, especially towards the end when my whining must have been insufferable. A special acknowledgment to Dr. Cecil Reynolds, colleague and friend, who believed in me long before I believed in myself. I thank my parents for their continued support, kindness, and babysitting. Lastly, I would like to acknowledge my family, David, Emma, and Leif, who forgave me the hours away, and never complained about the gift they were giving to me.

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A STUDY OF SUBJECTIVE SYMPTOMS ASSOCIATED WITH SEIZURES IN ADOLESCENTS

ABSTRACT

The purpose of this study was to develop a self-report questionnaire that would address subjective symptoms associated with seizures in adolescents. The study was a preliminary investigation as to the reliability and validity of the Seizure Disorder Questionnaire.

Two groups of subjects were studied. The seizure group consisted of 31 adolescents diagnosed with epilepsy and contacted through the Epilepsy Clinic at the Medical college of Virginia, the Comprehensive Epilepsy Clinic at the University of Virginia, Cumberland Hospital for Children and Adolescents in New Kent, Virginia, and the Williamsburg-James City County public schools. The control group consisted of 125 adolescents who did not have seizure disorders and were contacted through the Williamsburg-James City County Schools. It was hypothesized that the seizure group would affirm higher frequencies of symptoms associated with seizures than the control group, and that a significant difference would exist between the groups.

It was concluded that the reliability of the Seizure Disorder Questionnaire was moderate to high. The preliminary estimate of validity was supported by a significant difference between groups on 24 of the original items in the Seizure Disorder Questionnaire. A factor analysis of the 24 items suggested three factors that may represent separate sets of seizure disorder symptoms in the areas of physiology, perception, and memory.

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A STUDY OF THE SUBJECTIVE SYMPTOMS ASSOCIATED WITH SEIZURE DISORDERS IN ADOLESCENTS

CHAPTER 1

INTRODUCTION TO THE PROBLEM

Epilepsy may be defined simply as recurrent seizures that result from "intense and abnormal electrical activity in the brain" (Hynd & Orzbut, 1981). The name originates from the Greek word *epilambanein* which means "to seize upon", and was used by the Greeks to describe the circumstance in which someone was "seized by forces from without" (McIntosh, 1992, p.17). According to McIntosh, (1992) naturalistic descriptions of epilepsy or seizure disorders (the terms are synonymous) date as far back as 400 B.C. when Hippocrates argued that the bizarre manifestations associated with epilepsy were actually the symptoms of brain disorder and not mystical exhibitions. Hippocrates' writing, On the Sacred Disease, is considered to be the most definitive work on epilepsy until the writings of John Hughlings Jackson in the 19th century (Haynes & Bennett, 1992).

The observations and writings of such eminent physicians, however, did not dissuade common and predominant beliefs that epilepsy was a form of demonic possession, or an illness caused by such things as standing in the moonlight or animal spirits in the spinal cord (Spiers, Schomer, Blume, & Hochanadel, 1992). It was not until the mid-twentieth century that epilepsy came under the domain of neurologists rather than psychiatrists. With increased understanding of the origin and neuropathology of epilepsy many researchers since the mid 1950s

have refocused on the cognitive, personality, and psychosocial consequences of recurrent seizures. As a result, school psychologists, psychologists, and neuropsychologists in particular, have played an increasingly important role in the study, assessment, and treatment of the condition (Haynes & Bennett, 1992).

Epilepsy is the most prevalent neurological disorder, affecting 1% to 2% of the population, or 5 to 10 children in every thousand (Hermann & Whitman, 1992). However, some rates are estimated as high as 15 per thousand (Rose, Penry, Markush, Radloff, & Putnam, 1973). The rates for males are slightly higher than for females (Gillham, 1986). In the United States, 300,000 new cases of epilepsy are diagnosed every year, of these cases, 40% are individuals whose first seizure occurred in the first 18 years of life (McLin, 1992). In fact, the peak age of onset of seizure disorders is 4 years (Sugarman, 1989). Seizure types have different relative frequencies. In one series of 6,000 patients, 24% had seizures that could not be classified. Of the remainder, 38% had some type of generalized seizure and 62% some form of partial seizure (Gillham, 1986). In addition, epilepsy is more prevalent than all psychotic disorders combined (Dodrill, 1981).

The scientific understanding of epilepsy and its behavioral manifestations has been greatly enhanced by two major advancements. First, the development of the electroencephalogram (EEG) made possible the objective identification of events within the brain that are associated with seizures. Second, the development of anticonvulsant medications has led to an increasing understanding of and ability to control seizures (Mungas, 1992). These two developments are not, however, definitive tests of and about epilepsy. The EEG is reported to have substantial

problems with false negative readings (Hartlage, 1989), and anticonvulsant medications are reported to control seizures in only 50% of cases (Hauser & Heseldoffer, 1990). Hence, the study of epilepsy continues to provide impetus for scientific inquiry into the diagnosis of the cognitive and behavioral manifestations of the disorder, and the options for assessment and treatment.

In recent years, many school psychologists have incorporated the study of neuropsychological bases of behavior into their basic training (Haak, 1989). The school psychologists use batteries of assessment instruments that have been developed to provide standardized administration and normative comparison of students on a continuum of psychological and cognitive/intellectual constructs. It is here that the school psychologist will document the presenting problems of children and adolescents who are experiencing school difficulties that evidence in a wide variety of cognitive, emotional, social, and academic problems. Although the diagnosis of epilepsy is strictly in the domain of neurologists and medical practitioners, the initial referrals to these professionals are based on observations of problems in psychosocial and school-based functioning and may come from many different sources: The school psychologist may be one of these sources.

Epilepsy is also of interest to school psychologists, not only because it is manifested predominantly in childhood, but because it represents the interrelationship of brain disorders and psychosocial problems. As with most medical conditions affecting the brain, seizures have a wide variety of little known concurrent physical and behavioral manifestations (Dodrill, 1981a). Indeed, for school psychologists, the study of epilepsy in children and adolescents is important not only for

diagnosis and treatment of academic and psychiatric disorders but also has theoretical implications for understanding behavioral disorders in general (Neppe & Tucker, 1988). This assertion is supported by Hynd and Obrzut (1981) who state that: "The school psychologist not only needs to understand this condition and recommend modes of treatment, but he or she can learn a good deal about cerebral dominance, handedness, and hemispheric asymmetry from epileptic children" (p.688).

As with many other chronic disorders, epilepsy may be characterized by a spectrum of severity ranging from very mild to severe, intractable, and incapacitating (Hauser & Hesdorffer, 1990). Numerous studies have indicated that changes in behavior can occur between seizures (interictally) and are not limited to neural abnormalities in the immediate seizure or post-seizure states (Seidenberg & Berent, 1992). In addition, such factors as locus, type, extent, age of onset, and seizure manifestations may each or in combination have implications for how a child's adaptive behavior may be affected (Hartlage & Hartlage, 1989).

Children with epilepsy are more at risk of having educational and social problems than other children (Gillham, 1986). Students who are referred to special education have a wide variety of academic and psychosocial problems. It is essential, that the school psychologist be aware of the nature of many neurological conditions and the presenting symptoms of those conditions. In addition, it is important that seizure disorders are detected early: Dreifuss, Santilli and Tonelson (1983) state:

> If a child with a seizure condition is identified and treated early in life, the child may not develop epilepsy. Epilepsy may form when, through a kindling process, "epileptic pathways"

> are facilitated. When a child's seizure condition is detected early and treated, these pathways may not have a chance to become established, thus, the child may not become epileptic" (p. 12).

The term 'kindling' represents a process through which repeated electrical stimulation of the brain causes seizures to occur (Commission, 1977). Early detection also prevents the cumulative psychosocial effects associated with learning disabilities and possible school failure. Seizure conditions that are identified in early childhood allow professionals to alert the intervention systems, such as school-based special education assistance teams, to meet the programming requirements for students with special needs.

Documentation of the specific and observable behavioral manifestations of seizure activity in children and adolescents is common in the scientific literature. However, many of the behaviors are identical or similar to disorders that do not involve seizure activity (McIntosh, 1992), or are subclinical in nature (Dreifuss, Santilli, & Tonelson, 1983). Subclinical seizures are seizures that do not have observable or overt behavioral symptoms, but can be confirmed by EEG recordings. The issue of differential diagnosis is, therefore, presented to the school psychologist when behavioral manifestations are complex and extensive and the benefits of objective confirmation from instruments such as the EEG are not readily available. Presenting problems may be indicative of several disabling conditions and assistance from objective instruments is needed for differential diagnosis. The problem that this study examines is a natural extension of the latter issue and addresses the development

of an instrument that may assist in screening for the subjective symptoms associated with seizures.

Purpose and Objectives of the Study

The problem that this study addresses is that school psychologists must diagnose cognitive, psychosocial, and academic problems that many times are indicative of not only disabling conditions such as learning disabilities or emotional problems, but seizures as well. Many times, behaviors that are attributed to one condition may well be manifestations of epilepsy. However, because of a lack of objective assessment instruments for epilepsy being available to the school psychologist, symptoms of seizures may go unrecognized or misdiagnosed. The development of a screening instrument that assesses behaviors and symptoms specific to seizure disorders would assist professionals in determining whether further referrals to neurologists are necessary.

The purpose of the present study is to develop and evaluate an instrument, a self-report questionnaire, that can be used to assess behaviors and experiences specific to adolescents with seizures. The general research hypothesis is that children and adolescents with epilepsy experience a variety and yet marked set of subjective behaviors and experiences that are unique to their condition. Questions regarding these behaviors and experiences can be asked of adolescents referred for evaluation to assist assessment. Individuals who experience alterations in cognition and behavior due to a seizure disorder should affirm significantly higher frequencies of symptoms reflected in the questions

than those who do not experience seizures, and therefore the questionnaire may differentiate between the groups of individuals.

Two fundamental research questions arise from a research study that addresses the development of a screening instrument:

1) Is the instrument a reliable measure of symptoms associated with seizures in adolescents?

2). Is the instrument a valid measure of symptoms associated with seizures in adolescents?

Rationale for the Study

Epilepsy may be defined simply as recurrent seizures that result from "intense and abnormal electrical activity in the brain" (Hynd & Orzbut, 1981, p.406). Seizures are paroxysmal or sudden events of cerebral origin that reflect a 'temporary physiologic dysfunction of the brain, characterized by excessive and hypersynchronous discharge of cortical neurons' (Scheuer & Pedley, 1990, p.1468) Although the cause of the abnormal electric discharge within the brain cell is poorly understood, it is likely that it relates to some type of abnormality in the neuronal membranes, and is associated with a disturbance of consciousness (Kolb & Whishaw, 1990). According to Pellock, (1989) epilepsy is not a disease but rather a symptom of disordered brain function.

The initial clinical approach used by a physician for epilepsy diagnosis is "confirmation of electrocerebral discharges as responsible for observable seizure like phenomena" (McIntosh, 1992, p.31). The latter assessment is usually accomplished by a variety of electroencephalograhic (EEG) methods.

The EEG was developed by Hans Berger in 1929 and allows for the demonstration of abnormal brain electrical rhythms. Fluctuations in brain electrical activity are recorded by electrodes attached to the scalp The fluctuations in voltage that appear on the EEG have a fairly rhythmic character and are recorded on paper. The wave-like patterns that are produced will vary with the brain region being recorded as well as with the age and state of alertness of the patient. The major pathologic changes include waves that are too fast, too slow, or too flat, with all of these conditions being either focal or diffuse (Drury, 1989).

The ideal course for diagnosis of epilepsy is that the clinical episodes are classic, the EEG is confirmatory, and the response to medications is positive (Herman & Connell 1992). Unfortunately it is all too common that the clinical episodes are not classic. The EEG is not a definitive test because estimates of normal individuals with abnormal EEGs are approximately 25% (Hartlage & Hartlage, 1989). Furthermore, nearly 25% of individuals with recurrent seizures do not have abnormal EEGs. Indeed, in individuals with probable epilepsy, only 29 to 50 percent have epileptiform abnormalities on the first electroencephalogram: If multiple recordings are obtained, that proportion increases to 59 to 92 percent (Scheuer & Pedley, 1990).

There is also the question of the ability of surface EEG readings to record seizure activity in parts of the brain that are distanced from the scalp. It is not surprising, therefore, to have reports of studies where "half of all the seizures recorded in a large group of patients who were monitored with depth electrodes had no electrical manifestation at the cortical surface inside the skull" (Spiers, Schomer, Blume, & Hochanadel, 1992) Depth electrodes are not used in general clinical practice because

of the invasive nature of the procedure. Therefore, the extensive use of surface readings may lead to a substantial number of false negative EEG readings.

Another diagnostic tool that is used extensively by neurologists and neuropsychologists is the patient interview. The subjective experience of the individual with epilepsy is unusual and can be documented, to some extent, by asking questions about perception, sensation, and thinking. While some individuals have attacks that are easily recognized, at least some persons who have seizures are not aware of the events. However, upon questioning, the individuals will reveal that indeed they do have times when they cannot do what they are normally able to do or that they have experienced periods when they do unusual things and do not know why (Dodrill, 1986).

The psychologist or school psychologist may assist the neurologist in gaining knowledge of the inner experiences of the young client through the patient interview. The primary function of school psychologists is to conduct psychoeducational assessments with students who are evidencing problems in general education programming. A large number of seizure disorders present with behaviors that are similar to conditions common to special education, such as learning disabilities, mental retardation, emotional/behavior disorders, Attention Deficit Hyperactivity Disorder, and other disabling conditions. A screening device that would assist differential diagnosis by a school psychologist would be helpful in the general assessment and referral process.

Definition of Terms

Adolescents with seizure disorders are defined as 13 to 18 year old persons who a) have been diagnosed as having a seizures, but not yet on medication for the condition, b) have ongoing seizure conditions that are being treated with medication, and c) have been diagnosed with seizure disorders that require medical supervision without medication.

Ictal activity is the period of time when the seizure is going on in the brain.

Interictal period is the time period in between seizures.

Subjective symptoms are the symptoms that the individual with epilepsy experiences just before the seizure, during the seizure, or just after the seizure that may or may not be observable to others.

Sample

The study sample was restricted to adolescents and did not include adults because adolescents are within the age group that predominantly exhibits new onset epilepsy (as mentioned above, nearly all seizure conditions begin in the first 18 years of life).

Adolescents between the ages of 13 and 18 were chosen because they are more amenable to self-report inventories than children, not only because of reading level, but because they have the ability to think abstractly, formulate hypotheses, use deductive reasoning, and check solutions (Sattler, 1982). The latter formal cognitive operations were necessary for the student to respond to the questionnaire items in an accurate and thoughtful manner.

Limitations of the Study

The study was primarily designed to investigate the preliminary reliability and validity of the questionnaire. Due to the low incidence of adolescents with epilepsy in the general population, it was estimated that a maximum of 30 subjects could be gathered in a one year time period from the four study sites. The low number of subjects in this group was sufficient to conduct statistical analyses, but restrictive in terms of generalizing the results to a larger population.

Another limitation of the study concerned the comparison group. The subjects in the schools were not drawn randomly and individually from a student roster. This would have been the ideal way of drawing a random sample of subjects. Instead, for practical reasons the control subjects were randomly selected by class at each grade level. Although, only classes that all students were required to take were selected, subtle areas of systematic bias may have been introduced into the sampling. For example, special education classes were not available for sampling, therefore subjects with specific academic deficits were less likely to enter into the sample. The latter group, however, could have been accessed individually as many of the students were mainstreamed as much as possible. Therefore cluster sampling was used in this study, and any conclusions about the control sample representing the total population must be limited.

Summary and Overview of the Remaining Chapters

Epilepsy is a complex neurological condition that historically has been feared and considered indicative of mystic qualities within the individual. Today, the behavioral results of ictal phenomena are often

overlooked or attributed to other situations or pathological conditions. Indeed, the diagnosis of epilepsy is a difficult and complex clinical decision process. Modern science has many tools with which to study and diagnose epilepsy, however these tools are helpful only after a referral has been made. The present study focused on developing a self-report inventory intended to assist school psychologists and other professionals in differential diagnosis of students who are experiencing difficulties in school. The following chapters will address the research studies that have focused on the behavioral concomitants of epilepsy in children and adolescents, the development and administration of the Seizure Disorder Questionnaire, an analysis of the reliability and validity of the Seizure Disorder Questionnaire, and directions for future study.

CHAPTER 2

REVIEW OF RESEARCH AND LITERATURE

Overview of the Study of Psychosocial Aspects of Epilepsy

The study of the behavioral concomitants of epilepsy began with an observational treatise by Hippocrates in 400 B.C. and continued into the nineteenth century until John Hughlings Jackson (1835-1911), a neurologist who is considered to be the "father of English neurology", became the first individual to accurately describe epilepsy as an abnormal local discharge of the nerve tissue (Haymaker & Schiller, 1970 p.12). Jackson used clinical observation in his research, and he noted common personality changes in persons with epilepsy. In fact, he believed that researchers should study the nature of the convulsion, and by doing so one could localize the region of seizure focus and perhaps its cause (Haynes & Bennet 1992).

Twentieth century researchers began modern scientific analyses of epilepsy with the development of the EEG in the 1930s. The EEG allowed researchers to investigate the comparison of brain activity to physical activity. In addition, researchers such as Henri Gastaut collected evidence about personality changes common to patients with specific seizure types and their anatomical basis. For the first time there was strong anatomical evidence for the epileptic personality (Haynes & Bennet, 1992).

In 1948 a paradigm that linked seizure type with increased psychiatric risk was established. The paradigm, called the limbic system hypothesis, was based on the work of Gibbs, Gibbs, and Fuster who examined temporal lobe epilepsy, and has dominated research and thinking in the field for over 40 years (Hermann & Whitman, 1992). The link between temporal lobe epilepsy and the limbic system allowed for the examination of the limbic system's contribution to emotion, behavior, and cognition (Hermann Whitman, 1992), and, perhaps more importantly, yielded information pertaining to the organic precursors of psychopathology.

Until the 1970s, epilepsy research was focused on the establishment of the diagnostic and medical control of the condition. As stated above, it was important for research to establish a direct link between brain activity and psychological states. However, the assessment of the behaviors associated with epilepsy had not been addressed by the behavioral sciences. Hence, studies prior to the work of Dodrill (1974) were confined by medical research standards that included acceptability of low sample group numbers, and anecdotal information rather than objective measures of assessing behavior (Mungas, 1992).

Carl B. Dodrill (1980) was responsible for the development of the Washington Psychosocial Seizure Inventory (WPSI). The WSPI was formulated as a "complete test or inventory having several scales which would permit a comprehensive, systematic, and objective assessment of psychosocial problems associated with epilepsy" (Dodrill, Batzel, Queisser, & Temkin, 1980, p.123). The WPSI was followed a decade later by the Adolescent Psychosocial Seizure Inventory (Dodrill, 1990), a

similar instrument for adolescents 12 to 19 years of age. Both instruments are self-report inventories that are comprised of 132 and 139 items, respectively, that address 8 clinical scales which are comprised of areas such as Family Background, Vocational Adjustment and Adjustment to Seizures.

The WPSI and APSI were developed with subjects who had established seizure disorders. The focus was on the psychosocial aspects of having epilepsy. In addition, the goals of both instruments were "to develop empirical inventories that were brief, easy to administer, and easily completed and scored." (Dodrill, 1990). They were intended to be useful in a number of treatment and research contexts where an objective assessment of an individual with epilepsy was required.

Dodrill also responsible developed the Neurological Battery for Epilepsy, a modified Halstead-Reitan Neuropsychological Test Battery (Dodrill 1978) which remains the only battery in existence specifically developed for and standardized on persons with epilepsy. The purpose of the battery was to address problems specific to the diagnosis and management of epilepsy such as underlying brain dysfunction, epileptiform and nonepileptiform EEG changes, antiepileptic drugs, and effects of seizures themselves. Dodrill completed a formal validation study to insure that each test was sensitive to brain-related deficits in epilepsy, did not overlap excessively with other tests, and was able to show cross-validation in new patient samples (Dodrill & Matthews, 1992). The Neuropsycholocial Battery for Epilepsy requires training in the administration and interpretation of not only neuropsychological tests but also a thorough understanding of EEG theory and test results, surgical intervention, and medical management of epilepsy medications.

Although, many school psychologists have training in neuropsychological assessment, the average school-based psychologist would not have the credentials to administer and interpret the above battery.

Others (Bennett, 1987; Herman & Whitman 1992) have studied the risk factors associated with pyschosocial problems in individuals with epilepsy. A heterogeneous group of variables were conceptually categorized into three main groups by Herman Whitman and Anton (1992): the neurobiological group that includes but is not limited to factors such as age of onset and duration of disorder; the psychosocial group that includes locus of control, fear of seizures; and the medication group that includes such factors as monotherapy versus polytherapy and presence or absence of barbiturate medications. Studies that have used the above conceptualizations of the risk factors for psychopathology in persons with epilepsy include a study of depression in adults with epilepsy (Herman & Whitman, 1986) and social competence in children with epilepsy (Hermann, Whitman, Hughes, Melyn, & Dell, 1988). Both studies demonstrate that it is possible to identify multietiological predictors of psychosocial problems in this population.

In summary, the study of the brain-behavior relationship in epilepsy has historically been confined to the study of psychosocial variables in persons who have established seizure disorders. It has been well documented that individuals with epilepsy have distinct behavioral issues and characteristics that can be assessed by various empirical means. However, distinguishing the etiology of the behavioral problems

is dependent on the examination of the biological, psychosocial, and medical sources of disturbances in cognition, perception, and affect.

Classification and Etiology of Seizures

The International Classification of Epileptic Seizures (International League Against Epilepsy, 1989) identifies the formal diagnostic categories and types of seizures which is outlined in Table 1. Seizures are more frequent in the newborn and young children because of prenatal, perinatal, and postnatal conditions operating on the underdeveloped and vulnerable central nervous system. According to Sugarman (1984 p.41), the most common causes of seizures are:

Cerebral birth injury	43.0%
Congenital defects of the brain	40.0%
Cerebral circulatory defects	6.8%
Postnatal cerebral trauma	4.7%
Infectious diseases of the brain	3.7%
Familial cerebral degenerative diseases	1.3%
Lead poisoning	.9%
Brain tumor	.2%

Some seizure conditions are age specific, for example, absence seizures are rare in children below 2 years of age and most common between 5 and 19 years of age: These seizures tend to disappear with increasing age and are relatively rare in adults (Hartlage & Hartlage, 1989). The behavioral counterparts of absence seizures are less overt than those of generalized tonic-clonic convulsions, for example, and are not readily distinguishable from normal activity (Pinel, 1990): They also are less common than generalized tonic-clonic seizures. In children with

Table 1

Diagnostic Categories and Types of Seizures.

I. Partial Seizures
    A. Simple partial seizures
        1. With motor symptoms
        2. With somatosensory or special sensory symptoms
        3. With automatic symptoms
        4. With psychic symptoms
    B. Complex partial seizures
        1. Beginning as simple partial seizures and progressing to impairment of consciousness
            a. With other features
            b. With features as in I.A.1-4
            c. With automatisms
        2. With impairment of consciousness at onset
            a. With impairment of consciousness only
            b. With features as in I.A.1-4
            c. With automatisms
    C. Partial seizures evolving to secondarily generalized seizures
        1. Simple partial seizures evolving into generalized seizures
        2. Complex partial seizures evolving into generalized seizures
        3. Simple partial seizures evolving to complex partial seizures to generalized seizures
II. Generalized Seizures
    A. Absence seizure
        1. Absence seizures
        2. Atypical absence seizures
    B. Myoclonic seizures
    C. Clonic seizures
    D. Tonic seizures
    E. Tonic-Clonic seizures
    F. Atonic seizures
III. Unclassified Epileptic Seizures

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untreated absence seizures, 50% may have anywhere from a few seizures to a hundred or more in a 24 hour period. The implications for how this specific seizure disorder alters behavior are limitless. Often the undiagnosed condition is mistaken for daydreaming, stubbornness, memory failure, cognitive impairment, or opposition behavior (ILAE, 1990).

Complex partial seizures also involve unconscious behaviors such as chewing, or lip-smacking, walking, hallucinations of taste, smell, hearing, visual vertigo, memory disturbance, feelings of unreality, the presence of an aura and no awareness of the seizure having occurred (Sugarman, 1984). Other forms of seizure disorders that do not involve loss of consciousness, such as simple partial seizures, may have the individual experiencing olfactory hallucinations, gustatory experiences, flashbacks or deja vu. These episodes may also manifest with behavioral arrest for 10 to 30 seconds and may include minor automatisms such as chewing movements (Neppe & Tucker, 1988) Individuals who experience simple partial seizures in the temporolimbic areas of the brain may exhibit the ictal manifestations in the following areas: motor (automatisms staring, rapid eye movements, twitching, slurred speech jargon aphasia, speech arrests, head turning); sensory (headaches, focal pain, discomfort, malaise, clumsiness, numbness, bugs on skin); hallucinatory (visual, auditory, gustatory, olfactory) experiential (flashbacks, deja vu, jamais vu, feeling a presence, feeling possessed, feeling dead, impending doom); autonomic (flushing, apnea, shortness of breath, dizziness, vertigo sinus tachycardia, nausea, abdominal pain, vomiting); emotional/behavioral (embarrassment, sadness, crying, explosive laughter, serenity, irritability, orgasm/exhibitionism,

compulsions/obsessions, self-mutilation, hypomania, confusion); and other unusual symptoms such as forced singing may occur (Spiers, Schomer, Blume, & Hochanadel, 1992).

A unique feature of epilepsy, as compared to other childhood disorders is that most of the time the symptoms are not present. Many times when the symptoms are manifested, they are obscure, nebulous, and difficult to describe to and by the lay person, teacher, school psychologist, neuropsychologist, general practitioner, and even the neurologist. Sometimes seizure episodes may occur without observable signs, but may still disrupt the child's ability to attend, learn, or behave (Danielsen & Pedersen, 1979; Gillham, 1986). The physician has to "distinguish between the occurrence of epileptic seizures and other kinds of brief reversible alterations in consciousness, behavior, or both" (Epilepsy Foundation of America, 1981). These brief alterations in consciousness are easily confused with other conditions such as syncope (loss of consciousness due to anemia), some types of hysteria, hyperventilation, transient ischemic attacks, and breath holding spells in infants, narcolepsy, migraine, toxic effects of drugs, psychogenic fugue states, and impulsive bursts of aggression (Epilepsy Foundation of America, 1981).

For the most part, seizures that manifest with overt and sometimes dramatic alterations in behavior are easily spotted in the school, hospital, and family. However, there have been many cases of dramatic manifestations being misdiagnosed as psychosis, especially in cases of long term cocaine abuse (Merriam, Medalia, & Levine, 1988), delusional states (Drake, 1988), panic states (Reid, Raj, & Sheenan, 1988), aggressive disorders (White, & Screenivason, 1987), sleepwalking and

sleep disorders (Maselli, Rosenberg, & Spire, 1989; Stores & Bergel, 1989) anorexia nervosa, explosive disorders and barbiturate abuse (Bridgers, 1987), speech disorders (Deorina, Chevrie, & Hornung,1987), and obsessive-compulsive disorders (Kettel, & Marks, 1986). Scheuer and Pedley, (1990) list 18 disorders that may mimic epilepsy. They include: sleep disorders, migraine conditions, movement disorders, cardiovascular events, psychological disorders, breath-holding spells and gastroesophageal reflux. School personnel and clinicians may notice learning difficulties, lack of concentration, restlessness, fidgeting, language problems, and a vast array of cognitive deficits (Epilepsy Foundation of America, 1979). Estimates and research concerning emotional, behavioral, and cognitive deficits associated with epilepsy are replete in the history of epilepsy and recent literature: A comprehensive review is documented by Bennett and Krein, 1989. The citations listed above are by no means exhaustive, but indicative of the range of behaviors and conditions that may be presented to a school psychologist.

Psychopathology and Epilepsy

Epilepsy is a common disorder, and the more frequent a disorder, the higher the chance of it coinciding with other frequent disorders (Zeilinski, 1986). Although there is much discussion as to the frequency of various psychiatric disorders in persons with epilepsy, research , at this time, does not indicate that the incidence of psychiatric disorders in individuals with epilepsy is higher than prevalence of these disorders in the general population (Zielinski, 1986). However, the Isle of Wight studies by Rutter, Grahn, and Yule, in the 1970s, classified 6.8% of all

children as having a psychiatric disorder. Children with non-neurological chronic disorders had nearly double the percentage of psychiatric disorders, and children with epilepsy evidenced a much higher percentage of psychiatric disorders (34%). In addition, if the epilepsy was associated with lesions above the brainstem, the percentage rate rose to 58% (Zielinski, 1986). Generalization and replication of these results, of course, are difficult. Not only are the results localized to a specific population that may be very different from the population currently under study, but the years between 1976 and the present day may hold substantial differences in the etiology, diagnosis, and treatment of epilepsy.

There are many instances of episodic psychosis and epilepsy reported in the research literature and attempts have been made to classify the various types of pathogenic conditions. Wolf, Thorbecke, and Even (1986) listed nine classes of episodic psychosis associated with seizure disorders, many resulting from status epilepticus (repetitive seizures with little refractory period in between). Among the classes are: toxic psychosis, which may be caused by an overdose of antiepileptic medication; ictal episodes, that are organic states such as twilight, delirious, and hallucinoses; and "forced normalization", when seizure control results in a kind of clear consciousness episodic psychotic state.

Other common psychiatric disorders that can be associated with epilepsy are depression (Zielinski, 1986); intermittent explosive disorder and panic disorder (Monroe, 1989); rage attacks (Giakas, 1990); drug abuse/addictions (Kramer, 1990); anxiety disorder and chronic insomnia, (Chen, 1990); schizophrenia, (Erkwok, 1990; Diehl, 1990); religious psychopathology, (Daifuji, 1990); anorexia nervosa, (Signer, 1990);

delusional states, (Drake, 1988); speech disorders, (Deorina, 1987); obsessive compulsive disorder, (Kettel, 1986) and personality disorders in general (Welch, 1990). Although there has been much consternation about violent behaviors associated with epilepsy, extensive research indicates little or no correlation (Whitman, King, & Cohen 1986).

The etiological variables associated with epilepsy and psychopathology have been categorized into three main hypotheses: the neuroepilepsy, the psychosocial, and medication hypotheses. Many of the psychiatric disorders and conditions mentioned above may be thought of as stemming directly from seizure activity (Hermann & Whitman, 1986). The individual has abnormal electrical discharge in the brain and the concurrent behavior may be a panic attack, for example. This school of research hopes to localize behaviors with seizure activity in specific parts of the brain to assist in diagnosis and treatment. This approach is a biological explanation of seizure activity and any resulting psychopathology and is probably the area most researched.

Hermann (1986) derives the second hypothesis of psychosocial etiology from the "general observation that epilepsy exposes those who have it to many unique social and interpersonal stresses hypothesized to cause psychopathology" (p.7). The individual with epilepsy has many obstacles to normal everyday living. Mittan (1986) studied a large sample of persons with epilepsy and reported depression to be the most outstanding psychiatric symptom in the sample. Substantial numbers of subjects reported being worried about their health, feared having the next seizure alone, and feared brain damage. Approximately one quarter of the sample found that the psychiatric stress of having

epilepsy was so great that they felt that they were 'losing their minds', were afraid of the anticonvulsant medications causing permanent side effects, were afraid of being left alone, and were currently suicidal due to their seizure disorders. Others (Mungas, 1992; Zielinski, 1986) report an extremely high frequency of depression, suicidal thoughts, and fear of death with the next seizure. It therefore appears that the psychosocial sequelae of epilepsy are serious indeed, and probably highly individualized.

The third etiological hypothesis of psychopathology and seizure disorders is the medication hypothesis. While medications do have a therapeutic effect in seizure frequency, they may have side effects that cause behavior and cognitive problems. At least 17 anticonvulsants are currently marketed in the United States, seven of which are widely used and include Phenobarbital, Phenytoin, Primidone, Ethosuximide, Carbamazepine, Clonazepam and Valproate. The side effects of these medications range from sedation and cognitive impairment to hair loss and vertigo (Bagby, 1991). It should be kept in mind that anticonvulsant medications are fully effective for only 50% of the patient population. Therefore, many individuals will continue to have some seizure activity (Hauser & Hesdorffer, 1990).

Overview of the Study of Subclinical Seizures

Subclinical seizures are those seizures that are not behaviorally observable. The individual has an epileptiform discharge, a registered seizure, but does not have any overt symptoms that can be observed by others. There is no jerking of limbs, shaking, falling to the ground or other classic seizure symptoms. Indeed, in the true sense of the

definition of subclinical, there are no observable changes in consciousness or cognition or minor symptoms such as two-second stop-and-stare spells.

The study of subclinical seizures in terms of the recognition that many behaviors in young children are difficult to assess and that early diagnosis and prevention of epilepsy is paramount, can be generally traced back to a report by the Commission for the Control of Epilepsy and Its Consequences (1977). It was here that the need for the establishment of screening devices for the early detection of epilepsy (especially in children) was formally introduced by the U.S. Department of Education and Welfare. The Commission was convened to conduct a full study of the problems associated with epilepsy and create a nationwide plan for the treatment of epilepsy. The Commission found that: (a) The frequency and severity of seizures and secondary complications often could be minimized with early recognition and prompt treatment, yet no effective mass screening program existed, (b) Only a small percentage of children were subject to routine screening that included questions about epilepsy. When this was done, twenty percent of children with epilepsy were found not be receiving medication for their seizures, and (c) Neither teachers, social workers, nor nurses were sufficiently trained in the recognition of seizures.

The Commission's report included recommendations that called for: (a) The provision of neurological screening for individuals at risk, (b) The refinement of screening questionnaires, (c) The inclusion of questions on epilepsy in mass screening programs, (d) The coordination of early screening programs, (e) The development of epilepsy incidence surveillance, (f) The collection of data on epilepsy, (g) The

development and distribution of materials on identifying children with seizures, and (h) The convening of workshops on screening activities. However, the Commission's report was not formally incorporated into nationwide governmental programs. No standardized measures were developed for screening devices other than the traditional medical course of diagnosis and research. Some researchers continued to use simple yes/no informal questions and others utilized three page detailed forms (Dreifuss, Santilli, & Tonelson, 1982).

In the 1970s and 1980s the development of technology that allowed the videotaping of the subject while the EEG was recording (telemetric EEG and video monitoring) documented subclinical seizure activity. Over 40 studies researched the phenomenon of Transitory Cognitive Impairment (TCI) during subclinical epileptiform EEG discharges (Aarts, Binnie, Smit, & Wilkins, 1984) However, until 1987 the phenomenon was considered more as an "interesting curiosity to be studied in the EEG laboratory, than as a possible source of impaired psycho-social functioning in daily life" (Kasteleijn-Nolst Trenite, Bakker, Binnie, Buerman, & Van Raaij, 1988). Three studies (Binnie, Kasteleijn-Nolst Trenite, Smit, & Wilkings, 1987; Kasteleijn et al., 1987; & Aarts et al., 1984) addressed the direct link between subclinical seizures and concomitant psychosocial sequelae.

Kasteleijn-Nolst Trenite, Bakker, Binnie, Buerman and Raaij (1988) studied the psychological effects of subclinical epileptiform EEG discharges on scholastic skills with children. Twenty children with known subclinical EEG discharges underwent telemetric EEG and video monitoring during their participation in tasks of reading, arithmetic, manual dexterity, and at rest.

The subjects were recruited from two university outpatient clinics in the Netherlands. The criteria for acceptance to the study was that the child had documented discharges of the order of 1 discharge per 5 minutes in the waking eyes- open state. The tests were administered in a standardized order, with the subject responding orally to the reading and math tests (to allow for continuous monitoring). The child's behavior was registered with a video camera and the picture was presented on a split screen where the EEG recording was displayed as well. The monitor was not visible to the subject. The investigator presented the test materials and kept a log noting the times of all significant events and in particular errors, repetitions, hesitations, and signaled these to the EEG technician by means of a push button linked to the marker channel of the EEG machine. The EEG technician continually analyzed the EEG discharges and signaled the investigator to check for overt behaviors. The EEG clinician also determined various measures of the EEG discharge condition: no discharge, pre-discharge, discharge, post-discharge, and short, medium, and long duration. The tapes were then analyzed by two other investigators who did not have knowledge of the test results and the nature, time of onset, and duration of every discharge noted.

The results of the Kasteleijn-Nolst Trenite et al., (1988) study indicate that the correlation between discharge rate during tasks and reading and arithmetic quotients were not significant ($p > 0.05$). However, the discharge rate was found to be lower at rest than during the task domains (Wilcoxon test, $p<0.005$). There were no significant differences between task domains. Reading efficiency was significantly reduced during discharges with respect to the non-discharge ($p<0.03$)

and the post-discharge ($p<0.05$) conditions. Reading efficiency significantly decreased when discharge length increased ($p<0.05$). A Freidman test was utilized to perform a statistical analysis with order as the independent variable, no significant order effects were found ($p>.10$).

The authors' conclusions confirm the hypothesis that reading skills may be impaired when subclinical epileptiform EEG activity occurs. Also of note was the detection of pre-discharge impaired reading performance. The later may be due to the time that the discharge takes from deeper regions of the brain to the recording instrument which is placed on the scalp. The authors deny that the findings draw firm conclusions about the consequences of subclinical activity for the acquisition or exercise of academic skills, but the findings give rise to further studies with larger numbers of children

The major limitation of the Kasteleijn-Nolst Trenite et al. (1988) study is the lack of comparative data on children who do not have seizures, and children who have seizures less than 1 in 5 minutes. Both groups would reveal normative comparison data that would assist in the determination of variance in individual and group performance. For example, perhaps children who do not have seizures have repetitions, hesitations, and errors that may look like pre-discharge conditions on the EEG tape. In addition, those children with less frequent seizures may have significant decreased performance as well. The study does not address the issue of the frequency of discharges compared to academic performance and yet controls for this relationship by arbitrary cut off of 1 seizure per 5 minutes. The question of what frequency of discharge determines cognitive impairment is important and should be addressed by the Kasteleijn-Nolst Trenite et al. (1988) study if not only for

direction for future research. The assertion by the authors that larger numbers of children should be assessed in future studies to rectify the lack of representedness of the sample is supported. The demographic nature of the sample is not described in the study. It is likely that even if the sample was described in the published study the generalizability of the results to the United States would be limited due to cultural and academic differences between the countries involved.

The research directly supports the problem of the present study, namely, that epileptiform discharges occur without overt symptomatology and yet may result in changes in cognition or perception that would eventually come to the attention of a school psychologist due to reading or general academic problems of a the subject. This study also supports the general research hypothesis that subjective symptoms may be measured in terms of frequency and type.

Binnie, Kasteleijn-Nolst Trenite, Smit and Wilkins (1987) studied the interactions of epileptiform EEG discharges and cognition. The research was a replication study that involved 91 subjects with epilepsy who ranged from 8 to 62 years of age, 47 were male and 44 were female. The subjects were selected at a clinic in the Netherlands. A short-term memory test was presented as a television game and included a spatial and verbal version. Each trial was categorized on the basis of whether the response was correct or incorrect and whether or not an epileptiform discharge was present at any time from the two seconds preceding presentation of the stimulus to the completion of the last response. The Fisher's exact probability test was used to assess any positive association between discharges and errors at the .10 level of significance.

The results of the study were limited by the fact that transitory cognitive impairment (TCI) was only assessed if six EEG discharges were captured. The results were available for the spatial task on 86 subjects and on 73 for the verbal task. TCI was demonstrated with one or both of the tasks in half of the patients, and more readily with the spatial (44%) than the verbal task (28%).

This study also is limited by many of the same reservations for the last study. The lack of demographic information makes the assessment of generalizability of results limited. In addition, the range in ages of the subjects in this study may confound the results because of reaction time, length and course of the epileptic symptoms, developmental approaches to problem solving and memory, and other differences that can emerge in subjects who have age differences of up to 54 years. A control sample would have been very helpful in determining the developmental threats to validity in this research. However, in this study as with others of TCI, the objective data associated with video-telemetry and EEG monitoring presents strong evidence of the link between seizure activity and interruptions in cognition.

Another study investigating the psychosocial correlates of subclinical seizure activity was conducted by Siebelink, Bakker, Binnie and Kasteleijn-Nolst Trenite in 1988. This study assessed the effects of subclinical activity on general intelligence. Twenty one Dutch children with epilepsy, 15 with documented subclinical seizures and 6 without, were studied by video telemetry during the administration of an intelligence test, the Revised Amsterdamse Kinder Intelligentie Test (RAKIT, shortened version). The test was normed on the Dutch population and yields a normalized standard score of 15 with an S.D. of

5. The test was comprised of six subtests that measured constructs such as concept production, word meanings, and perceptual reasoning.

A global IQ was calculated for each subject. The difference of the standard score for each subtest from the mean for the entire test series was calculated and expressed as a subtest deviation score. The profiles formed by the six subtest deviation scores were analyzed by the Friedmann 2-way ANOVA method. The mean IQ for the sample group was 87.4 (S.D.=18.2), which was significantly lower than the norm (M=100, S.D.=15) for the test battery (z= -3.84, $p<0.001$). Deviation scores per subtest between the two groups of subjects showed no significant differences ($p<0.10$, Mann-Whitney U Test). However, the group of subjects with discharges showed a significant deviation in scores on the subtest entitled Learning Names which assesses short-term verbal learning ($t(20) = -3.05$, $p<0.01$). In general, the lower test scores for the sample were chiefly due to the performance on the above subtest for both subgroups.

The Seibelink, et al. (1988) study addressed the type of cognitive impairment associated with subclinical seizures. The use of an instrument that is not applicable to subjects in the United States limits the generalizability of these results per se. In addition, the unavailability of the actual test materials of the RAKIT makes an evaluation of the appropriateness of the instrumentation unlikely. The lack of any test evaluations in the appropriate literature (Kramer, & Close-Conoley, 1992; Keyser & Sweetland, 1991; Keyser & Sweetland, 1992; Gilger, & Gilger, 1987) adds to the difficult of interpreting the value of the instrumentation. Information about the RAKIT was gleaned from four studies reported (by abstract only) in an data base in the United

States (PSYCHLIT) (Dekker, Drenth, & Zaal, 1990; Op-Heij, Eling, Renier, & Declerck, 1990; Resing, & Bleichrodt 1989; Resing, Bleichrodt, & Drenth, 1986). In all of the studies the RAKIT is described as a new (1987) test of intelligence. The norm base was 1,211 normal children, 196 children with learning disabilities, and 205 children with mental retardation. The shortened version of the test has six subtests that appear to measure constructs that are similar to American intelligence tests such as long-term verbal learning and recall, visual perception, spatial orientation, motor dexterity and speed, perceptual reasoning, and verbal fluency. The tasks in the subtests, however, are not similar to subtest tasks on tests such as the Wechsler Intelligence Scale for Children-III (1991) or the Kaufman Assessment Battery for Children (1983). For example, a subtest called "Hidden figures" is a task where a complex figure is presented together with six smaller figures, one of which is also concealed in the complex figure and must be identified. Again, deductions that can be made from this information is that the test has a substantial and apparently representative norm sample, and has a variety of subtests that attempt to measure appropriate areas of cognition and information processing. This information is restricted by a lack of information as to the theoretical underpinnings of the test and the methodology used in the reliability and validation of the instrument. In summary, information about the RAKIT and therefore the instrumentation used in the Seibelink et al. (1988) study is limited at best. In addition, the low number of subjects, and lack of demographic information limits interpretation. However, the research design could be easily replicated with assessment instruments and subjects in other areas: perhaps the orientation towards the nature of intelligence is not so important as the

standardized and norm based methods of measurement for this case. Therefore, in general, this study supports the documentation of subclinical seizures in children, and the potential negative effects on cognition.

Perhaps the only study that has directly addressed the recommendations of the Commission for the Control and Prevention of Epilepsy of blending the research about subclinical epileptiform discharges and screening children for epilepsy, was by Dreifuss, Santilli and Tonelson in 1982. The researchers were staff members of the Comprehensive Epilepsy Center at the University of Virginia in Charlottesville, Virginia. The primary purpose of the study was "to develop and to validate an instrument to screen children for undetected seizure conditions." The stated objectives included (a) validating the screening instrument, the Seizure Screening Scale, (b) determining the prevalence of epilepsy in the selected population, (c) determining the frequency of children with undetected seizure disorders in the selected population, and (d) determining if the screening method was beneficial and cost effective.

The Seizure Screening Scale consisted of 34 items addressing behaviors and symptoms associated with seizures, and determined by 'yes' or 'no' responses (see Appendix A for an example of the Seizure Screening Scale). The scale was sent to the parents of all 3rd grade (1003) children in the Albemarle and Charlottesville Virginia public schools, with a 97% response rate. Twenty-seven parents were asked to fill out the scale a second time approximately nine months after the first administration. The 100 children most at risk (determined by number of 'yes' responses) and 30 controls (30 subjects randomly picked from the

remaining group) were asked to participate in a neurological examination with EEG.

The initial validity of the Seizure Screening Scale was determined by examining the face validity with a random sample of 100 parents (before the scale was fully accepted) to determine if the items were easy to understand and made sense to the parents. Their responses were incorporated into the final writing of the 34 items. The content validity was determined by a literature review and by expert analysis of the items by several neurologists. In addition, the content validity was also assessed by the development of a table of specifications for the items on the scale and the removal of irrelevant items.

The reliability for the Seizure Screening Scale was determined by the test-retest method which yielded a mean phi coefficient of .59, and a range of .23 to .86. The Kuder-Richardson 20 technique was used to obtain a measure of the internal consistency of the scale and yielded a coefficient of .78. Fourteen of the questions were deleted after a item/total analysis of the internal consistency reliability data and a review of the percentage of responses by the parents of diagnosed epileptics and those parents of children without seizure disorders. The deleted items were 1, 3, 10, 14, 17, 18, 19, 20, 22, 25, 31, 32, 33, and 34. The estimates for reliability slightly increased for the scale when computed without the 14 items.

The criterion related validity was determined by correlating the results of the Seizure Screening Scale with the final diagnoses as determined by the neurological examination and EEG. It was found that the experimental group was much more likely than the control group to be placed in the at-risk categories. Twenty-three of the 67 experimental

children who received neurologic examinations and EEGs were diagnosed as having epilepsy, placed under continued observation for probable epilepsy, or history suspicious. None of the fifteen control group children examined were placed in any of these at risk groups. Discriminant function analysis was used to assess five epileptic children, all of them could be classified as epileptic. In addition, a random sample of five normal children, all were classified as normal.

The prevalence of epilepsy question was determined by evidence on the EEG and calculated to be 13 children per thousand. The determination of the frequency of children with undetected seizure disorders was calculated by recovering the Seizure Screening Scale protocols of those children who were diagnosed with seizure disorders by the neurologic exam and EEG and who not been previously diagnosed; these children comprised 8.5% of the sample. The cost effective determination was judged to be effective by the acceptance of the reliability and validity information and the fact that the scale required little time in administration and scoring. The authors accepted the reliability and validity of the scale, and suggest a further validation study without the 14 items marked for deletion. The authors also suggest expanding the demographic structure of the sample by age and geographic area.

The limitations of the Dreifuss, Santilli, and Tonelson (1982) study center around the reliability of the scale. The test-retest phi coefficient of .58 was somewhat low. However this would be expected with so few items. Another factor that may have interfered with the reliability of the scale was the nine month period in between administrations of the scale. The researchers were trying to guard against practice effects or

memory, however, it would seem that maturation of the subjects (8 year olds) over a nine-month period would be much more of a threat to consistency of observations by the parents. A period of one month would have been a better and may have guarded against both issues. Another problems with the administration of the scale was that the parents filled out the instrument at home. Therefore the standardization of administration and the reliability of results that come with the procedure were not available. In addition, the variability of the sample was reduced because the 27 test-retest subjects were chosen from the top 100 at risk respondents, the subjects were already close together on the construct being measured (or the criteria for at-risk subjects) and therefore reliability may have been reduced.

The validity of the scale appears to be satisfactory notwithstanding the above reservations about the reliability. The combination of construct and criterion related validity procedures were confirmed by technology that produces evidence of epileptiform discharges. However, the issues of response bias on the part of the parents could be raised in that it is difficult to determine if the construct is a desirable outcome or undesirable outcome. In other words, did some parents respond with more 'yes' responses because they were eager to find a diagnosis for worrisome behaviors on the part of their children, or did some parents respond negatively because they were reluctant to admit symptoms that may be indicative of epilepsy? A more in-depth investigation into face validity may have revealed parental attitudes towards epilepsy and insight into possible response bias.

Other limitations of the study were that demographic variables such as race and socioeconomic level, gender and so on were not described or addressed. The call by the authors for certain areas such as geographic area and age to be expanded into further studies is acceptable, but the disregard of race and ethnic variables is unacceptable. The cultural implications about attitude towards normal child behavior, research, epilepsy, and medical professionals must be taken into account when parents are being asked to observe their children. Another important source of study, the academic performance of the subjects, was also ignored. Teacher observations of the subjects may yield important results especially if compared with parent observations.

The Dreifuss, Santilli and Tonelson (1982) study supports the present study in terms of the ability of a relatively small number of items to discriminate between children with seizures and children who do not have seizures. Many of the items retained in the Dreifuss, Santilli, and Tonelson (1982) and the present study focus on physiological symptoms such as jerking of limbs, trouble with walking, eye blinking etc. A factor analysis was not performed in the Dreifuss, Santilli, and Tonelson (1982) study, therefore it is not possible to compare possible factors that emerge from the item analysis. The most distinct difference between this study and the present study is who was answering the questionnaire items. The observations of parents are necessary for the evaluation of young children because they do not posses the higher level operations needed for self-report inventories. Adolescents, on the other hand, possess the ability to describe their own perceptions, cognitions, and emotions. The latter group, therefore, may

be able to identify more symptoms of seizures or provide more accurate observations about seizures because they may address subclinical sensations as well as observable ictal phenomena. Parents of young children report their observations of the child. The reports are of behaviors, but also are reports of the parents perceptions of what the child is doing or how the child is feeling. Hence, researchers may be measuring parental perceptions more than frequencies of behaviors and including a source of error that confounds the definition of the construct at hand.

Another difference between the Dreifuss, Santilli, and Tonelson (1982) study and the present study is the use of the EEG to document the discriminant function of some of the items. The later feature is a distinct strength in the research design of the study because of the objective nature of the technology (notwithstanding criticisms documented in the research literature about the reliability and validity of EEG recordings). Drawing the subjects from the general population as opposed to working with subjects who have already been diagnosed with epilepsy nearly eliminates research concerns, such as in the present study, about medication effects. In addition, working with new onset subjects allows the observation of symptoms without the subject being influenced with the psychosocial variables associated with having a disorder that carries stigma.

In summary, the research literature regarding the behavioral and psychological concomitants of seizures in children and adolescents has changed slowly from the study of overt classic symptoms to the incorporation of subtle changes in cognition and memory. Attempts to develop screening instruments for prevention and diagnostic purposes

are scare and the field of medicine continues to use nonstandardized methods for evaluation and screening of symptoms related to epilepsy. The field of psychology uses, as a rule, standardized instruments to measure psychological constructs however the instruments have not been developed to assess seizures specifically. It is important, in this study, that subclinical seizures are addressed because they contribute heavily to the construct being measured, and are not well known by professionals or lay persons. Hence this study attempts to incorporate subclinical seizures into the definition of epilepsy through addressing items in the self-report inventory designed to describe internal processes at the time of ictal activity. The need for a seizure screening instrument has been documented by the federal government and the medical community and the development is confounded by fundamental questions as to the definition of seizures and the heterogeneous nature of the population to be studied.

CHAPTER 3

METHODOLOGY

In Chapter 3 the methods and procedures of the study will be presented. For the purpose of presentation, the chapter has been divided into five sections, namely: statement of the research questions; description of the subjects; description of the research instrument, the Seizure Disorder Questionnaire; description of the procedures; and treatment of the data.

Statement of the Research Questions

The following research questions were presented for testing in the study: Is the Seizure Disorder Questionnaire a reliable measure of the subjective symptoms associated with seizure activity? Is the Seizure Disorder Questionnaire a valid measure of subjective symptoms associated with seizure activity?

Description of the Subjects

The subjects selected for the study ranged from 13 to 18 years of age. The subjects were divided into two samples, the control group which was comprised of 125 adolescents who did not have seizure disorders and were contacted through the public schools; and 31 adolescents in the seizure disorder group who were contacted through two epilepsy clinics, a children's hospital, and the public schools. The

group characteristics in terms of age, gender, grade, and race are presented in Table 2.

The age of 13 was chosen for the lowest age level of the sample because of the reading ability necessary for many of the items on the questionnaire. The average 8th grader would read on a 8th grade reading level, however, if the student had mild to moderate reading difficulties, the reading ability may be reduced to 6th, or 5th grade level. If a lower age was chosen, such as 11, then those students with reading problems may need items on a 3rd or 4th grade reading level. The latter level of complexity made the formulation of many items on the questionnaire impossible. Therefore, the lower age of 13 for the study was formulated on the determination of the potential lowest reading level for that group in conjunction with the quality and readability of items.

The upper age of 18 for the study was primarily guided by the upper limit of new onset epilepsies reported in the literature, and the average age of most 12th graders in the high school chosen for the study. A sample that contained 19 year olds would have changed the nature of the sample somewhat because many of the 19 year olds would be out of school and in different settings thereby introducing potentially different characteristics into the sample.

Control Group

The size of the control sample was determined by considering the necessity of having equal groups at the five grade levels to represent a sample of adolescents who do not have epilepsy. Grade and not age levels were chosen because of practical considerations in administering the questionnaire in the public schools. Public school officials believed

Table 2

Comparisons in Percentages of the Control and Seizure Groups on the Variables of Gender, Age, Grade, and Race.

Variables	Control Group	Seizure Group
Gender		
Female	67.2	61.3
Male	32.8	38.7
Age		
13	16.8	9.7
14	21.6	12.9
15	18.4	38.7
16	20	9.7
17	24	12.9
18	5	16.1
Grade		
8	20	58.1
9	20	9.7
10	20	6.5
11	20	12.9
12	20	12.9
Race		
White	74.4	67.7
African American	22.4	32.3
Asian	1.6	0
Latino	1.6	0

that randomly assigning students by age would be cumbersome and interfere with classroom activities. Selection by grade level, would allow for entire classes at different grade levels to participate at one time in the study and, therefore, allow the classroom teacher to plan for one period for the administration. It was estimated that 25 subjects per grade level would result in an appropriate number for the sample (n=125). The size would allow for adequate representation at each grade level, and overall representation of the control group for the study.

The 8th grade subjects for the study were contacted at the three middle schools in the Williamsburg-James City County, Virginia school district. The schedule of all classes was consulted, and the classes were numbered. A number was then randomly picked from the table of random numbers, and the corresponding class was selected for the study. This procedure was followed at all three schools. After the data were collected, 25 cases were randomly picked from the subject pool for inclusion in the study, to achieve equal representation of subjects at each grade level.

The 9th through 12th-grade subjects were contacted at the high school in the Williamsburg-James City County School district. The above sampling technique was not available at this school because of practical considerations associated with size and scheduling of classes. Therefore, the classes of subjects at each grade level were picked by the administrator of the school. Each class that was picked was required for all students and was representative of core subjects such as English and History. A combined information and consent form was sent home with the students and addressed both the student and parents. The form contained a short description of the study, the purpose, and the

voluntary and confidential aspects of participation. The form requested that the student and parents sign where appropriate and return the form to the teacher (see Appendix B for an example of the consent form).

Seizure Group

The size of the seizure group was determined primarily by addressing the minimum number of subjects that would allow for adequate statistical analyses. This avenue was chosen because adolescents with epilepsy are rare in the population, and must primarily be contacted through epilepsy clinics. Clinic staff at the two epilepsy clinics that participated in the study estimated that less than 10 subjects per site could be gathered in a one year period. Hence, it was estimated that 20 to 30 subjects would be gathered in a reasonable amount of time for the study if subjects were also obtained from other sites such as the public schools or hospitals. If, for any reason, more subjects could be contacted, then the seizure group would have been larger. However, data collection ran for over 14 months and 31 subjects were successfully contacted. This number of subjects is not uncommon in research with individuals who have seizures. In fact, this number exceeds the number in many studies cited in the literature similar to that of the present study.

The sample of subjects for the adolescents with seizure disorders (or the seizure group) was limited by size and demographic area because of the low incidence of the population. There are two epilepsy clinics in Virginia, the Medical College of Virginia Epilepsy Program and The University of Virginia Comprehensive Epilepsy Program. The subjects contacted through these programs were outpatients, and very few in number. Other subjects in this group were contacted through the local

public schools and a rehabilitation hospital for children and adolescents. The mixed nature of the agencies involved and the demographic differences of those establishments suggested a varied sample that would be adequate for the initial validation of the questionnaire.

A substantial limitation to the present study was the lack of availability of subjects with new onset epilepsy. The study of the seizure sample must be limited to the study of individuals who have seizure disorders and medication therapy. Any significant difference found between the seizure and control groups may be due, in part, to the side effects of anticonvulsant medications. Although three of the subjects with seizures were not on medication and their response styles on the questionnaire may be reviewed separately, the low number of these subject disallows statistical comparisons of subjects on medication, and subjects who were not on medication. The present study was designed with the intent to use only subjects who were diagnosed with new onset epilepsy. The questionnaire was to be administered immediately following the physician's diagnosis and before therapeutic levels of medications was attained. However, the practical results of locating new onset subjects were disappointing. The most frequent age of onset is four years, hence new diagnoses for adolescents are rare. In addition, the physicians involved were of the opinion that the effects of medications would not affect the results. They believed that the adolescents were well aware of the subjective symptoms associated with ictal activity and therefore the need to discriminate between ongoing and new onset subjects was specious. However, the later assertions are not supported in the literature and may still present a limitation to the present study.

The subjects in the seizure group were contacted through the Epilepsy Clinic at the Medical College of Virginia (2 subjects), the Comprehensive Epilepsy Program at the University of Virginia, Charlottesville (20 subjects), Cumberland Hospital for Children and Adolescents, New Kent, Virginia, (4 subjects) and Toano Middle School and Lafayette High School in the Williamsburg-James City County School District (5 subjects). The variety of institutions that participated in the study allowed for the sample to be representative of the different types of seizures in terms of adaptive functioning. Most of the sample were students in the public schools who were being monitored by the University of Virginia clinic, five subjects were being monitored by private physicians, and four patients had severe seizure disorders that required in-patient residential hospitalization.

Nearly all of the subjects in the seizure group were on anticonvulsant medication(s), and the types of medication varied widely. Three of the subjects were not on medication but were still being medically supervised for a seizure condition. None of the subjects had new onset cases of epilepsy. Table 3 indicates the nature of the seizure group sample by defining the seizure type and medication used for current control of seizures.

The epilepsy clinics at the Medical college of Virginia and the University of Virginia are similar in nature. Both programs are affiliated with state universities, and both clinics are concerned with the outpatient management of individuals with epilepsy. The patients from the clinics represent all levels of socioeconomic status. Many patients do come to the clinics because they are state supported institutions which do provide medical care for free or scaled fees. However, the clinics are

Table 3

Seizure Type and Medication of Seizure Group Subjects.

Seizure Type		Medication	
Unknown	12	Tegretol	12
Partial Complex	11	Dilantin	3
Tonic-clonic	6	Depakote	3
Absence	2	Dilantin, Tegretol	1
		Depakote/Zarontin/Tegretol	1
		Valproate/Depakote	1
		No medications	3

also known for their superiority of services and attract individuals in higher income groups. Race and gender demographics for the clinics are representative of the local communities.

Both the Medical College of Virginia and the University of Virginia were approached with a research proposal for the study. The Internal Review Boards of the institutions reviewed the proposal and gave formal approval. An information sheet, which was similar to the consent form for the public schools, was drafted for the patients at the clinics and described the nature of the research and the voluntary participation of subjects (see Appendix A for an example of the Consent Form).

The selection of patients from the clinics was determined by age and by the nature of the medical condition. Patients that were being monitored for idiopathic epilepsy, but not necessarily having overt

seizures were included in the sample as well as patients who were reporting seizure activity. The only distinguishing factor that would disallow the subject from participating in the study would be documented mental retardation (indicated by psychological test scores in the patient's file). It was determined that mental retardation would disallow the subject being able to read the questionnaire and perhaps understand the purpose of the study. Medical demographic information was collected from each subject patient file. The information documented date of last seizure, seizure type, type of medication being used, last dose of the medication, how long on the medication, and blood level (see Appendix C for example of the Medical Demographics Form).

Cumberland Hospital for Children and Adolescents is an 84 bed inpatient hospital that serves individuals who have traumatic brain injury, chronic illness, epilepsy, and other long-term medical conditions. The hospital was approached for inclusion in the study and the research proposal was approved by the Internal Review Board. The patients selected for the study were individuals who were admitted to the hospital with a primary diagnosis of seizure disorder. Two patients had seizures that were estimated to be resultant of traumatic brain injury (at an early age) and one patient had seizures from the post trauma of a brain tumor. The fourth patient had a history of 'organic personality syndrome'. The subjects selected at Cumberland hospital were included in the study to represent the more acute and serious sequelae of seizures with known etiology. The fact that they were contacted in an inpatient facility testifies to the severity of dysfunction associated with their

seizure conditions, and the variety of causes that might be associated with epilepsy.

The subjects with seizure disorders in the public schools were selected with the assistance of the school nurses. The school nurses identified students who were being monitored for seizures and approached the student and the student's parents and reviewed the information and consent form. If the parents gave consent, the school nurse referred the student's name to the researcher. To maintain confidentiality of the student, no identification or contact took place until the form was signed. Out of seven students that were approached, two declined participation in the study.

Description of the Research Instrumentation

The questionnaire used in the study was entitled the Seizure Disorder Questionnaire. It was comprised of 135 questions that addressed the behavioral concomitants of epilepsy. Each subject was instructed to read the question about a behavior and then determine, from his or her own experience, the frequency of the behavior. The questions were arranged in numerical order on the left side of the page and answer boxes were arranged next to the question in a 5 choice Likert scale. The five choices for answers were: Once a day (or more), Once a week (or more), Once a Month (or more), Once a Year (or more), and Never. The subject was directed to put a question mark in the box after any question they did not understand.

The front page of every questionnaire had directions on how to fill out the questionnaire and spaces for demographic information consisting of the name of the subject, birthdate, grade, race, and date of

administration (see Appendix D for an example of the Seizure Disorder Questionnaire.

The 135 items were developed through a study of the behaviors and subjective accounts of individuals who have epilepsy cited in the research literature. When a behavior was cited in a research study or article about epilepsy, a question would be formed to reflect that behavior or experience. For example, Bagby, (1981) cited patients with epilepsy seeing flashing or twinkling lights, therefore an item was formed "I see flashing or twinkling lights". Some items were added that were worded differently but addressed the same behaviors that may evidence in different ways. For example, "My hands and/or fingers will twitch or shake for no reason" and "My hands or fingers will jerk or twitch for no reason". The generation of new items ceased when the research literature was exhausted for new behaviors and/or experiences.

Other items were generated by referring to other instruments that were self-report inventories in the general area of study such as The Washington Psychosocial Seizure Scale (Dodrill, 1980), the Adolescent Psychosocial Seizure Scale (Dodrill, 1991) and the Behavior Assessment Scale for Children (Reynolds, 1992). These instruments were reviewed to check for style of display of the questionnaire, style of instructions, and the constructs that they addressed.

A face validity item was added to the end of the questionnaire. The item asked the subject to "Now please answer one more question...please circle the number on the scale below that best describes how well you think this questionnaire measures seizure disorders (epilepsy or fits)." The scale simply listed the numbers one through ten

across the page. Under the number one the words "not very well" were placed and under the number ten the words "very well" were placed.

The first draft of the questionnaire was tested for reading level by three different reading level formulas: The Fry method, the Smog method, and the Flesch method (Fuchs, & Fuchs, 1986). It was determined that the instructions and some questions were at an 8th grade reading level. Those items were then modified to bring the overall reading level of the questionnaire to a 6th grade level. The rationale for a 6th grade reading level was that allowances for lower reading ability should be made for the youngest subjects. If the youngest subjects in the study were in the 8th grade, then 6th grade reading materials should address subjects with less than average reading skills. A 6th grade level was also the lowest reading level possible for the inclusion of all of the items. Any attempts to further reduce the reading level substantially reduced the number of items and therefore eliminated many symptoms cited in the research literature.

The Seizure Disorder Questionnaire was shown to individuals with professional and lay expertise in the readability of items and instructions, and the accuracy of content and construct being measured. The lay persons consisted of six adolescents ranging from 13 to 17 years of age. They were asked to complete the questionnaire with the standard instructions and then give feedback to the researcher. These individuals were timed when they were filling out the questionnaire. The average time that was taken to complete the questionnaire was 15 minutes.

The following professionals were approached for their opinions about the questionnaire: 6 neurologists, 3 neuropsychologists, 2 school

psychologists, 1 teacher of the Hearing Impaired and Deaf, 1 Licensed Practical Counselor, 2 Registered Nurse Clinical Research assistants at the Medical College of Virginia, and the President of the Epilepsy Foundation of America (Registered Nurse and Assistant Director of the Comprehensive Epilepsy Program at the University of Virginia). The results of the analyses by the professionals resulted in the rewording of some items, but no deletions or additions.

Description of the Procedures

The procedures for the collection of data were formulated with the goal of maintaining standardization of administration. The more similar the administration of the questionnaire, not only between groups but within groups as well, the more stable the results. Any departure from standard practice would change the meaning of scores.

The procedures for data collection in the epilepsy clinics began with the training of the research assistants who were to assist in the administration of the questionnaire. The three assistants approached the subject with the information and consent form, and the parents and subject were allowed to read the form and make a decision with as little explanation from the clinician as possible. This would allow for as much standardization as possible in terms of the initial explanation of what the study was about. The assistants directed the subject or parents to the researcher if any fundamental questions could not be answered adequately by the assistant, or if the subject or parents appeared worried or unduly apprehensive about participating in the study. The subject, after signing the consent form, filled out the questionnaire in an area of the waiting room or separate waiting room that was as free from

distraction as possible and well lit. The assistant read the instructions aloud with the subject and then asked the subject if he or she had any questions. The subject was left alone to complete the questionnaire if it appeared to the assistant that the subject understood the questionnaire and had no problems filling it out. However, the assistant let the subject know that she would be checking on him or her periodically. If the subjects had any questions that addressed the content of the items on the questionnaire, the assistant was instructed to answer that the subject should "answer what he or she thinks best" or "say what has been happening to him or her in the past year".

The administration of the questionnaire for subjects at Cumberland hospital was conducted by the researcher. The psychometrician who was trained to administer the questionnaire screened the subjects for reading and visual motor abilities and determined that oral administration would be the most appropriate form of administration in the subjects that were presented for the study. The researcher made an appointment with the subject and reiterated the nature of the study from the information and consent form (that had been signed by the parents and subject previously). The subject was then shown the instructions and the researcher read them aloud at the same time. The researcher would then read the sentence aloud and wait for a response. The researcher prompted or reminded the subject of the answer options several times during the administration. A blank copy of the questionnaire remained in front of the subject to serve as a visual cue for answer options as well.

The administration of the questionnaire for the seizure group in the public schools was conducted by the researcher and the

administration guidelines were followed as for those at the other public school research sites. The school library was the location for the administration of the questionnaire, and a quiet area of the library was used for individual administration. The subjects filled out the questionnaire by themselves and the examiner was present in case the subjects had questions.

In summary, the subjects for the seizure group were contacted on an individual basis, and the questionnaire was completed in the same manner. Due to the difficulty of locating the seizure subjects, in that most of the subjects were contacted at six monthly visits and lived a long distance from the clinic, only a single administration of the questionnaire was possible.

The administration procedure for the control group in the public schools was similar to the seizure group. The subjects were collected from the classroom and escorted to the school library where a special area of tables were set aside for the subjects. The instructions were read aloud to the group and the researcher asked if there were any questions. The researcher requested that the subjects begin to fill out the questionnaire. When the group of subjects was finished the questionnaires were collected and students were allowed to go back to their classes.

The second administration was administered two weeks after the first administration. The subjects were contacted in their classroom and escorted to the library. The subjects were asked to fill out the questionnaire a second time. The researcher explained that the questionnaire was exactly the same as the one that they had already filled out, and that there was an important research reason as to why

they were being asked to fill it out a second time. The reason would be explained and discussed when the administration was over. When the class of subjects was finished with the second administration, the researcher asked them if they knew why they had been asked to repeat the administration. In all cases several subjects suggested that the researcher was trying to see if they were giving the same results. This was affirmed, and a short explanation of reliability was given. The subjects were then thanked for their participation and returned to the classroom.

The period of two weeks between administrations was determined by consideration of the advantages of test-retest reliability procedures. A relatively short period of time was necessary so as to make sure that developmental or maturational changes in the subject did not influence a change in scores from one administration to another. In addition, due to the questionnaire monitoring mostly events such as the frequency of headaches or other perceptual problems, test-retest procedures were not likely to be influenced by practice (Anastasi, 1988). Hence, a short period of time between administrations (two weeks) allowed for little medical change in the subject and enough time to disallow any possible effects of memory.

In summary, the administration of the questionnaire was changed according to which group was being addressed. The control group was administered the questionnaire in group form on two occasions. The seizure group was administered the questionnaire individually, and in four cases, orally as well. The implications as to how the difference between individual and group administration influenced the results are not known (Anastasi, 1988). It may be that the individual oral administration may influence the results because the examiner and the

examinee had more personal, or one-on-one contact. Perhaps this made the subject project any feelings or perceptions that they have about the examiner into their style of responding. However, the oral administrations of the questionnaire numbered five, and represent the more extreme cases of severe seizures. The issue of contamination between examiner and seizure severity is difficult to disseminate at best. The responses of the group administration subjects may have been influenced by the lack of individualized contact and it is difficult to project how this may have affected the response style of the examinee.

Treatment of the Data

The data collected from the control and seizure groups were analyzed to estimate the reliability and validity of the Seizure Disorder Questionnaire. The reliability was assessed by determining the Pearson Product Moment correlation coefficient for the first and second administration of the questionnaire with the control group. The two administrations were also compared by a t-test for paired samples. The internal consistency coefficient was calculated using the Cronbach's Alpha formula for the first administration of the questionnaire with the control group, and the single administration of the questionnaire with the seizure group.

The validity of the questionnaire was addressed by several methods. The face validity was calculated with the mean score on the face validity item that was situated at the end of the questionnaire. A t-test for independent samples for the control and seizure group, along with a chi-square analysis between items was used to evaluate any significant differences between groups. After non-significant items were

deleted and an item bias analysis was conducted with a chi-square crosstabulation between frequency and race and gender, reliability tests were repeated. In addition, a discriminant analysis of the remaining items and a factor analysis was conducted.

CHAPTER 4

RESULTS

This chapter of the dissertation will address the presentation of the results. The chapter has been divided into five sections that report the analyses of the reliability and validity of the Seizure Disorder Questionnaire.

Section 1 contains the results of three tests of reliability for the initial 135 items on the questionnaire. Section 2 contains an analysis of the significant differences between the control and seizure groups as a whole, and the significant differences between specific items between groups. Section 3 addresses the reliability of the significant questionnaire items found in Section 2. Section 4 displays the results of a discriminant analysis performed on the significant items between groups and item bias and, Section 5 presents the results of a factor analysis of the items found in Section 4 that discriminate between groups and are not bias in terms of race or gender.

Initial Analyses of Reliability of the Seizure Disorder Questionnaire

The reliability of the questionnaire was estimated, initially, by three methods, test-retest, internal consistency, and a test for significant difference between Administration 1 and Administration 2. The test-retest reliability with the control group was estimated with a Pearson

product moment correlation coefficient and found to be moderate to high (.79). The calculation of the internal consistencies for the control group and the seizure group were estimated with Cronbach's alpha coefficient, and the results were .96 and .97 respectively, indicating high internal consistency for both groups. The calculation of any significant difference in means between Administration 1 and Administration 2 of the control group was estimated with a t-test for paired samples. The results of the test indicated there were no significant differences between the administrations, $t(114) = 1.28$, $p > .203$.

Analysis of Significant Differences Between Groups and Items and Face Validity

The analysis of the difference between the control and seizure groups (for the entire 135 items) was calculated with a t-test for independent samples and was found to be significant ($t(32.36) = -2.55$, $p < .016$) The group mean for the control group was 149.91 (SD 14.38) and the group mean for the seizure group was 162.62 (SD 25.89).

The analysis of the significant difference between items for the control and seizure groups was calculated with the chi-square test. The crosstabulations that were yielded by these calculations indicated that the expected cell level for most of the items exceeded the percentage advisable to make the chi-square a valid test of significance. This was due to the fact that the options for responses were on a five-point Likert scale and the sample size for the seizure group was small ($n=31$), hence some cells did not have enough scores to yield acceptable expectancies. Therefore, the Likert scale was collapsed into two categories, choices of once a year or more and never were combined into one score, and once a

month or more, once a week or more, and once a day or more were collapsed into the other score which represented "once a month or more". In this way, a 2x2 chi-square table could be calculated which also had the benefit of a Fisher's exact test in crosstabulations that still yielded less than desirable cell expectancies. The results of the chi-square analysis of items yielded 55 items that were significantly different between groups at the .05 level (See Appendix D for text of 55 items [marked with asterisks on the example of the Seizure Disorder Questionnaire]).

The face validity of the Seizure Disorder Questionnaire was assessed by the calculation of the mean scores on the face validity item. The mean score for the seizure group was 6.1, and the mean score for the control group was slightly higher at 6.6. The mean score for the combined sample was 6.4.

Analysis of Reliability of Significant Items

The three methods of testing reliability mentioned above were again used to evaluate the reliability of the 55 remaining items. The results of the test-retest Pearson correlation coefficient was .70 which was significant at the .01 level. The Cronbach's alpha measure of internal consistency for the 55 items remained high (.89). The results of a t-test between the control and seizure group remained significant t (31.29) = -4.01, p<.000. The t-test for paired samples was, again, not significant t (118) = -.61, p>.545.

Analysis of Item Discrimination Between Groups and Item Bias

The results of the discriminant analysis of the 55 items yielded canonical discriminant function coefficients of .1 or above in 39 of the

items. One of the items was duplicated, Q25 "I see things that are not real" and Q 104 "I see things that I know are not real". Question 104 was deleted because it had a lower discriminant function coefficient. Hence, 38 items were retained as discriminating between groups.

An item bias analysis was performed at this time by calculating a crosstabulation between race and the remaining 38 items using a chi-square statistic with reference to the Mantel-Haenszel coefficient. The groups of African American, Asian, American Indian and Other were collapsed into two categories because of the lack of subjects in the latter three groups (3 subjects) making cell expectancies too low for reliable statistical estimation. The analysis yielded 14 items that were significantly different at the .05 level between 'White' and 'African-American and other' groups. The 14 items were considered biased in that some cultural element was operating in the discrimination of items and that they should be deleted from the 38 item pool. The deleted items are presented in Table 4. A further evaluation of the item bias in terms of race was completed to evaluate whether there was a significant difference between the two groups for race after the deletion of the 14 biased items. A t-test for independent samples was performed and the results were non-significant $t(55.22) = -1.55$, $p > .128$.

A test-retest Pearson correlation coefficient for the 24 items was calculated and found to be .64. Cronbach's Alpha coefficient of internal consistency for the control group was .95, and a t-test for paired samples was found to be non-significant $t(119) = -1.31$, $p > .193$. In addition, a t-test for independent means was performed with the group variable and found to be non-significant $t(86.47) = -1.15$, $p > .253$. The 24 remaining

items are listed in Table 5 as they appear in text so as to facilitate interpretation.

Table 4

Items Biased for Race

Item #	Item Text
4.	I have fallen to the ground suddenly, for no reason
24.	I do some things over and over again (its like I can't stop doing them)
27.	My body shakes for no reason
30.	My fingers and/or hands will twitch or shake for no reason
33.	My body will suddenly get stiff
50.	I have problems learning new things
58.	I have a hard time remembering what is said to me
70.	I cannot sleep at night
74.	I have trouble figuring out what people have said to me
81.	I think about killing myself
82.	There are times when I go without sleep for long periods of time, for no reason
118.	I have hit people or things, suddenly for no reason
119.	I have gotten really angry and yelled at people, suddenly, for no reason
128.	My behavior gets out of control

Table 5

Items Remaining After Analysis.

Item #	Item Text
11.	I have felt like I was lost, or did not know where I was
14.	I have double vision (see two of everything)
25.	I see things that I know are not real
44.	I walk in my sleep
51.	I have problems when I read
59.	I have trouble speaking
63.	I have fainting spells
64.	I see flashing or twinkling lights for no reason
66.	There are times when I forget what I've just been doing
72.	I feel that there are several different people inside of me
76.	I feel dizzy
79.	I am bored with everything
85.	I have thoughts or ideas that come into my mind (and I cannot get rid of them even if I want to)
92.	My hands or fingers will jerk or twitch for no reason
98.	I am absent from school
100.	I get confused, suddenly, for no reason
105.	There are times when I have to swallow a lot, for no reason
106.	Sometimes I feel like a lot of warm water is rushing over my skin (even though there is not any there)
107.	My hands shake
111.	It is hard for me to pay attention to what someone else is saying
114.	I have a hard time figuring out what people are saying to me
116.	My teachers say that I daydream
123.	I have a hard time remembering what I am supposed to do on my homework
125.	Once I get started on something it is hard for me to change to something else.

Analysis of Factors

A factor analysis was conducted with the remaining 24 items. The analysis used was a principal components analysis with a varimax rotation. The analysis yielded the extraction of eight factors. The factor, eigenvalue, percent of variance and the cumulative percentage of variance for each factor is presented in Table 6.

Table 6

Results of Factor Analysis.

Factor	Eigenvalue	% of Variance	Cumulative %
1	7.13546	29.7	29.7
2	1.85004	7.7	37.4
3	1.63045	6.8	44.2
4	1.36263	5.7	49.9
5	1.30947	5.5	55.4
6	1.21229	5.1	60.5
7	1.09054	4.5	65.0
8	1.01301	4.2	69.2

Items that yielded coefficients larger than .35 were selected from the rotated factor matrix from the factor analysis. The factors and the corresponding item text are presented in Table 7.

Table 7

Item Distribution in Factors

Factor 1

Item #	Item Text
14	I have double vision (see two of everything)
92	My hands or fingers will jerk or twitch for no reason
100	I get confused suddenly for no reason
105	There are times when I have to swallow a lot, for no reason
106	Sometimes I feel like a lot of warm water is rushing over my skin (even though there is not any there)
107	My hands shake

Factor 2

Item #	Item Text
25	I see things that I know are not real
72	I feel that there are several different people inside of me
79	I am bored with everything
85	I have to do somethings over and over to make sure they are perfect
114	I have a hard time figuring out what people are saying to me
125	Once I get started on something it is hard for me to change to something else

Factor 3

Item #	Item Text
51	I have problems when I read
66	There are times when I forget what I've just been doing
100	I get confused, suddenly for no reason
123	I have a hard time remembering what I am supposed to do on my homework

Table 7 (con't)

Factor 4

Item #	Item Text
11	I have felt like I was lost, or did not know where I was
106	Sometimes I feel like a lot of warm water is rushing over my skin (even though there is not any there)
116	My teacher say that I daydream

Factor 5

Item #	Item Text
63	I have fainting spells
76	I feel dizzy

Factor 6

Item #	Item Text
59	I have trouble speaking
72	I feel like there are several different people inside of me

Factor 7

Item #	Item Text
44	I walk in my sleep
59	I have trouble speaking

Factor 8

Item #	Item Text
14	I have double vision (see two of everything)
72	I feel that there are several different people inside of me
98	I am absent from school
106	Sometimes I feel like a lot of warm water is rushing over my skin (even though there is not any there)

An informal survey of seven professionals in the field of psychology, school psychology, and neuropsychology indicated that Factor 1 may represent physiological aspects of seizures or some other neurological condition. Factor 2 may represent the psychological and or perceptual aspects of seizures or some other neurological condition, and Factor 3 may represent deficits in memory related to seizure activity or some other condition.

Summary of Analysis of Research Questions

In summary, the two main research questions for this preliminary study revolved around the ability of the Seizure Disorder Questionnaire to reliably measure a valid construct associated with seizure symptoms. The reliability of the Seizure Disorder Questionnaire was evaluated by using estimates of test-retest, internal consistency, and significant differences between administrations. At all stages of analysis (progressive deletion of items that did not discriminate, or items that were bias), the test-retest correlation and internal consistency were moderate to high. In addition there were no significant differences in the administrations of the questionnaire with the control group.

The validity of the questionnaire was estimated by using an estimate of face validity, significance differences between the control and seizure groups, significant differences between groups on the items, discriminant analysis, evaluation of item bias, and factor analysis. Initially a significant difference between the control and the seizure group was found. In addition, 55 items were found to be significantly different between groups. A discriminant analysis of the 55 items yielded 38 items that discriminated between groups. Of these items, 14

were found to be bias in terms of race and were deleted from the item pool, and one duplicated item was deleted. The remaining 24 items were subjected to a factor analysis which presented eight factors. The first three factors appear to contain consistent item loadings that represent different constructs which adhere to observations in the research literature describing seizure symptomatology.

CHAPTER 5
DISCUSSION

Review of the Purpose and Objectives of the Study

The purpose of this study was to develop a self-report instrument that addressed behaviors and experiences specific to adolescents with seizure disorders and/or epilepsy. The general research hypothesis was that adolescents with epilepsy experience a variety and yet common set of subjective sensations, behaviors and experiences that are distinct from adolescents who do not have epilepsy. The specific research hypothesis was that the common experiences of adolescents with epilepsy could be itemized and formed into a questionnaire that would distinguish the seizure and non-seizure groups in an experimental situation. Specific research questions pertaining to the reliability and validity of the Seizure Disorder Questionnaire were posed.

Review of the Literature

The study of epilepsy is a very complex process. The medical, biological, and psychosocial aspects of seizures are nebulous at best. The population of individuals with epilepsy is heterogeneous because the condition is manifested differently depending on age of onset, etiology, area of the brain that is effected, premorbid psychosocial functioning, adaptive abilities of the individual, and medical diagnosis and treatment.

The literature regarding the study of seizure disorders in children and adolescents documents a myriad of behaviors and sensations that an individual with epilepsy may experience. The study of psychopathology and epilepsy documents the seriousness of the behavioral and psychological ramifications of seizure activity in the brain, not only before diagnosis and therefore as a direct result of ictal or discharge phenomena but also of the psychosocial ramifications of the individual coming to terms with the diagnosis of epilepsy. The study of 'epileptic personalities' has centered mainly around temporal lobe epilepsy. For many years researchers have studied the personality characteristics and behaviors that seem to be associated with this condition. Other researchers have tried to objectify the study of behavior and epilepsy with the development of neuropsychological test batteries, and self-report inventories that address the psychosocial aspects of epilepsy after diagnosis.

The issues that surround the diagnosis of epilepsy in children in the medical arena are primarily about EEG analysis and the documentation of ictal phenomena. When presented with the unusual behaviors exhibited by a patient, the medical professional must make deductions as to their origin. Many times, the organic nature of the behaviors such as automatisms or observable lapses of consciousness are evident, and even without EEG confirmation, the physician can begin treatment. However, a recent avenue of research regarding subclinical seizures or seizures that do not evidence in observable behaviors, has documented the existence of Transitory Cognitive Impairment. This later phenomena has established the fact that even in individuals who are being controlled for seizure activity, seizures may still occur and

interrupt normal cognitive functioning. This line of research has initiated a new trend where the definition of seizure activity is being reviewed. Up until the 1980s seizures were defined in part by the overt behavior that accompanied the discharge. This can no longer be the case. Subclinical discharges interrupt the functioning of the individual as much as the clinically observed behaviors and must be addressed and documented.

The difficulty of determining a diagnosis of epilepsy is well documented. The unreliability of the EEG allows for much more clinical judgment to enter into the decisions made along the way to a diagnosis of epilepsy. However, the contribution to this diagnosis from psychology is of judgments made about the individual's behavior based on instruments (psychological tests) that are not developed to assess seizures specifically. Given the heterogeneous nature of the condition and the lack of objective instruments to diagnose epilepsy, it is not difficult to understand the frequent documentation of misdiagnoses by professionals at many levels.

As school psychologists work with children and adolescents and assist in the diagnosis of behavioral and neurological disorders, instruments that support objective analyses of behavior are essential. Indeed, the fact that research is beginning to emerge that indicates that many forms of epilepsy can be prevented by early detection and treatment, suggests school psychologists are necessary contributors to the prevention and diagnosis of epilepsy and in need of instruments that attempt to address seizure disorders.

Review of the Instrument and Procedures

The Seizure Disorder Questionnaire contained 135 items that were developed from documented observations and reports of behaviors associated with seizures in the research literature on epilepsy. The questionnaire contained demographic information and instructions to the subject on the front page, the 135 items, and a scale to assess face validity. Professionals and experts in the appropriate fields of study were consulted to assist with the content validity of the items.

The subjects used in this study were from 13 to 18 years of age and divided into two groups, the control and seizure groups. The control group was comprised of 125 adolescents who did not have seizure disorders. The group was divided into sections of 25 students at 5 grade levels, 8 through 12. The control group completed the questionnaire in the public schools in a group format. The questionnaire was administered two weeks later to the same students in a standardized manner.

The seizure group was comprised of 31 adolescents who had documented seizure disorders. The subject were contacted at the Comprehensive Epilepsy Center at the University of Virginia, Charlottesville, Virginia; the Epilepsy Clinic at the Medical College of Virginia, Richmond, Virginia; Cumberland Hospital for Children and Adolescents, New Kent, Virginia; and the Williamsburg-James City County Public Schools, Virginia. The questionnaire was administered by clinic staff and the researcher on an individual basis. In 4 cases the researcher orally administered the questionnaire to subjects who had difficulty reading.

Review of the Results

Two research questions were posed as to the reliability and the validity of the Seizure Disorder Questionnaire. The results of the analysis of the questionnaire indicate that the reliability of the instrument was confirmed with a test-retest Pearson Product Moment correlation coefficient (r) of .79 which indicates a moderate correlation between Administration 1 and Administration 2 of the questionnaire. The test-retest estimate was supported by the results of a t-test for paired values between Administration 1 and Administration 2 of the questionnaire which was not significant $t(118) = -.61$, $p > .545$. The reliability of the instrument is also supported with a high Cronbach's Alpha coefficient of internal consistency of .89.

The preliminary tests for validity of the Seizure Disorder Questionnaire included the calculation of the overall mean response on the face validity scale of 6.40 (range from 1, "the questionnaire did not measure seizures very well", to 10 "the questionnaire measured seizures very well") indicating a general belief by the subjects participating in the study that the questionnaire was adequately measuring what it was purporting to measure.

A t-test for independent samples was conducted and a significant difference between the control and seizure groups was found $t(31.29) = -4.01$, $p < .000$. Crosstabulations using a chi-square test for significance between the control and seizure groups for individual items yielded 55 items that were significant between groups. A discriminant analysis was conducted on the 55 items, and 39 items were found to discriminate between the control and seizure groups. A crosstabulation between race and gender and the remaining items indicated that 14 items were biased

for race. The later items were deleted from the item pool. After the removal of one duplicated item, 24 items remained that were reliable, discriminated between groups, and were not biased as to race or gender. A factor analysis was performed on the 24 items and 8 factors were extracted that accounted for approximately 70% of the variance. Three factors were retained as representing constructs related to seizures, Factor 1, which accounted for 29.7 percent of the variance, Factor 2 which accounted for 7.7 of the variance, and Factor 3 which accounted for 6.8% of the variance. Due to inconsistent item loadings, or the small number of items for a single factor, Factors 4 through 8 were not named.

Discussion

The analysis of the data collected relative to the principle objectives of the study indicated that there are significant differences in symptoms between adolescents with seizure disorders and adolescents without seizure disorders as measured on the Seizure Disorder Questionnaire. This assertion can be made on the basis of the establishment of the instrument's reliability and the discriminatory ability of 24 items. In addition, the extrapolation of three main factors that are associated with seizure disorders in the research literature support the validity of the instrument. The item text associated with the three factors are listed in Table 8.

There are no objective means by which the above three factors can be named as constructs that measure psychophysiological traits or conditions. A small qualitative analysis using professionals in the field to peruse the factors and name underlying constructs allowed some basis for conjecture. Indeed, individuals who are clinically involved with

Table 8

Three Factors Associated with the Remaining 24 Items

Item #	Question
Factor 1	
14	I have double vision (see two of everything)
92	My hands or fingers will jerk or twitch for no reason
100	I get confused suddenly for no reason
105	There are times when I have to swallow a lot, for no reason
106	Sometimes I feel like a lot of warm water is rushing over my skin (even though there is not any there)
107	My hands shake
Factor 2	
25	I see things that I know are not real
72	I feel that there are several different people inside of me
79	I am bored with everything
85	I have to do something's over and over to make sure they are perfect
114	I have a hard time figuring out what people are saying to me
125	Once I get started on something it is hard for me to change to something else
Factor 3	
51	I have problems when I read
66	There are times when I forget what I've just been doing
100	I get confused, suddenly for no reason
123	I have a hard time remembering what I am supposed to do on my homework

persons who exhibit psychophysiological conditions accumulate internal norms or clinical acumen based on long term observations of individuals and the diseases or neuropsychological disorders that effect everyday living. The relative cohesiveness of the clusters of items in the three factors make professional judgments about the underlying constructs appear valid.

The research literature on seizure disorders and physiological manifestations of ictal phenomena such as represented by Factor 1 is replete with reports of double vision, fingers or hands twitching or jerking, hands shaking, and sudden states of mental confusion. The conditions of the sensation of warm water on the skin and repetitive swallowing are less known or reported, however, they are not unusual. In addition, as has been stated previously, up until the 1980s research about epilepsy was almost exclusively driven by the physical and overt manifestations of the condition.

Factor 2 appears to represent the psychosocial and perceptual/psychological aspects of epilepsy. Visual hallucinations, forced thoughts, obsessive attention to detail, and the potential for serious psychological pathology such as multiple personalities, are also well researched areas of study in epilepsy. These symptoms or perceptions are also subjective and subclinical. We cannot observe an individual feeling that they have several different people inside of them, we cannot observe the individual seeing something that is not real (unless he or she documents the image as he or she is hallucinating i.e., directing others to observe the same phenomena). Indeed, if we were to observe perceptions indicated in Factor 2 only, a diagnosis of psychopathology would be made rather than assumptions about seizure

discharges within the brain. However, if a school psychologist is confronted with psychophysiological manifestations as in Factor 1 at the same time as the characterlogical aspects of Factor 2, the diagnosis may be quite different.

The underlying theme for Factor 3 appears to be that of memory. The questions seem to relate to lapses in recent memory ('There are times when I forget what I have just been doing', 'I have a hard time remembering what I am supposed to do on my homework', 'I get confused suddenly for no reason') and may be related to absence seizures, or perhaps even seizures in general.

The International League Against Epilepsy classification of seizures (see Table 1 for review) tends to group seizure symptoms in four categories: (a) motor, (b) somatosensory or special sensory, (c) automatic, and (d) psychic symptoms. The motor, somatosensory, and automatic symptoms appear to coincide with Factor 1 items in terms of the physiological actions, body movements, and visual/perceptual items selected by subjects with seizures. The somatosensory and psychic symptoms appear to coincide with Factor 2 in terms of hallucinations (a basic altering of perception), and the subject admitting to having difficulty in changing activities, boredom, and feeling as if several different people are inside of the subject. Factor 3 may coincide probably only with psychic symptoms. Interruptions in memory that result in symptoms such as sudden confusion, problems in reading, and remembering daily tasks are psychogenic and evidence in psychological ways.

It may be assumed that the Seizure Disorder Questionnaire measures a significant difference in 24 subjective symptoms between

adolescents who have seizures and adolescents who do not have seizures. As to whether the subjective symptoms are directly related to seizure activity and are not symptoms that are associated with other types of neurological or psychological disorder is a limitation of the present study that will be discussed in the next section. However, if indeed, the questionnaire does not assess other disorders, and that individuals with different disorders would subscribe to significantly different items, then we would be able to make the assertion that the Seizure Disorder Questionnaire allows us to measure three aspects of symptoms associated with seizure activity: physiological symptoms, psychological symptoms and memory. In addition, that the three areas should be included in any diagnosis regarding epilepsy. In more concrete terms, if a school psychologist administers the questionnaire and the subject scores significantly in all or any of the areas suggested by the three Factors, further investigation of the subject's neuropsychological status should be conducted.

The present study is a preliminary study that addresses the integrity of the questionnaire to measure subjective symptoms in a reliable and valid way. The development of a scale that would indeed measure behaviors that are associated with seizures could only begin with a pilot study to assess the feasibility of its construction: The present study appears to have satisfied the requirement of a preliminary assessment of the Seizure Disorder Questionnaire.

In terms of prior studies that have addressed the same constructs, Dreifuss, Santilli and Tonelson (1983) constructed a 34 items questionnaire for the parents of third grade children. The study yielded a Seizure Screening Scale (SSS) that was reliable and valid and contained

23 items. Several of the items on the scale are similar to the items that remain on the Seizure Disorder Questionnaire (SDQ) notwithstanding the fact that one scale uses the observation reports of parents of the subjects and the present study uses self-reports. The items that are similar tend to center around sleep problems, jerking of limbs, trouble with reading, difficulty paying attention to others or following directions, and daydreaming. The differences between the two questionnaires, of course, are distinct and should be kept in mind when reviewing the similarities between studies. Namely, the studies used subjects that were a minimum five years apart in age with significant developmental differences, the persons completing the questionnaires were from different perspectives (parent versus self-report of adolescent), and the circumstances of administration were different in that the SSS was sent to the subjects and the SDQ was filled out with trained examiners. The preliminary success of both the SSS and the SDQ validate that the notion that questionnaires that address seizure symptoms, both clinical and subclinical, can yield reliable and valid assessment results.

Discussion of the Limitations of the Study

There were a number of problems and limitations that were encountered in the process of implementing this research study which should be considered when interpreting these data. The question of the whether the side effects of anticonvulsants confounded the responses from the seizure group is significant indeed. However, the possibility of locating enough subjects who are between the ages of 13 and 18 who have new onset epilepsies and are not yet on medication is highly unlikely. In the present study, only three subjects were not on

medication, and it took approximately a 16 month period of data collection to contact the three subjects. In addition, the three subjects who were not on medication were different than new onset subjects in that they had been medically managed with medications and were not currently taking medications. This group may have different types of seizure disorders, and may have different medical issues than subjects who have just been diagnosed and never had anticonvulsant medical therapy. In future studies, any subjects who are not on medication or are newly diagnosed should be examined to assist with the extrapolation of seizure versus medication symptoms. Perhaps the expansion of the collection of data to many more sites would enhance the possibility of collecting enough subjects who are not on medication in a reasonable time frame.

Another limitation of the study was the demographic make-up of both groups of subjects. While the White and African American ratio were satisfactory in terms of a preliminary study in Virginia, no information is available to assist in the examination of other items that may favor other cultures. Therefore, the generalizability of the present study is limited. The expansion of further study to other geographical areas that would incorporate groups such as Latino, American Indian, and Asian subjects in both samples would allow for a more detailed analysis of the effects of race on the response style and validity of items.

The number of subjects in the seizure group was limited and due to the heterogeneous nature of seizure disorders it would be better if the seizure group number was much larger. Some types of seizure disorders exhibit more severe motor and physical manifestations than others. Other types exhibit more consciousness and memory deficits. Therefore

a large sample of seizure subjects would assist in delineating underlying factors and reducing the risk of finding significant differences due to the small sample size.

In addition, the small numbers disallowed tabulation of the frequency of symptoms for the different groups. Therefore, the frequency columns had to be collapsed and reduced to either the subject having the symptoms once a year or never, and once a month or more. The surface implications of this dichotomy appears to be either the subject has the symptom or they do not. It would be interesting to assess whether a larger number of subjects would demand a collapsing of columns. A larger number would allow for the investigation of the question as to if there is a true dichotomy of having the symptom or not or whether the dichotomy is purely a function of low numbers of subjects in this study. Again, future study would have to incorporate many more research sites that would allow for increased number of seizure subjects in a reasonable time frame. It may also be possible that with a larger sample of subjects with seizures, analyses of symptoms between seizure types would yield important information.

Another limitation of this study is the lack of construct validity. The 24 items are reliable and valid in terms of discriminant function and item bias. However, the symptoms that are being reported for the seizure group may well be symptoms that are associated with a variety of other neurological and medical conditions such as, but not limited to: Traumatic Brain Injury, Tourette's Syndrome, Diabetes, and Attention Deficit Hyperactivity Disorder. Therefore, the analysis of the construct validity of the questionnaire is not complete. Until the construct

validity is satisfied the generalizability of the results of the study are severely limited.

Due to the present study being a pilot or preliminary investigation of the reliability and validity of a self-report screening questionnaire for seizure disorders, the practical limitations exceed the practical implications at this time. The end result of this study is that the 24 remaining items indicate the basis for further studies either using the same items or expanding the items to represent larger areas of construct for the factors. The natural extension of the present study is to conduct further trials and analyses of the Seizure Disorder Questionnaire.

Suggestions for Future Research

Several avenues for further study were brought to light by the results of the present study. One avenue of study may be to take the remaining 24 items and replicate the present study using subjects from wider geographic region(s) and a larger sample of subjects with seizures from a larger selection of clinics, hospitals, and schools. The study would replicate an analysis of gender and racial bias with the items, and include subjects that are new onset as well as ongoing cases of seizure disorders. This avenue of study would satisfy the limitations of the present study.

Another avenue of future study would be to replicate the administration of the 24 items and also administer several other established tests that may represent the three factors identified in the present study (perhaps a test of memory, psychological functioning, and psychomotor skills). The later tests would be valid and reliable

instruments that would provide criterion-related validity information to the study, and allow for a more in-depth analysis of the factors involved.

The present study is limited by construct validity, therefore, other groups of subjects that have different neuropsychological and physiological conditions must be contacted for further study. The groups that would be most likely be associated with symptoms that are similar to seizure manifestations are adolescents with severe learning disabilities, emotional disturbance, Attention Deficit Hyperactivity Disorder, Traumatic Brain Injury, and Diabetes. In addition, due to the population of seizure disorders being heterogeneous (Commission, 1977) further study may delineate subjects with seizures by seizure type, and investigate the differences between seizure type and response profile on the questionnaire. In addition, confirmation of ictal activity with EEG and possibly an evaluation of Transitory Cognitive Impairment may assist in identifying subgroups of individuals in the seizure group.

The focus of a preliminary validation study for an instrument is to answer fundamental questions as to whether the theoretical understanding of a disorder can be translated into a practical and objective measure of the disorder. Fundamental questions must be investigated such as, in the instance of this study, will adolescents be able to understand questions/statements about thoughts, perceptions, actions, and experiences that are outside the mainstream of normal experience?, will adolescents take the questionnaire seriously?, will adolescents answer statements about frequency of symptoms in a consistent and stable manner?, is it possible to contact patients with epilepsy who wish to participate in activities that require intimate

information? Do state authorities and medical researchers value research that focus' on the behavioral counterparts of seizure disorders? For the most part, the answers to the above general questions have be answered affirmatively by this preliminary investigation. The adolescent subjects in the control and seizure groups were very cooperative and they answered the questionnaire items in such a manner that indicates that they did take the matter seriously, and that they could measure the frequency of their behaviors in a consistent manner. The medical community that was contacted for this study was very receptive and helpful. The study of epilepsy in the medical community has been a long and difficult course and the reception for another discipline to enter the investigation of seizure disorders, in this case, has been gracious. The fundamental questions for the Seizure Disorder Questionnaire have been answered. The reliability of the instrument is acceptable, and the preliminary estimates of validity give rise for future study that will clarify the nature of subjective symptoms that are associated with epilepsy.

Appendix A

Example of the Seizure Screening Scale.

THERE ARE MANY REASONS FOR CHILDREN TO HAVE SEIZURES, FITS, OR CONVULSIONS, SOME OF THESE REASONS ARE: TOO LITTLE CALCIUM IN THE BODY, NOT ENOUGH SUGAR IN THE BODY, OR BRAIN CELLS THAT ARE TOO ACTIVE. YOUR ANSWERS TO THE QUESTIONS ON THIS FORM WILL HELP US TO DETERMINE IF YOU CHILD MAY HAVE ONE OF THESE PROBLEMS. HOWEVER, MANY CHILDREN WILL DO OR EXPERIENCE THINGS WHICH WILL ALLOW YOU TO ANSWER "YES" TO SOME OF THE QUESTIONS. "YES" ANSWERS DO NOT MEAN THAT YOUR CHILD HAS A PROBLEM.

PLEASE ANSWER ALL OF THE QUESTIONS TO THE BEST OF YOUR ABILITY.

PLEASE CHECK ONE ANSWER FOR EACH OF THE QUESTIONS.

1. Has your child ever fainted, blacked out, passed out, or had a falling out spell?
2. Has your child ever had strange or unusual movements of his (her) arms or legs?
3. Does your child sometimes utter while talking or say words that sound garbled?
4. Does your child sometimes have trouble hearing?
5. Does your child sometimes have a hard time following directions?
6. Is your child sometimes clumsy or uncoordinated?
7. Has your child ever had trouble walking (frequent imbalance, falling like a tree, melting like jello?
8. Has your child ever had spasms or jerking of his(her) arms or legs?
9. Has your child ever had fever spasms or convulsions and a high fever at the same time?
10. Has your child ever had encephalitis, meningitis, or any sickness of the brain?
11. Has your child ever had short (a second to a minute or two) spells of acting strange or doing unusual things?
12. Does your child sometimes rolls his (her) eyes in an unusual way?

13. Does your child blink his (her) eyes more than you think he (she) should?
14. Does your child have any other unusual eye movement?
15. Does your child stare into space more than you think he (she) should?
16. Does your child often daydream or seem to be in a daze?

To the best of your knowledge, how many times in the past six months has your child: (please check one answer per question)

17. Wet the bed?
18. Had nightmares or night terrors?
19. Sleepwalked?
20. Talked or cried out in her (her) sleep?
21. Is your child often restless while sleeping?
22. When your child wakes up in the morning or after a nap, have your notice blood or vomit on his (her) pillow?
23. Does your child sometimes complain of a sore tongue and/or sore muscles when he (she) wakes up in the morning or after a nap?
24. Does your child sometimes skip or repeat lines or words while reading aloud?
25. Does your child stare or become dazed when he sees a flickering light (for example, a candle, the TV when there is a vertical or horizontal jumping, or a tree-lined road on a sunny day?
26. How well does your child read? Below grade level__ At grade level__ Above Grade level ___
27. Has your child ever had a convulsion seizure, or fit?
28. Has your child ever visited a doctor or clinic for fits or seizure?
29. At the present time, does this child take medicine for seizure or fits?
30. Has your child ever had an electroencephalogram (brain wave test, EEG).
31. Does your child sometimes seem to be in a daze or trance for awhile after getting up in the morning or after a nap?
32. Does your child have episodes of unusual or unexplainable behavior which he (she) cannot remember?
33. Has anyone in your family had seizures, fits, or convulsions?
34. Has your doctor ever thought that you child had low blood sugar or calcium?.

Appendix B

Example of the Subject and Parent Consent Form

SUBJECT AND PARENT CONSENT FORM

A STUDY OF THE SUBJECTIVE SYMPTOMS ASSOCIATED WITH SEIZURE DISORDERS IN ADOLESCENTS

A DOCTORAL DISSERTATION STUDY BY ELAINE FLETCHER-JANZEN

Dear Patient and Parents:

As a part of a doctoral dissertation study, Elaine Fletcher-Janzen, and research staff at Cumberland Hospital are trying to find out about teenagers with seizure disorders (or Epilepsy). Sometimes teenagers may experience seizures with specific thoughts, movements, or emotions. We would like to ask all kinds of teenagers between the ages of 13 and 18 if they ever experience things that sound like seizures.

We have therefore come up with a questionnaire that will ask straightforward questions about things like headaches, ringing in the ears, and other medical and psychological conditions. The questionnaire takes about one hour to fill out.

All of the results will be confidential and will become a part of the patient file. Our asking you (or your child)to fill out this questionnaire does not mean that we think you (or your child)may have Epilepsy, we are asking many different kinds of people about many different kinds of symptoms.

Hopefully, we will be able to gain some important information and help teenagers who have Epilepsy. If you have some questions that you would like answered before you give your consent, please feel free to call Elaine Fletcher-Janzen at (804) 229-6378. Thank you for your participation.

I agree to participate in the above study by filling out the Seizure Disorder Questionnaire. I understand that my participation is voluntary and that I may terminate my participation at any time.

Patient Signature_____Date_____

Parent or Guardian Signature_____

Witnessed by _____Date_____

Appendix C

Example of Medical Demographics Form

SEIZURE DISORDER QUESTIONNAIRE
MEDICAL DEMOGRAPHICS FORM

NAME OF PATIENT_____TEST #DT_____

MEDICAL DIAGNOSIS:_____
_____
_____

IF SEIZURE DISORDER, TYPE: _____
_____
_____

DATE OF LAST SEIZURE: _____

MEDICATIONS

ANTICONVULSANTS:

1.	2.
NAME:_____	NAME:_____
LAST DOSE:_____	LAST DOSE:_____
HOW LONG ON MED:_____	HOW LONG ON MED:_____
BLOOD LEVEL:_____	BLOOD LEVEL:_____

OTHER MEDICATIONS:

1.	2.
NAME:_____	NAME:_____
LAST DOSE:_____	LAST DOSE:_____
HOW LONG ON MED:_____	HOW LONG ON MED:_____
BLOOD LEVEL:_____	BLOOD LEVEL:_____

NOTES TO RESEARCHER:

Appendix D

Example of the Seizure Disorder Questionnaire

SEIZURE DISORDER QUESTIONNAIRE

We are trying to find out about people who have seizure disorders (epilepsy or fits). The questions below are about things that we all feel, see, hear, or do from time to time. Some questions may seem funny, strange, or scary, and that is ok. There are no right or wrong answers. Please try to answer the questions as honestly as you can.

A lot of the questions ask about doing something "for no reason". This means that there is no reason why you do this action. It just happens on its own, or you cannot figure out why it happens.

INSTRUCTIONS

* Answer the questions by putting a check mark in one of the boxes next to the question.

* If you do not know what the question means just put a question mark (?) in the "never" box.

* Talk only about what has been happening to you in the past year.

* REMEMBER THAT YOUR ANSWERS WILL NEVER BE SHOWN TO ANYONE ELSE EXCEPT THE PERSONS WHO WILL COUNT THE ANSWERS. YOUR ANSWERS ARE CONFIDENTIAL.

Name_____ Date:_____

Date of Birth:_____ Grade in school:_____ Female___ Male____

Race: White_____African American_____Hispanic_____

Asian_____American Indian_____Other_____

PLEASE TURN THE PAGE AND BEGIN...

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
1) I HAVE HEADACHES					
2) I SUDDENLY GET SLEEPY					
3) I HEAR BUZZING OR HUMMING IN MY EARS					
4) I HAVE FALLEN TO THE GROUND, SUDDENLY, FOR NO REASON					
5) MY MOUTH MAKES CHEWING MOVEMENTS FOR NO REASON					
6) I CAN GET VERY CONFUSED, SUDDENLY, FOR NO REASON					
7) I SMELL STRANGE ODOURS (SMELLS) THAT SHOULD NOT REALLY BE THERE					
8) I STARE OFF INTO SPACE FOR A FEW SECONDS					
9) I HAVE BLACKED OUT (FAINTED, LOST CONSCIOUSNESS)					
10) I HAVE BLACKED OUT FOR A FEW SECONDS					
11) I HAVE FELT LIKE I WAS LOST, OR DID NOT KNOW WHERE I WAS					
12) I HAVE A FEELING THAT I'VE DONE SOMETHING BEFORE, EVEN THOUGH I KNOW THAT I REALLY HAVE NOT (ITS CALLED DEJA VU...THE I'VE BEEN HERE BEFORE FEELING)					
13) A SCENE OR MEMORIES WILL FLASH IN FRONT OF ME JUST LIKE IT WAS HAPPENING ALL OVER AGAIN (IT FEELS REAL, BUT I KNOW ITS NOT)					
14) I HAVE DOUBLE VISION (SEE TWO OF EVERYTHING					
15) I SEE OBJECTS OR THINGS MOVE WHEN THEY ARE NOT SUPPOSED TO					
16) I SUDDENLY GET STRANGE TASTES IN MY MOUTH					
17) I GET ANGRY, SUDDENLY, FOR NO REASON					
18) I HEAR VOICES, OR NOISES THAT I KNOW ARE NOT REAL					
19) I FORGET THINGS					
20) I FEEL SAD, SUDDENLY, FOR NO REASON					
21) I FEEL LIKE I AM FORCED TO SAY THINGS OVER AND OVER AGAIN FOR NO REASON (ITS VERY HARD FOR ME TO STOP)					

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
22) I HAVE SEEN THINGS CHANGE SIZE WHEN I KNOW THEY ARE NOT SUPPOSED TO					
23) I FEEL AFRAID, SUDDENLY, FOR NO REASON					
24) I DO SOME THINGS OVER AND OVER AGAIN (ITS LIKE I CAN'T STOP DOING THEM)					
25) I SEE THINGS THAT I KNOW ARE NOT REAL					
26) PARTS OF MY BODY TWITCH OR JERK FOR NO REASON					
27) MY BODY SHAKES FOR NO REASON					
28) I HAVE TIMES WHEN I SUDDENLY FEEL DREAMY (LIKE HALF ASLEEP BUT AWAKE TOO)					
29) I THINK THAT PEOPLE ARE OUT TO GET ME					
30) MY FINGERS AND/OR HANDS WILL TWITCH OR SHAKE FOR NO REASON					
31) I AM VIOLENT, SUDDENLY, FOR NO REASON					
32) MY HEAD WILL JERK TO THE SIDE, SUDDENLY, FOR NO REASON					
33) MY BODY WILL SUDDENLY GET STIFF					
34) SOMETIMES I SUDDENLY REALIZE THAT I DO NOT KNOW WHERE I AM					
35) I HAVE FLASHBACKS					
36) I SHOUT, SUDDENLY, FOR NO REASON					
37) I LAUGH, SUDDENLY, FOR NO REASON					
38) I HAVE BEEN AFRAID THAT I AM LOSING MY MIND (GOING CRAZY)					
39) THE CORNERS OF MY MOUTH TWITCH FOR NO REASON					
40) I HAVE SHORT DAYDREAMING SPELLS					
41) I GET REALLY NERVOUS, SUDDENLY FOR NO REASON					
42) I STOP WHAT I AM DOING AND STARE FOR A A FEW SECONDS OR MINUTES					
43) SOMETIMES THE WAY I TALK SOUNDS FUNNY (LIKE I SLUR MY WORDS, EVEN EASY ONES)					
44) I WALK IN MY SLEEP					
45) PARTS OF MY BODY FEEL NUMB					
46) PARTS OF MY BODY FEEL SUDDENLY WEAK (FOR NO REASON)					

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
47) I STUTTER WHEN I SPEAK					
48) I HAVE FORGOTTEN NAMES OF EVERYDAY OBJECTS, THINGS, OR PEOPLE					
49) I AM CLUMSY					
50) I HAVE PROBLEMS LEARNING NEW THINGS					
51) I HAVE PROBLEMS WHEN I READ					
52) SOMETIMES I FEEL A STRANGE FEELING IN MY STOMACH THAT MOVES UP TO MY CHEST AND THROAT					
53) I HAVE TROUBLE SLEEPING					
54) THERE ARE TIMES WHEN I CANNOT SIT STILL (I JUST HAVE TO MOVE AROUND A LOT)					
55) I THINK THAT PEOPLE WANT TO HURT ME					
56) I FAIL A TEST IN SCHOOL					
57) I HAVE A HARD TIME MAKING FRIENDS					
58) I HAVE A HARD TIME REMEMBERING WHAT IS SAID TO ME					
59) I HAVE TROUBLE SPEAKING					
60) I HAVE TROUBLE BREATHING					
61) I HAVE PROBLEMS IN SPORTS					
62) I WORRY ABOUT EVERYTHING HAVING TO BE JUST RIGHT					
63) I HAVE FAINTING SPELLS					
64) I SEE FLASHING OR TWINKLING LIGHTS FOR NO REASON					
65) I CAN BREAK OUT IN A SWEAT SUDDENLY, FOR NO REASON					
66) THERE ARE TIMES WHEN I FORGET WHAT I'VE JUST BEEN DOING					
67) SOMETIMES I CANNOT SPEAK OR TALK, EVEN IF I WANT TO (LIKE MAKE THE SOUNDS OR GET THE WORDS OUT)					
68) I THINK THAT THERE IS SOMETHING WRONG WITH MY BODY					
69) I THINK THAT MY BODY IS OVERWEIGHT					
70) I CANNOT SLEEP AT NIGHT					
71) I HAVE A LOT OF TROUBLE REMEMBERING FACES					

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
72) I FEEL THAT THERE ARE SEVERAL DIFFERENT PEOPLE INSIDE OF ME					
73) SOMETIMES I HAVE TROUBLE FIGURING OUT HOW FAR OR CLOSE SOMETHING IS TO ME					
74) I HAVE TROUBLE FIGURING OUT WHAT PEOPLE HAVE SAID TO ME					
75) I DO THINGS TO HURT MYSELF (ON PURPOSE)					
76) I FEEL DIZZY					
77) MY HEART BEATS REALLY FAST, SUDDENLY FOR NO REASON					
78) I FEEL LIKE I AM CHOKING (EVEN THOUGH I KNOW THERE IS NO REASON FOR IT)					
79) I AM BORED WITH EVERYTHING					
80) I THINK ABOUT DEATH					
81) I THINK ABOUT KILLING MYSELF					
82) THERE ARE TIMES WHEN I GO WITHOUT SLEEP FOR LONG PERIODS OF TIME, FOR NO REASON					
83) I THINK ABOUT DOING STRANGE THINGS A LOT					
84) I THINK ABOUT DOING BAD THINGS A LOT					
85) I HAVE TO DO SOME THINGS OVER AND OVER TO MAKE SURE THEY ARE PERFECT					
86) I HAVE THOUGHTS OR IDEAS THAT COME INTO MY MIND (AND I CANNOT GET RID OF THEM EVEN IF I WANT TO)					
87) I FEEL LIKE I AM GOING TO THROW UP					
88) MY BODY WILL SUDDENLY GO LIMP, OR WEAK FOR NO REASON					
89) MY LEGS WILL JERK SUDDENLY, FOR NO REASON (DURING THE DAY TIME)					
90) MY EYES WILL BLINK REALLY FAST FOR NO REASON					
91) I STUMBLE OR FALL TO THE GROUND A LOT, FOR NO REASON					
92) MY HANDS OR FINGERS WILL JERK OR TWITCH FOR NO REASON					
93) I FALL ASLEEP AT ODD TIMES OF THE DAY					

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
94) IT IS REALLY HARD TO WAKE UP IN THE MORNING					
95) I WET THE BED					
96) WHEN I WAKE UP MY BODY HURTS ALL OVER					
97) WHEN I WAKE UP MY TONGUE HURTS					
98) I AM ABSENT FROM SCHOOL					
99) I HAVE TROUBLE WITH MATH					
100) I GET CONFUSED, SUDDENLY, FOR NO REASON					
101) I HAVE ALLERGIC REACTIONS					
102) I HAVE PROBLEMS WITH LOW BLOOD SUGAR					
103) I GET A FUNNY FEELING (LIKE A TINGLING SENSATION) AROUND MY MOUTH					
104) I SEE THINGS THAT ARE NOT REAL					
105) THERE ARE TIMES WHEN I HAVE TO SWALLOW A LOT, FOR NO REASON					
106) SOMETIMES I FEEL LIKE A LOT OF WARM WATER IS RUSHING OVER MY SKIN (EVEN THOUGH THERE IS NOT ANY THERE)					
107) MY HANDS SHAKE					
108) I HAVE TO TALK TO SOMEONE ABOUT MY PROBLEMS					
109) I THINK ABOUT GOD AND CHURCH (AND RELIGIOUS THINGS)					
110) I TALK ABOUT MYSELF					
111) IT IS HARD FOR ME TO PAY ATTENTION TO WHAT SOMEONE ELSE IS SAYING					
112) I GET BORED WITH THINGS, REALLY FAST					
113) I CANNOT FOLLOW WHAT IS GOING ON IN CLASS					
114) I HAVE A HARD TIME FIGURING OUT WHAT PEOPLE ARE SAYING TO ME					
115) OTHER KIDS SAY THAT I DO STRANGE THINGS					
116) MY TEACHERS SAY THAT I DAYDREAM					

	Once a day or more	Once a week or more	Once a month or more	Once a year or more	Never
117) MY TEACHERS SAY THAT I DO NOT PAY ATTENTION					
118) I HAVE HIT PEOPLE OR THINGS, SUDDENLY FOR NO REASON					
119) I HAVE GOTTEN REALLY ANGRY AND YELLED AT PEOPLE, SUDDENLY, FOR NO REASON					
120) OTHER PEOPLE SAY THAT I THINK STRANGE THINGS					
121) OTHER PEOPLE SAY THAT I TUNE OUT, OR I DAYDREAM TOO MUCH					
122) MY TEACHERS CORRECT MY BEHAVIOR					
123) I HAVE A HARD TIME REMEMBERING WHAT I AM SUPPOSED TO DO ON MY HOMEWORK					
124) I HAVE A HARD TIME FOLLOWING WHAT IS GOING ON IN CLASS					
125) ONCE I GET STARTED ON SOMETHING IT IS HARD FOR ME TO CHANGE TO SOMETHING ELSE					
126) I HAVE SHORTNESS OF BREATH (CANNOT SEEM TO CATCH MY BREATH, FOR NO REASON)					
127) I HAVE FORGOTTEN IMPORTANT THINGS (LIKE MY TELEPHONE NUMBER OR ADDRESS)					
128) MY BEHAVIOR GETS OUT OF CONTROL					
129) THERE ARE TIMES WHEN I HAVE TO STAY REALLY BUSY					
130) I SCREAM, SUDDENLY, FOR NO REASON					
131) I CRY, SUDDENLY, FOR NO REASON					
132) I MAKE A POPPING OR SMACKING SOUND WITH MY LIPS (OR MOUTH) FOR NO REASON					
133) I SPIT, SUDDENLY, FOR NO REASON					
134) I RUB MY HANDS TOGETHER, SUDDENLY FOR NO REASON					
135) I HAVE BECOME REALLY SCARED, SUDDENLY, FOR NO REASON					

NOW PLEASE ANSWER ONE MORE QUESTION.....PLEASE CIRCLE THE NUMBER ON THE SCALE BELOW, THAT BEST DESCRIBES HOW WELL YOU THINK THIS QUESTIONNAIRE MEASURES SEIZURE DISORDERS (EPILEPSY OR FITS).

1 2 3 4 5 6 7 8 9 10

Not very well Very well

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