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The relationship of feeding problems with the use of antiepileptic medication among persons with severe and profound mental retardation

Rinita B. Laud
Louisiana State University and Agricultural and Mechanical College

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THE RELATIONSHIP OF FEEDING PROBLEMS WITH THE USE OF ANTIEPILEPTIC MEDICATION AMONG PERSONS WITH SEVERE AND PROFOUND MENTAL RETARDATION

A Thesis

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By
Rinita B. Laud
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Abstract

Epilepsy and/or seizure activity are frequently occurring phenomena and a significant co-morbid condition for persons with severe to profound intellectual disability (Burke, McKee, Pathak, Donahue, Parasuraman & Baltenhorst, 1999). The majority of seizure activity leads to deficits across a number of social, physical, occupational, and personal variables, and if left untreated, may lead to death in these individuals. The treatment of this condition frequently utilizes anti-epileptic medication, but these medications are often associated with a variety of side effects such as dental complications and disturbed gait. Previous researchers have suggested that these side effects may be manifested in forms of maladaptive behaviors such as aggression and destructiveness (Matson, Mayville, Bamburg & Eckholdt, 2001), but studies have not yet been conducted to determine if side effects of antiepileptics may manifest as feeding problems in this population. Given that complications with feeding may incorporate some of the variables mentioned above (i.e., dental complications), a relationship between the two is likely. The purpose of this study was to evaluate feeding problems associated with the use of three different types of antiepileptic medications on individuals with severe to profound mental retardation as compared to their matched controls. Individuals across three groups (clients on carbamazepine, n = 20; clients on valproate, n = 18; and clients on phenytoin, n = 22) were compared to three separate control groups matched on age, gender, race, and level of MR. They were compared across items related to feeding problems on the Screening Tool of Feeding Problems (STEP). Implications of these data are discussed.
Introduction

Historically, individuals with mental retardation (MR) have received little in the way of money and organized efforts toward assessment and treatment for their deficits. It has only been since the 1850’s that the first public and private institutions for persons with mental retardation were established in the United States (Hodapp & Dykens, 1996). Since then, greater amounts of attention have been directed toward this population. Specifically, assessment tools made especially for these individuals have been constructed and a variety of treatment interventions have been applied. While there continues to be a considerable debate over a multitude of issues concerning assessment and treatment, substantial progress has been made and will most likely continue for years to come.

In addition to possessing a variety of deficits in intellectual and adaptive areas, persons with MR must often cope with physical abnormalities as well. The frequency and severity of these may vary with the degree of the individual’s intellectual impairment. Epilepsy is among the most common of these abnormalities, and may present additional difficulties in a number of areas of functioning. The condition of epilepsy in people with mental retardation has recently been receiving more attention from researchers, as well as providers and administrators. This reflects advances that have been made in the treatment of epilepsy in general and the need to extend these advances to people with epilepsy and mental retardation (Coulter, 1993). Unfortunately, medication side effects of antiepileptic medications, the primary treatment approach for epilepsy in all populations, are abundant (Mayville & Matson, 2000). Side effects of
antiepileptic medications often include variables such as sedation or adverse cognitive effects that may further diminish the quality of life for those with MR. Behavioral changes due to medication are also concerns (Rutecki & Gidal, 2002) addressed in many clinical spectrums. Although studies show that behavioral manifestations of side effects due to antiepileptic medications do exist, research has not looked at the relationship between those on antiepileptic medications and feeding problems. The present study represents the first step toward establishing a relationship between these two areas of research. This approach would help enable future clinicians to make arguments for or against the use of certain antiepileptic drugs when weighing the benefits of various interventions for this underserved population.

**Mental Retardation**

As stated earlier, the major area of clinical practice and research for individuals with MR has grown since the 1850’s. The reader should not be surprised, then, that the treatment history before then was largely one of neglect. To begin with, the idea of mental retardation was in and of itself a difficult concept to understand and accept. In ancient Greece and Rome, infanticide was a common practice when children were suspected to be developmentally delayed. For example, children were often thrown off the edge of cliffs when found to be “defective” (Biasini, Grupe, Huffman, & Bray, in press). In 1690, John Locke was the first to distinguish between mental retardation and mental illness, “Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all” (Doll, 1962).
The first step towards the evolution in the care and treatment of the mentally retarded was initiated by Jean-Marc-Gaspard Itard and Edouard Seguin in the early to mid-nineteenth century. Itard developed a broad educational program for a young child who was deaf and mute. Itard’s educational approach became widely accepted and passed down to other physicians, namely Edouard Seguin, who then developed a comprehensive approach toward the education of the mentally retarded. These broad educational approaches were modified and are still in use today (Biasini, et al., in press).

Over the next 50 years, a newly developed test of intelligence by Binet was translated into English and the Vineland Social Maturity Scale was developed. This scale was used to assess the adaptive skills of individuals suspected of having mental retardation. With the emergence of these assessment techniques, clinicians now believed it was possible to determine who was mentally retarded and to provide them with appropriate training in residential training schools (Biasini, et al., in press).

When the deinstitutionalization movement began in the later half of the twentieth century and mentally retarded individuals began living in the community, those prominent in the behavior modification movement began demonstrating that aberrant behavior among those with MR could be treated (Matson & Sevin, 1994). Treatment services began becoming available to mentally retarded individuals and their families, and schools began placing emphasis on special programs for the developmentally delayed. This finding was significant because it implied that simply being labeled “MR” no longer suggested that nothing could be done to improve that person’s quality of life.

The definition of mental retardation has varied over time; early classifications
were based on social competence, but more objective and intellectual criteria evolved following the development of standardized intelligence tests in the early 1900's (Mathias & Nettlebeck, 1992). Substandard intellectual functioning, independent of adaptive functioning, was considered when evaluating for mental retardation before the 1960’s (Scheerenberger, 1987). However, in 1961, the American Association on Mental Deficiency (AAMD) included in its definition of mental retardation the component of “associated impairment in adaptive behavior” (Heber, 1961). This new addition, although controversial, has been adopted into today's definition of mental retardation. The current definition as stated in the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV, American Psychiatric Association, 1994) is a combination of older and newer definitions by AAMD of mental retardation, and includes three criterion: (1) significantly subaverage intellectual functioning (IQ of 70 or below on standardized intelligence test); (2) concurrent deficits or impairments in present adaptive functioning; and (3) onset before the age of 18 years. Although the classification of substandard cognitive functioning is objective and measurable (commonly defined as two standard deviations below the mean on standardized intelligence tests), critics argue that the concept of adaptive behavior is much more difficult to define and measure (Zigler, Balla, & Hodapp, 1984). Despite this debate, the classification of mental retardation currently includes the concept of adaptive behavior, and this inclusion helps to provide valuable information that may prove useful in placement decision making and treatment planning.

Seizures and Epilepsy

As mentioned earlier, epilepsy in people with mental retardation has begun receiving more attention from researchers as well as providers and administrators. Much
of this is due to the advances in technology and treatment that have enabled clinicians to provide better interventions for their clients. This section will explain the definition of seizures and epilepsy, the prevalence of epilepsy, the etiology of the disorder, the classifications of seizure activity, and finally the treatment common in the field.

**Definition**

A seizure is commonly viewed as a discrete event characterized by a sudden, excessive, and disorderly (abnormal) discharge of neurons in the brain that is accompanied by an abrupt alteration in motor and/or sensory function and/or consciousness (Aicardi, 1986). The neuronal discharge may not be detectable by routine scalp recordings of the electroencephalogram (EEG) in some seizures that do not affect consciousness (partial simple seizures), but detectable alterations of the EEG is usually present in seizures that do affect consciousness (partial complex and generalized seizures) (Coulter, 1993). The evaluation of an individual with mental retardation who is suspected to have seizures or epilepsy begins with a determination of whether the behavioral events in question were really seizures (Coulter, 1993). Other causes for these seizure-like behaviors include psychiatric disorders, muscle spasms (particularly in people with cerebral palsy), paroxysmal movement disorders (such as tics, choreoathetosis, or dystonia), vasovagal or cardiac syncope, sleep disorders (such as narcolepsy or cataplexy), and migraine (Donat & Wright, 1990). Given these other plausible explanations of seizure-like activity, a diagnosis of a seizure disorder includes behavioral observations and ruling out these other possible causes.

The definition of epilepsy is slightly more complex as various texts will explain it in different ways. Epilepsy is commonly viewed today as a disorder characterized by
multiple seizures (Trimble, Ring, & Schmitz, 2000). Seizure frequency specifications for epilepsy diagnosis have included at least two within a two-year period. However, as pointed out by Hopkins and Appleton (1996), in practice, a diagnosis of epilepsy is frequently given if more than one seizure of any type is reported. Hopkins and Appleton (1996) also stated that the definition of a seizure should also involve awareness of the seizure to the person experiencing it and/or to an observer, given that abnormal neuronal activity may in and of itself not indicate what is commonly defined as a seizure. In addition, some argue that a continuing tendency for the individual to have seizures should be acknowledged in a diagnosis of epilepsy, as more than one seizure induced by traumatic events would not be representative of what is known as epilepsy (Hopkins & Appleton, 1996). The debate continues on what exact frequency and duration of seizure activity would be adequate to meet criteria for epilepsy, but most would agree that two or more within a two year span is adequate.

**Prevalence**

Defined in this way, epilepsy affects approximately 1% of the general population. However, it is well established that epilepsy is more prevalent in persons with mental retardation than in the general population, with prevalence increasing as intellectual functioning decreases (Bird, 1997). Altogether however, prevalence studies indicate that between 5% to 50% of persons with mild to moderate impairment have epilepsy, and between 26% to 67% of persons with severe to profound impairment have this condition (Blomquist, Gustavson, & Holmgren, 1981; Coulter, 1993; Rutter, Tizard, Yule, Graham, & Whitmore, 1976; Deb, 1997; Hollingsworth, 1978; McGrother, Hauck, Bhaumik, Thorp & Taub, 1996).
When considering the prevalence rates of epilepsy among those with mental retardation, it is important to understand that the presence of comorbid physical and neurological impairment, particularly cerebral palsy, influence the prevalence estimates greatly. Eriksson, Erila, Kivimaki, and Koivikko (1998) found that cerebral palsy was the single most important risk factor for severe epilepsy. Additionally, as observed by Eriksson and colleagues (1998), persons with mental retardation and cerebral palsy who have epilepsy tend to display a common set of characteristics, including a high initial seizure frequency, early onset of seizures and multiple types, an increase in drug resistance, lower long term remission rates, and a higher seizure recurrence rate following anticonvulsant medication discontinuance. High prevalence rates of epilepsy may also be due to other factors such as age, diagnosis of Down's syndrome, Alzheimer's, Rett syndrome, Angelman syndrome, Lesch-Nyan syndrome and Lowe syndrome (Deb, 2000).

**Etiology**

The etiology behind epilepsy has been explained by theories ranging from the supernatural to the biological. Most explanations rely on medical discrepancies in the central nervous system or other areas of the body. A multitude of potential causes for seizures exist, but the etiology is unknown in approximately 50% of cases (Rothner, 1983). In infants, genetic metabolic defects, anoxia, perinatal injury, and congenital brain defects are among the most common (Lennox, 1960; Volpe, 1981), while in children, brain infections, trauma, vascular disease, endocrine disorders, and exposure to toxins have been cited as more common causes (Lennox, 1960; Rothner, 1983). Head trauma is a common cause of seizures in young adults (Hopkins & Appleton, 1996; Rothner, 1983),
and tumors are suspected as the cause underlying first seizures in persons over the age of 20 (Rothner, 1983). In patients over the age of 50, cerebrovascular disease (i.e., stroke) is the most common cause of seizures (Rothner, 1983). Where no abnormality of the brain or nervous system is found, a genetic predisposition for epilepsy is often present (Rothner, 1983). To summarize, Cole (2002) broke down the possible causes of epilepsy in the MR population into four distinct areas: Perinatal injury, remote central nervous system infection, trauma, and developmental and genetic brain disorders.

**Perinatal Injury** – While the incidence of perinatal injury has decreased because of improvements in obstetric care and technique, difficulties during delivery continue to be a major risk factor for later development of sometimes disabling seizures (Cole, 2002). Neurological injury during delivery may be related to prematurity, birth trauma (i.e. forceps delivery), or perinatal hypoxia. Specifically, injury to the cortex and disruption of normal neuronal migration are both likely to contribute to the later evolution of seizures (Cole, 2002).

**Remote Central Nervous System Infection** – A history of remote central nervous system infections is commonly found in institutionalized patients with epilepsy and central nervous system dysfunction. Neonatal or childhood meningitis, for example, may cause extensive gray matter injury with associated neurological deficits and chronic seizures (Cole, 2002).

**Trauma** – Significant traumatic brain injury may result in severe seizure disorders and neurocognitive dysfunction. Hemorrhage and depressed skull fracture are important risk factors for posttraumatic seizures, whereas diffuse axonal injury may contribute to cognitive and behavioral disturbance (Cole, 2002).
Developmental and Genetic Brain Disorders – Structural disturbances of brain
development can occur throughout the period of brain formation and maturation. Recent
advances in neuroimaging, especially the development of magnetic resonance imaging
(MRI), have allowed the identification of a wide variety of developmental brain
abnormalities, and advances in genetics are leading to identification of an increasing
number of specific genetic abnormalities responsible for developmental disturbances
(Cole, 2002). In accordance with all of these theories, it is safe to say that the etiology of
epilepsy in individuals with MR is related to the cause of the retardation itself (Mayville
& Matson, 2000).

Classification of Seizure Activity

The International Classification of Epileptic Seizures (ICES) is widely recognized
as the primary system for classification of seizure activity. There are many different
subtypes of seizures, but most all of the common seizures in the MR population can be
classified under two primary divisions (Coulter, 1993). The two divisions under ICES
classification rules are generalized seizures (those that are generalized from onset) and
partial seizures (those that are partial or focal and their onset may or may not lead to
generalization).

Generalized Seizures - Generalized seizures are of two types – convulsive and
nonconvulsive. The common convulsive type is the tonic-clonic (grand mal) seizure. In
this particular type of generalized seizure, the patient may sense its approach by
experiencing symptoms such as the following: apathy, depression, irritability, and
occasionally ecstasy. In more than half the cases, some type of movement occurs before
consciousness is lost (Holmes, 1997). In others, there is palpitation, a sinking, rising, or
gripping feeling, or some other supernatural sensation in another part of the body. Much less often the seizure may strike without warning, in which the individual will suddenly lose consciousness and fall to the ground. Tonic-clonic seizures are the most identifiable and easily diagnosed of the generalized seizures, as they typically involve a loss of consciousness with a simultaneous onset of generalized stiffening of the flexor or extensor muscles (tonic phase), followed by generalized jerking of the muscles (clonic phase) (Holmes, 1997).

The classic nonconvulsive generalized seizure is known as the absence (petit mal) seizure. This type may be more difficult to recognize or diagnose. Absence seizures are characterized by a sudden onset of impaired consciousness and an accompanying blank facial appearance. Clonic activity (e.g., rapid eye blinking, jerking of the arms), automatisms (simple behaviors which cannot be recalled, including rubbing the face or hands, licking lips, or chewing), and automatic phenomenon (e.g., pupil dilation, flushing, sweating) may also be present in complex absence seizures (Holmes, 1997). Often times, these seizures may be so brief that the patients themselves are not aware of them. To some observers, it may even seem as if the individual that is experiences this particular type of seizure is simply daydreaming.

Minor motor seizures such as myoclonic, tonic, or atonic seizures may be also characterized under the heading of absence seizures. Myoclonic seizures are more brief, shock-like contractions that may involve the entire body, but more commonly are confined to one muscle or group of muscles. Frequently called “myoclonic jerks”, these seizures may accompany an absence seizure or precede a generalized tonic-clonic episode (Holmes, 1997). Tonic seizures are characterized by a brief period of sudden
increased tone in the extensor muscles which often result in a patient falling to the ground if he or she is standing (Holmes, 1997). Finally, an atonic seizure (also known as "drop attacks") involve a sudden loss of muscle tone which may lead to falling, and are often accompanied by myoclonic jerks before, during, and after seizure activity (Holmes, 1997).

**Partial Seizures** – Partial seizures differ from generalized seizures largely in their location of origin. In generalized seizures, the location of origin is largely unknown, and there is no reason to think that it resides in the cerebral cortex. On the contrary, partial seizures are clearly the product of a demonstrable lesion in some part of the cerebral cortex (Holmes, 1997).

Partial seizures can be divided into two main categories: Simple partial and complex partial, depending on whether consciousness is retained or disturbed. Simple partial seizures most often arise from foci in the sensorimotor cortex and are those in which there is no disturbance in consciousness; subtypes include: with motor signs (i.e., focal motor seizure with spreading movement), with somatosensory or special sensory symptoms (i.e., visual, auditory, olfactory), with autonomic symptoms or signs (i.e., sweating, flushing, papillary dilation), and with psychic symptoms (i.e., dysphasia, cognitive, affective, illusions) (Drefuss, 1981).

Complex partial seizures most often have their focus in the temporal lobe on one side of the other and are those in which consciousness is disturbed to some degree; subtypes include the following: simple partial onset followed by impairment of consciousness (with either simple partial features or automatisms), and those with
impairment of consciousness at onset (with either impaired consciousness only or with
automatisms).

Treatment for Epilepsy

The treatment of epilepsy can be divided into three main categories: surgical
measures, behavioral treatment, and the use of antiepileptic medications. Because the
focus of this paper is primarily on antiepileptic medications, the other two categories will
not be discussed as thoroughly.

Surgical Measures – Patients with developmental disabilities, including
retardation and global developmental delay, are not ideal candidates for epilepsy surgery
(Olson, 2002). This is primarily due to the fact that most individuals with MR have an
increased likelihood of diffuse brain dysfunction, consequently meaning that there is an
increased chance that a focal cortical resection will not confer a major improvement in
their seizure frequency and severity (Olson, 2002). However, by applying the basic
principles of epilepsy surgery selection to this population, patients with a reasonable
likelihood of good seizure control can be identified.

Another form of surgery that has been developed recently is a vagus role
stimulator. Vagus nerve stimulation (VNS) was initially introduced in humans in 1988,
commercially introduced in Europe in 1994, and commercially introduced in the United
States in 1997 (Schachter & Saper, 1998). VNS is implemented using the following
products: a battery-powered implantable pulse generator, a bipolar platinum stimulation
lead, a programming wand and software for an IBM compatible laptop computer, an
intraoperative tunneling tool, and hand held magnets. The generator is subcutaneously
implanted in the patient’s left chest and is programmed externally with the laptop
computer, using the programming wand. The stimulation lead wire is inserted through an incision in the neck, attached to the vagus nerve, and tunneled subcutaneously down the neck and to the generator. The device is programmed to deliver intermittent electrical stimulation to the left vagus nerve, and consequently reduce seizure activity. Passing a magnet over the device activates an internal switch, which can be used to suspend VNS or to provide an extra dose of stimulation (Wilfong, 2002). VNS therapy meets many of the challenges presented by the MR population with difficult-to-control seizures, but this procedure is still relatively new.

In addition to this, it is important to remember that other options must always be considered first before the option of surgery. For example, in cases where a reasonable trial of antiepileptic drugs has failed to provide adequate seizure control, little is lost by investigating the possibility of surgical treatment of medically refractory seizures (Olson, 2002).

Behavioral Treatment – Although medical intervention is the most common form of treatment for individuals with epilepsy, the notion that seizures may result from an interaction of biological and environmental factors has lead to new behavioral treatments. Current efforts to proliferate a behavioral medicine approach to epilepsy are currently focused primarily outside of the realm of MR, but a groundwork within the area of MR has been established upon with further efforts can be built (Mayville & Matson, 2000).

A number of researchers have recently explored the use of contingency management in treating children and mentally retarded adults with epilepsy. Gardner (1967) demonstrated that treatment involving altering reinforcement contingencies helped
eliminate psychogenic seizures in a 10 year old girl. Gardner also suggested that a functional relationship between seizure activity and parental attention was evident.

Another study was used to demonstrate how the interruption of antecedent behavioral chains could inhibit seizure activity of varying types (Zlutnick, Mayville, & Moffat, 1975). Five children with varying degrees of MR and several other related problems (i.e., autism) participated in a study in which their seizure activity was significantly reduced utilizing techniques such as interruption (firmly grasping the individual and stating "No!") and differential reinforcement (verbal praise, receipt of candy following successful redirection) just prior to the seizure activity.

Although a handful of studies have been done supporting the use of behavioral interventions for people with MR and epilepsy, there still lies a need for more scientifically rigorous studies in order to draw firm conclusions about the efficacy of these treatments.

Antiepileptic Medications – Drug treatment is by far the most widely effective mode of treatment for epilepsy (Mycek, Harvey, Champe, 1997). However, epilepsy in the MR population is often particularly difficult to treat for several reasons: the presence of several different seizure types, the presence of significant brain abnormality or dysfunction, initial resistance to antiepileptic medication, and early onset of epilepsy (Alvarez, 1998). Consequently, practices of antiepileptic medication use in this population often incorporate methods normally avoided with the population at large (i.e., polypharmacy). One study confirmed this by surveying antiepileptic medication use in a sample of 143 adults with MR (Deb and Joyce, 1999). The authors found that 42% of this sample were receiving polypharmacy and of this percentage, 28%, 12.6%, and 1.4%
were taking two, three, and four antiepileptic medications respectively. Given the toxicity of some antiepileptic medications, monotherapy is usually preferred over polypharmacy.

Antiepileptic medication, when used appropriately and in therapeutic dosages, can be efficacious in preventing seizure activity. However, when choosing which medication to administer, it is important to obtain an accurate seizure diagnosis first and foremost. This is particularly important because different antiepileptics may be better for different types of seizures. For example, studies have demonstrated that carbamazepine is the drug of choice for the treatment of partial epilepsy (Pellock, 2002).

Although there are a number of antiepileptic medications to choose from, the study at hand compares only three of the most common ones. Consequently, those three particular medications will be discussed in great detail, while the other medications will be briefly summarized.

**Carbamazepine (Tegretol)** - Closely related to imipramine and other antidepressants, carbamazepine is a tricyclic compound effective in the treatment of bipolar depression. It has also proven to be efficacious in treating individuals with epilepsy as well (Pellock, 2002). For many neurologists, carbamazepine is the first drug of choice for the treatment of partial epilepsy, particularly for its lack of sedation and low incidences of cosmetic, cognitive, and behavioral side effects. It is not shown to be effective for absence, atonic, and myoclonic seizures and may actually worsen these seizure types (Perruca, Gram, Avanzini, & Dulac, 1998). Adverse behavioral side-effects have been documented in this population, but reports are few and have been limited to exacerbation of pre-existing behavior problem in patients taking carbamazepine for
behavioral or psychiatric reasons (Friedman, Kastner, Plummer, Ruiz, & Henning, 1992). While neurotoxicity can occur, it tends to be dose related and reversed with a decrease in dosage (Waisburg & Alvarez, 1998). In addition to the side affects mentioned above, researchers suggest that carbamazepine may irritate the stomach, and nausea and vomiting may occur (Mycek, Harvey, & Champe, 1997). Obviously, problems such as these may be manifested as feeding or mealtime behavior problems.

Valproate (Depakote/Depakene) – Valproate is an especially attractive choice for the treatment of epilepsy in the MR population because of its acceptable tolerability profile and ability to reduce multiple seizure types (Friis, 1998). Valproate is very effective against absence seizures, however, it is also effective with tonic clonic attacks (Pellock, 2002). Some evidence also exists that valproate is effective in partial seizures (Pellock, 2002). Few adverse effects are reported in patients that use valproate, but hepatotoxicity associated with valproate treatment, though rare, is potentially fatal and can be more likely to occur in persons with MR (Friis, 1998). Additionally, coagulation problems, hemorrhaging, or easy bruising may occur, and these factors may exclude patient with self-injurious behavior from this treatment (Alvarez, et al., 1998). Finally, valproate has been found to possibly cause nausea and vomiting in individuals with epilepsy (Mycek, Harvey, & Champe, 1997). Problems such as these are often considered feeding or mealtime behavior problems in this population.

Phenytoin (Dilantin) – Phenytoin is the oldest, nonsedative antiepileptic drug, introduced in 1938 following systematic research in the laboratory (Pellock, 2002). Phenytoin is also known as one of the most effective drugs against partial seizures and generalized tonic clonic seizures. However, the adverse side effects of phenytoin are
numerous and wide-ranging, and present special problems to individuals with mental and physical complications (Mayville & Matson, 2000). Most troubling are the adverse neurological effects, which are often irreversible (Iivanainen, 1998). Deterioration of intellectual and cognitive functioning, drowsiness, truncal or limb ataxia, progressive motor coordination complications, and loss of locomotion have all been documented (Iivanainen, 1998). Few studies exist evaluating the side effects of this medication in this population, however, it does appear that certain mentally retarded individuals may be more adversely affected by specific phenytoin side effects than individuals with normal intelligence (Mayville & Matson, 2000). Iivanainen, Viukari, and Helle (1977) found a 28% rate of cerebellular atrophy secondary to phenytoin toxicity in a sample of 131 patients with MR, with 23.5% of the sample displaying a persistent loss of locomotion. Finally, as related to this study, researchers suggest that phenytoin may cause gastrointestinal problems (nasea, vomiting) and possibly gingival hyperplasia (gums to grow over the teeth) (Mycek, Harvey, & Champe, 1997). Obviously, side effects such as these may be manifested as feeding or mealtime problems.

**Other Antiepileptic Medications** - Although carbamazepine, valproate, and phenytoin are used frequently when treating epilepsy in the MR population, there are some other anti-epileptics that are used with this population as well.

Phenobarbital, the most familiar of the barbiturates, has been used as an antiepileptic in persons with MR since its introduction in 1912 (Alvarez, 1998). This particular antiepileptic has been shown to be somewhat efficacious for simple partial seizures, but not very effective for complex partial seizures (Mycek, Harvey, & Champe, 1997). In addition, phenobarbital use in persons with mental retardation has been
associated with depression (Trimble & Corbett, 1990), lowered frustration tolerance (Gay, 1984), hyperactivity (Burd, Kerbeshian, & Fisher, 1987), conduct disorder (Trimble & Corbett, 1990), and exacerbation of pre-existing hyperactive and aggressive behavior (Ingram, 1986).

Several of the benzodiazepines show antiepileptic activity. Clonazepam and clorazepate are used for chronic treatment of epilepsy. While clonazepam is effective in absence and myoclonic seizures, clorazepate is efficacious in the treatment of partial seizures when used with other drugs (Mycek, Harvey, & Champe, 1997). Of all the antiepileptics, benzodiazepines are often considered the safest and most free from severe side effects, although they may have sedative properties (Mycek, Harvey, & Champe, 1997). Despite this, their efficacy isn’t well proven, thus they are often only used in adjunctive roles and emergency situations.

There are a number of newer antiepileptic medications that have surfaced within the last 20 years. These newer medications have been reported to be efficacious and are reported to have fewer adverse effects (i.e., gabapentin, lamotrigine, tigabine, zonisamide, toptrimate, vigabatrin, oxcarbazepine, etc.) (Mayville & Matson, 2000). The research demonstrating the efficacy of these newer drugs is limited, but multiple drug trials are being done in order to draw firm conclusions. Perhaps the biggest drawback of using the newer agents is a different spectrum of side effects, which includes anorexia and behavioral changes. Although these side effects do exist with these newer drugs, the possibility of producing a significant reduction in seizures makes the effort worthwhile (Rutecki & Gidal, 2002). Additionally, the relationship of these drugs to problems such as feeding and mealtime behaviors is of considerable importance.
Feeding and Mealtime Behaviors

Individuals diagnosed with mental retardation have a higher prevalence of comorbid disorders and behavior problems than the general population (Borthwick-Duffy, 1994; Matson & Barret, 1993). One area that continues to be a growing concern among clinicians with MR clients are feeding and mealtime problems. Although feeding problems are a serious health concern for clients with MR, most of the research on feeding disorders has focused on children, primarily without MR. The literature that examines feeding problems among adults with MR is small in quantity, and consists primarily of case studies that use functional based assessments that are descriptive in nature. This section will explain the background, prevalence, identification, evaluation, and treatment of feeding and mealtime problems.

Background of Feeding and Mealtime Problems

The area of feeding problems in individuals with MR was initially described in 1983. Linscheid (1983) described ten mealtime problems including tantrums, bizarre food habits, multiple food dislikes, food-texture selectivity, delay or difficulty in chewing, sucking, or swallowing, delay in self feeding, pica, excessive overeating, too little food eaten, and rumination. In 1989, Sisson and Van Hasselt suggested that feeding problems could be divided into four categories: 1) lack of independent skills, 2) disruptive behavior, 3) eating too much or too little, and 4) selectivity by type or texture. Currently, a wide variety of different disorders, diagnoses, skill deficits, and excess behaviors fall under the rubric of "feeding problems." These include: (a) failure to thrive (FTT), a term descriptive of children who have trouble gaining weight, often due to serious pediatric ailments (Harnill, Drizd, Johnson, Reed, Roche, & Moore, 1979, Heffer
& Kelly, 1994; Stickler, 1984); (b) feeding disorder of infancy or early childhood, a formal diagnostic category for children who persistently fail to eat adequately and gain weight; (c) rumination disorder, characterized by repeated regurgitation and re-chewing of food; and (d) pica, which is the persistent eating of non-nutritional substances (Girolami, P.A. & Scotti, J.R., 2001). Problems such as food refusal have often been associated with infants and children (Johnston, 1993; Parry, 1994; Riordan, Iwata, Finney, Wohl, & Stanley, 1984), but these problems are also prevalent among older individuals with MR as well.

To date, the identification of feeding problems among adults with mental retardation has not been systematically formalized. In state hospitals and developmental centers, a nutritional management committee usually consisting of an occupational therapist, a nutritionist, and a physician among others are in charge of identifying feeding problems. In addition to this, staff and caregivers are encouraged to alert physicians when problems occur during mealtimes. Without a formal system for identifying feeding problems, however, prevalence estimates are difficult to ascertain. In the next section the prevalence of feeding and mealtime problems in the MR population will be explored.

Prevalence of Feeding and Mealtime Problems

Due partly to the lack of a formal identification system for identifying feeding problems, the prevalence estimates for the occurrence of feeding problems vary. Researchers estimate that mealtime problems occur among one third of the children with developmental disabilities (Gouge & Ekvall, 1975; Palmer, Thompson, & Linscheid, 1975), but Perske, Clifton, McClean, & Stein (1977) have found that the greater the level of the retardation, the more prevalent the problem. For example, 80% of severely or
profoundly retarded individuals are estimated to have mealtime problems (Perske, et al., 1977). Matson, Gardner, Coe, and Sovner, (1991) estimated the prevalence of eating disturbance at 27.5% among a sample of 506 individuals with MR residing across two state-run facilities. Matson, et al., (1991) also found that feeding problems appear to be more prevalent among those with more profound levels of MR.

As prevalence estimates show that feeding problems are relatively more common among the profoundly retarded individuals than the mild and moderate, it becomes increasingly difficult to identify and assess these problems. When patients are nonverbal and unable to describe their symptoms, it becomes the clinician’s job to identify the problem through observable behaviors. For example, a client who is feeling nauseous may refuse food or eat only a small portion. In order to determine the best course of treatment, it is necessary for the clinician to be able to observe certain behaviors, identify the association of the problem with its antecedents, and subsequently take the most appropriate form of action that fits the client’s needs. For example, if a patient has been on an antiepileptic for a significant amount of time and suddenly begins ruminating their food (bringing food past his/her airway repeatedly) on a daily basis, it may be rumination resulting from gastro-esophageal reflux disease (GERD). Essentially, the client may not be ruminating for attention, self stimulation, or escape. Rather, it could be a side effect of antiepileptic use. In this case the clinician may want to consider titrating the client’s neuroleptics, or eliminating any anticholinergic medications. On the other hand, if the individual refuses to eat certain foods (i.e. tomatoes) because it exacerbates their GERD, then the clinician may consider a different intervention to suppress the reflux (i.e. acid-suppressing medication, or modifying the individual’s diet). Clearly, identifying feeding
problems and their antecedents are a very important step toward finding the most appropriate treatment for an individual, and this will be discussed next.

Identification of Feeding and Mealtime Problems

As mentioned previously, there is currently no formal identification process for feeding problems, and feeding problems due to the use of antiepileptics or psychotropic medications may be overlooked or treated inappropriately. However, some rating scales have proven useful for identifying the presence of feeding problems in individuals with mental retardation. Scales such as the Reiss Screen (Reiss 1988) and the Diagnostic Assessment for the Severely Handicapped-II (DASH II) (Matson, et al., 1996) include items that address problems related to weight gain or loss resulting from overeating or insufficient eating. Recently, a new scale has been developed that focuses strictly on common feeding problems in persons with MR. This tool is known as the Screening Tool of Feeding Problems (STEP) and allows for the quick and efficient identification of specific feeding and mealtime behavior problems exhibited by individuals with MR (Matson & Kuhn, 2001).

The STEP is a measure developed specifically for the assessment of common feeding problems among those with MR. There are 23 items on the STEP representing five rationally derived categories/subscales of feeding problems. These include: (1) aspiration risk, (2) selectivity, (3) skills, (4) food refusal related behavior problems, and (5) nutrition related behavior problems. These questions are designed in a Likert-type format, with three possible responses for both frequency and severity of the target behavior in the last month: (0) = never occurs, (1) = occurs between 1 and 10 times,
(2) = occurs more than 10 times, for frequency ratings; and (0) = causes no harm or problems, (1) = causes minimal harm or problems, and (2) = causes serious injury or problems, for severity ratings (Matson & Kuhn, 2001). The STEP possesses acceptable test-retest ($r = .72, p<.01$) and cross rater reliability ($r = .71, p<.01$). In addition, items on the STEP related to pica and rumination were significantly correlated with DSM-IV diagnoses of rumination and pica (Matson & Kuhn, 2001). To date, the STEP represents the only measure specific to feeding problems in the MR population.

**Evaluation of Feeding Problems**

Once a feeding problem(s) has been identified using observation methods as well as the tools described above, an interdisciplinary team for evaluation and treatment is essential. An evaluation such as this may incorporate input from a physician, occupational therapist, dietician, and psychologist. With the combined effort of all of these disciplines, the client stands a better chance of having every aspect of possible treatment addressed. The following paragraphs explain how each discipline can contribute toward a successful treatment plan for the individual.

A physician would be imperative for a medical assessment in which the following is assessed: the client’s upper gastrointestinal anatomy to ensure that the individual can protect his/her airway during swallowing (Babbitt, Coe, Cataldo, Kelly, Stackhouse & Perman, 1994); the mucosal lining of the esophagus, stomach and duodenum which provides information about whether medical conditions exist (i.e., esophagitis, esophageal reflux) (Babbitt et al., 1994); the upper gastro-intestinal tract for evaluating motility (Babbitt et al., 1994); and measuring intraesophageal pressure which provides information about peristalsis and thus esophageal motility (Patti, Diener, Tamburini,
Molina, & Way, 2001). The medical information gathered by physicians may help identify feeding problems that occur due to medical conditions and the client can then be treated specifically for each condition. In addition to this, an occupational therapist plays an important role that contributes toward the well-being of the client.

An occupational therapist helps examine the individual's coordination and physical ability to perform various tasks necessary for feeding (O'Brien, Repp, Williams, & Christophersen, 1991). The skills evaluated that are necessary for oral feeding include oral pharyngeal reflexes and oral-motor skills that include sucking, swallowing, chewing, and tongue control. Skills evaluated necessary for self-feeding include hand-eye coordination, motor development, and gross reflective movements. All of these skills, once evaluated by the occupational therapist, can identify feeding problems that may be due to an individual's physical inability to perform feeding tasks. In addition to the expertise provided by the physician and occupational therapist is the dietician, whose skills are essential for nutritional knowledge.

A dietician provides valuable information pertaining to feeding problems (O'Brien, et al., 1991). For example, just as for normal growing children, eating all the necessary nutrients is important to maintain health in an individual with mental retardation. A dietician is able to evaluate a client's diet and ensure that all the necessary nutrients are consumed. In addition to this, a dietician can assess food allergies or identify when a client may have an inability to digest certain foods. Finally, a dietician can evaluate an individual's weight and recommend a diet which provides the right amount of calories to ensure the client's health. Although there are many feeding problems and mealtime behaviors that may be accounted for by the disciplines mentioned
above, it is also important to have a psychologist who can identify environmental variables that contribute to or exacerbate feeding problems.

A psychologist can identify feeding problems that exist due to behavioral issues. For example, if a client does not enjoy mealtime, he/she may become physically aggressive in the dining area. Consequently, he/she may be led out of the dining area and put into a quiet room. Behaviorally, physical aggression during feeding times serves as an escape function for this particular client. A psychologist may conduct an analogue functional assessment to determine what exact function the client’s behavior is serving (Iwata, et al., 1994). By manipulating the consequence following the feeding problem behavior, the function can be identified and addressed.

Clearly, the use of an interdisciplinary team including a physician, occupational therapist, dietician, and psychologist may help in identifying feeding problems and aide in developing an appropriate treatment. Since the lack of research in this area does not permit firm conclusions on many areas related to feeding problems, it is therefore essential that more systematic research is done to ensure that health care professionals are better equipped to deal with the dangers that may arise in the future.

Treatment of Feeding Disorders

Literature related to feeding disorders has focused primarily on the functional and medical aspects of eating behavior. Little is known about treatment for specific feeding problems. Studies have shown that treatment usually incorporates multiple components including different reinforcement strategies (i.e., contingent attention or tangible reinforcement), noncontingent reinforcement escape extinction, antecedent manipulation, and negative reinforcement techniques (Cooper, et al., 1995). These procedures are
frequently cited in the treatment of food refusal and food selectivity (Cooper et al., 1995). In addition to these procedures, aversive techniques are sometimes used in the treatment of life-threatening behaviors such as pica and rumination (Gravestock, 2000).

In regards to behavioral treatment for the development of appropriate mealtime behavior (i.e., appropriate utensil use and chewing behavior), instructions, prompts, modeling, manual guidance, behavioral rehearsal, and contingent attention have all been successfully utilized (Sisson & Dixon, 1986). Behavioral techniques have also been effective in reducing behaviors that interfere with feeding such as mealtime rapid eating (Favell, McGimsey, & Jones, 1980), and mealtime sloppiness (Cipani, 1981).
Purpose

The purpose of the current study was to evaluate the relationship between feeding problems and the use of specific types of antiepileptic medications. Previous research shows that many antiepileptic medications used with this population have adverse side effects, some of which exacerbate behavior problems (i.e., increase in SIB, aggression, destructiveness) (Kerr, 2002). In addition to this, side effects of many of these medications have properties that are related to stomach problems and dental complications, and these specific side effects may manifest themselves as feeding and mealtime behavior problems. Feeding and mealtime behavior problems are extremely common among individuals with mental retardation (Matson & Kuhn, 2001), and consequently has become a growing area of research among clinicians in the field. Palmer, Thompson, and Linscheid (1975) estimated that 33% of persons with mental retardation had severe feeding difficulties and problems. Furthermore, the consequences of untreated feeding problems can be serious, if not fatal.

Given the extensive research on antiepileptics, researchers generally agree that phenytoin is associated with the most frequent and most severe adverse side effects when compared to other antiepileptics, although other antiepileptics have minor side effects as well. Consequently, it was hypothesized that those individuals that were on phenytoin were most likely to have significantly more feeding problems than their matched controls, while those on carbamazepine and valproate are not expected to differ significantly from their matched controls.
Method

Participants

Information was obtained on 120 individuals residing at the Pinecrest Developmental Center (PDC) in central Louisiana. PDC is a state-run facility that consists of individual homes under 24 hour supervision. Approximately 650 individuals are housed at PDC and the gender, race, and level of mental retardation vary throughout the center. Approval from the Institutional Review Board (IRB) was obtained.

The present study was divided into three separate parts, each with one experimental group and one control group. The experimental groups consisted of the following: (1) a group of 20 clients who were only on carbamazepine, (2) a group of 18 clients who were only on valproate, and (3) a group of 22 clients who were only on phenytoin. All participants were on these medications for at least five months. All the experimental groups also maintained the following criteria: (1) no participant had an axis I disorder, (2) no participant was on any psychotropic medication, and (3) each participant had to receive a diagnosis of either tonic-clonic epilepsy or tonic-clonic and partial epilepsy from a staff neurologist.

Each experimental group was matched to non-medicated controls. They were matched case by case according to age (within 10 years), gender, race, and level of mental retardation. Members of the control group were not on any medications, did not have any instances of seizure activity, and did not have any Axis I diagnoses. Diagnoses of mental retardation were made previously by licensed psychologists using DSM-IV criteria.
Dependent Variable

*The Screening Tool for Feeding Problems (STEP)* – The STEP is a 23 item informant based questionnaire that was designed to screen for a variety of feeding problems. This test consists of five rationally derived subscales (1) aspiration risk, (2) selectivity, (3) feeding skills, (4) refusal related behavior problems, (5) nutrition related behavior problems. Test-retest reliability ($r = .72$) and crossrater reliability ($r = .71$) were found to be acceptable. In addition, the rumination and pica subscales demonstrated criterion validity through a correlation with DSM-IV diagnoses for rumination and pica (Matson & Kuhn, 2000).

Procedure

Data was gathered by interviewing the primary caregiver for each of the 120 selected clients on the STEP. Due to the participant’s inability to self report, caregivers who were particularly familiar with the feeding habits of the participants were interviewed. First the staff were questioned on the frequency of each item. If the staff rated the frequency as either a “1” (occurring between 1 and 10 times in the last month) or a “2” (more than 10 times in the last month), the interviewer questioned the staff on item severity. The severity questions could also be rated on a scale from 0 to 2. A rating of “0” (caused no harm/problems), “1” (caused minimal harm or problems) or “2” (caused serious injury or problems) comprised the severity scale. Although the items on severity provided important information for clinicians, only frequency items were assessed for the purposes of this study. This was primarily due to the fact that the frequency items appeared to be the most objective of the two. All STEP questionnaires
were administered within a 3 week period by bachelor and masters level college graduates.

**Experimental Design**

This design was divided into three separate studies because each experimental group was matched to a separate control group. Therefore, comparisons could not be made across experimental groups and separating those groups into different studies appeared to be the most logical method of design. The first study looked at the differences between participants on carbamazepine and their matched controls, the second study looked at the differences between participants on valproate and their matched controls, and the third study looked at the differences between participants on phenytoin and their matched controls.

Since the analyses for each study consisted of 5 t-tests, a Bonferroni correctional formula was utilized to minimize the inflation of alpha error. According to Stevens (1996), setting the original alpha level to .10 is considered acceptable in situations where the chances of making a Type II error is of greater consequence than of making a Type I error. Because of the possible life threatening nature of feeding disorders, concerns of overlooking any significant results may be of serious consequence (i.e., injury or even death). Therefore, an alpha level of .10 was used. Given these considerations, a final alpha level of .02 was used after the Bonferonni correctional procedure was applied.
Results

For each study, an analysis was done to determine whether there were significantly more participants on G-tubes in the experimental group versus their matched controls. A G-tube is a device that allows nutrients to enter a client's body through a tube connected to their stomach. A participant that is on a G-tube is not able to engage in many of the behaviors on the STEP (i.e., eat only certain foods, vomit) and this could have consequently confounded the results. Only in the second study (the valproate experiment) were there significantly more G-tube feeders in the experimental group than in the control group. For this reason, the same analyses were run after removing the G-tubers from the experiment, and the same results were found.

Because of the large number of comparisons evident in the design, only five subscales of the STEP were analyzed. The five were statistically derived subscales chosen due to their relatively high inter-item consistency (see Matson & Kuhn, 2001), and to their inclusion of items stated in the literature on adverse side effects of seizure medications. The literature specifically stated that individuals on these particular seizure medications have shown adverse side effects such as vomiting and food refusal (Mycek, 1997); consequently, it was ensured that the five chosen subscales included items related to these particular side effects. Table 1 on the next page shows the five empirically derived subscales, their content, and their inter-item consistency.

Study I

Clients in the carbamazepine group were matched successfully on age (within 10 years), gender, race, and level of MR with controls in a matched cohorts design (Hinkle,
Table 1

Inter-item consistency

<table>
<thead>
<tr>
<th>Factor</th>
<th>Coefficient α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Refusal Items</td>
<td></td>
</tr>
<tr>
<td>selective by type of food</td>
<td></td>
</tr>
<tr>
<td>eats small amount</td>
<td></td>
</tr>
<tr>
<td>spits out food</td>
<td></td>
</tr>
<tr>
<td>pushes food away</td>
<td>.70</td>
</tr>
<tr>
<td>selective by feeder</td>
<td></td>
</tr>
<tr>
<td>Stealing/Pica</td>
<td>.66</td>
</tr>
<tr>
<td>steals food at mealtime</td>
<td></td>
</tr>
<tr>
<td>eats non-food items</td>
<td></td>
</tr>
<tr>
<td>steals food at other times</td>
<td></td>
</tr>
<tr>
<td>Feeding Skills</td>
<td>.56</td>
</tr>
<tr>
<td>cannot feed independently</td>
<td></td>
</tr>
<tr>
<td>requires special equipment</td>
<td></td>
</tr>
<tr>
<td>requires special positioning</td>
<td></td>
</tr>
<tr>
<td>Eats Large Amount/Fast Eater</td>
<td>.53</td>
</tr>
<tr>
<td>eats all available food</td>
<td></td>
</tr>
<tr>
<td>eats too quickly</td>
<td></td>
</tr>
<tr>
<td>insufficient chewing</td>
<td></td>
</tr>
<tr>
<td>Vomit/Rumination</td>
<td>.42</td>
</tr>
<tr>
<td>problem behavior during meals</td>
<td></td>
</tr>
<tr>
<td>ruminates</td>
<td></td>
</tr>
<tr>
<td>vomits</td>
<td></td>
</tr>
</tbody>
</table>

Wiersma, & Jurs, 1998). Prior to the main analyses, a chi square analysis was used and no significant difference was found in the use of the G-tube between participants on carbamazepine and their matched controls, $X^2 (1)=.00, N = 40, NS$. The main analyses consisted of 5 independent sample t-tests that were conducted using each of the empirically derived subscales as the dependent variables, and group (experimental and control) as the independent variables. A Bonferonni correctional procedure was used to minimize the inflation of alpha error, leaving a significance cutoff level of $p<.02$. Based on these analyses, it was determined that the only feeding problem that was significantly different between the participants on carbamazepine ($M = 3.25$) and their matched controls ($M = 2.00$) was the feeding skills subscale, $t(38) = 2.47, p<.02$. Table 2
illustrates a comparison between the two groups of the means and standard deviations for each of the subscale scores. This table also includes the statistical results of each analysis.

Table 2

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Carbamazepine</th>
<th>Control</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Refusal Items</td>
<td>M 1.15</td>
<td>1.40</td>
<td>p = .66</td>
</tr>
<tr>
<td></td>
<td>SD 1.98</td>
<td>1.64</td>
<td></td>
</tr>
<tr>
<td>Stealing/Pica</td>
<td>M .00</td>
<td>.35</td>
<td>p = .12</td>
</tr>
<tr>
<td></td>
<td>SD .00</td>
<td>.99</td>
<td></td>
</tr>
<tr>
<td>Feeding Skills</td>
<td>M 3.25</td>
<td>2.00</td>
<td>p = .02*</td>
</tr>
<tr>
<td></td>
<td>SD 1.62</td>
<td>1.59</td>
<td></td>
</tr>
<tr>
<td>Eats large amount/fast eater</td>
<td>M .45</td>
<td>.50</td>
<td>p = .88</td>
</tr>
<tr>
<td></td>
<td>SD 1.05</td>
<td>1.05</td>
<td></td>
</tr>
<tr>
<td>Vomit/Rumination</td>
<td>M .20</td>
<td>.30</td>
<td>p = .57</td>
</tr>
<tr>
<td></td>
<td>SD .52</td>
<td>.57</td>
<td></td>
</tr>
</tbody>
</table>

*significance found with alpha set at .02

To elucidate which individual items were accounting for the majority of the between-group variance, an item analysis was conducted. The three individual items that compromised the empirically derived feeding skills subscale were: cannot feed himself/herself independently, requires special equipment for feeding, and requires special positioning during feeding. Three independent t-tests were utilized and no significant differences between the participants on carbamazepine and their matched controls were found on each individual item. A Bonferonni correctional procedure was used to minimize the inflation of alpha error, leaving a significance cutoff level of p<.02. However, it was apparent that the item regarding whether the participants needed special equipment seemed to be nearing significantly greater proportions in the carbamazepine group (M = 1.65) than the control group (M = 1.10), t(38) = 1.95, p=.06. Table 3 illustrates a comparison between the two groups of the means and standard deviations for
each of the individual item scores. This table also includes the statistical results of each analysis.

Table 3
Means, standard deviations, and statistical results for each individual item score

<table>
<thead>
<tr>
<th>Item</th>
<th>Carbamazepine</th>
<th>Control</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot feed independently</td>
<td>M 1.00</td>
<td>.500</td>
<td>p = .12</td>
</tr>
<tr>
<td></td>
<td>SD 1.03</td>
<td>.89</td>
<td></td>
</tr>
<tr>
<td>Requires special equipment</td>
<td>M 1.65</td>
<td>1.10</td>
<td>p = .06</td>
</tr>
<tr>
<td></td>
<td>SD .75</td>
<td>1.02</td>
<td></td>
</tr>
<tr>
<td>Requires special positioning</td>
<td>M .60</td>
<td>.40</td>
<td>p = .48</td>
</tr>
<tr>
<td></td>
<td>SD .94</td>
<td>.82</td>
<td></td>
</tr>
</tbody>
</table>

*significance found with alpha set at .02

Study II

Clients in the valproate group were matched successfully on age (within 10 years), gender, race, and level of MR with controls in a matched cohorts design (Hinkle, Wiersma, & Jurs, 1998). Prior to the main analyses, a chi square analysis was used and a significant difference was found in the use of the G-tube between the participants on valproate and their matched controls, $X^2 (1, N=36) = 4.5$, $p<.05$. Specifically, the group on valproate had significantly more G-tube feeders than their matched controls. The main analyses consisted of 5 independent sample t-tests that were conducted using each of the empirically derived subscales as the dependent variables, and group (experimental and control) as the independent variables. A Bonferonni correctional procedure was used to minimize the inflation of alpha error, leaving a significance cutoff level of $p<.02$. Based on these analyses, it was determined that there were no significant differences in feeding problems between the participants on valproate and their matched controls. However, those participants on valproate ($M = 3.11$) did appear to be approaching significance regarding differences in feeding skills than their matched controls ($M =$
1.78), $t(34) = 2.28, p = .03$. Because the groups were already shown to differ significantly with respect to having more G-tube feeders in one group, the G-tube feeders were removed from the pool and the t-tests were rerun. Results were the same. Specifically, participants on valproate ($M = 3.14$) still had more feeding skill problems than those in the control group ($M = 1.78$), $t(30) = 2.09, p < .05$, and these results were approaching significance. Table 4 illustrates a comparison between the two groups of the means and standard deviations for each of the subscale scores after G-tube feeders were removed. Table 4 also includes the statistical results of each analysis.

Table 4
Means and standard deviations for each empirically derived subscale

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Valproate</th>
<th>Control</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Refusal Items</td>
<td>$M = 1.07$</td>
<td>$1.56$</td>
<td>$p = .43$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.94$</td>
<td>$1.50$</td>
<td></td>
</tr>
<tr>
<td>Stealing/Pica</td>
<td>$M = 7.14E-02$</td>
<td>$.17$</td>
<td>$p = .54$</td>
</tr>
<tr>
<td></td>
<td>$SD = .27$</td>
<td>$.51$</td>
<td></td>
</tr>
<tr>
<td>Feeding Skills</td>
<td>$M = 3.14$</td>
<td>$1.77$</td>
<td>$p = .05$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.88$</td>
<td>$1.80$</td>
<td></td>
</tr>
<tr>
<td>Eats large amount/fast eater</td>
<td>$M = 1.21$</td>
<td>$.33$</td>
<td>$p = .11$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.85$</td>
<td>$.69$</td>
<td></td>
</tr>
<tr>
<td>Vomit/Rumination</td>
<td>$M = .50$</td>
<td>$.39$</td>
<td>$p = .69$</td>
</tr>
<tr>
<td></td>
<td>$SD = .85$</td>
<td>$.70$</td>
<td></td>
</tr>
</tbody>
</table>

* significance found with alpha set at .02

Study III

Clients in the phenytoin group were matched successfully on age (within 10 years), gender, race, and level of MR with controls in a matched cohorts design (Hinkle, Wiersma, & Jurs, 1998). Prior to the main analyses, a chi square analysis was used and no significant difference was found in the use of the G-tube between the participants on phenytoin and their matched controls, $X^2 (1) = .29$, $N = 44$, NS. The main analyses consisted of 5 independent sample t-tests that were conducted using each of the
empirically derived subscales as the dependent variables, and group (experimental and control) as the independent variables. A Bonferonni correctional procedure was used to minimize the inflation of alpha error, leaving a significance cutoff level of $p<.02$. Based on these analyses, it was determined that there were no significant differences on feeding problems between the participants on phenytoin and their matched controls. However, those participants on phenytoin ($M = 2.82$) did appear to be approaching significance regarding differences in feeding skills than their matched controls ($M = 1.91$), $t(42) = 2.07$, $p = .05$. Table 5 illustrates a comparison between the two groups of the means and standard deviations for each of the subscale scores. Table 5 also includes the statistical results of each analysis.

Table 5

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Phenytoin</th>
<th>Control</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Refusal Items</td>
<td>$M = 1.45$</td>
<td>$1.36$</td>
<td>$p = .87$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.73$</td>
<td>$1.81$</td>
<td></td>
</tr>
<tr>
<td>Stealing/Pica</td>
<td>$M = .23$</td>
<td>$.18$</td>
<td>$p = .53$</td>
</tr>
<tr>
<td></td>
<td>$SD = .53$</td>
<td>$.39$</td>
<td></td>
</tr>
<tr>
<td>Feeding Skills</td>
<td>$M = 2.82$</td>
<td>$1.91$</td>
<td>$p = .05$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.59$</td>
<td>$1.31$</td>
<td></td>
</tr>
<tr>
<td>Eats large amount/fast eater</td>
<td>$M = .32$</td>
<td>$.73$</td>
<td>$p = .20$</td>
</tr>
<tr>
<td></td>
<td>$SD = 1.13$</td>
<td>$.94$</td>
<td></td>
</tr>
<tr>
<td>Vomit/Rumination</td>
<td>$M = .55$</td>
<td>$.23$</td>
<td>$p = .15$</td>
</tr>
<tr>
<td></td>
<td>$SD = .91$</td>
<td>$.43$</td>
<td></td>
</tr>
</tbody>
</table>

* significance found with alpha set at .02
Discussion

The present study sought to examine possible feeding problems associated with the use of three different antiepileptics commonly utilized to control seizures in individuals with mental retardation. Overall, it appears that seizure medications do not have a significant effect on the frequency of feeding problems in the MR population as measured by the STEP. This certainly does not mean that seizure medications do not have any effect on feeding, rather, it seems that the effects are not enough to cause a significant difference in frequency of feeding problems when compared to others that are not on seizure medications. This finding is reassuring given that such a large number of severely handicapped persons require these drugs. However, it does appear that the one area that may differ in the MR population with people that are on seizure medications is in the feeding skills area. As discussed below, there may be a specific deficit (i.e., lack of motor control) that occurs more often in people with a seizure disorder, and this may consequently lead to impairment in the area of feeding skills. It is unclear as to whether these differences are due to the medication side effects, or the inherent differences between those that need antiepileptic medications and those that do not, but this would certainly be an informative avenue for future research.

As stated earlier, it was hypothesized that participants on phenytoin would be the most likely to have significantly more feeding problems than their matched controls. This hypothesis was based on previous literature that stated that phenytoin has been associated with more adverse side effects than other seizure medications (Vining, et al., 1999). Other sources such as The Handbook of Psychiatric Drug Therapy compares carbamazepine "favorably with the older anticonvulsant, phenytoin". Later, the
handbook asserts that valproic acid is "slightly worse than carbamazepine, but superior to phenytoin..." (1995, p. 124). Despite these findings, the present study found few feeding problems in any of the antiepileptic groups as compared with their matched control groups. Only one particular between-group difference was found. Participants on carbamazepine were significantly more likely to have some sort of feeding skill problem, as compared to their matched controls. The analysis of between-group differences for the feeding skills subscale compared the frequencies of the three items that made up the empirically derived scale. These items were whether the client could feed him/herself independently, whether the client required special equipment for feeding (i.e., G-tubes, scoop dishes), and whether the client required special positioning during feeding. An item analysis revealed that no significant differences between the participants on carbamazepine and their matched controls were found on each individual item. However, it was apparent that the item regarding whether the participants needed special equipment seemed to be nearing significantly greater proportions in the carbamazepine group than the control group. This suggests that participants that were on the antiepileptic carbamazepine were more likely to need special equipment when eating than their matched counterparts.

Although this finding was only significant in the carbamazepine group, participants in the valproate and phenytoin groups were both very close to significance in this subscale as well, when compared to their matched controls. Since it seems that all three of the medication groups were significantly (or close to significantly) more likely to have a feeding skills problem, it does not seem that it is the property of one certain antiepileptic medication that is causing these problems. Rather, it could be that a person
that has a seizure disorder is simply more likely to have a feeding skills problem. For example, perhaps someone with a seizure disorder has less control over their motor skills (Kerr, 2002; Mycek, 1997), and therefore needs special equipment in order to eat properly. The task of sorting out which of these differences was attributable to adverse medication effects can be difficult given the base rate of physical and behavior problems often present in this population (Alvarez, et al., 1998). However, because the prevalence of feeding problems and epilepsy in individuals with mental retardation is growing, these results may yield some useful information that can aid researchers and clinicians in the field. Specifically, these results may help researchers to understand that although other behaviors may be a result of the use of specific antiepileptics, frequency in feeding problems do not seem to be correlated with these types of seizure medications. Furthermore, being able to eliminate some possible causes of feeding problems can then help clinicians in making efficacious treatment decisions (Cooper, et al., 1995).

Although this study was not making comparisons across medication groups, it is important for researchers and clinicians to be aware of the dosage levels involved with the medications they are evaluating. The dosage level for each participant was calculated and categorized into one of 3 groups: high, medium, and low dosage. A low dosage level was defined as a person receiving 0-50% of a usual daily dose. A medium dosage level was defined as a person receiving 50-100% of a usual daily dose. Finally, a high dosage level was defined as a person receiving over 100% of a usual daily dose. The average daily dosage for participants in the carbamazepine group was in the medium to high range. The average daily dosage for participants in the valproate and phenytoin groups were in the low and low to medium range, respectively.
One issue that was not addressed in this study was the common practice of polypharmacy. Although all the participants in the experimental groups of this study were only on one antiepileptic at one time, it is common for patients to be on more than one antiepileptic simultaneously (Mycek, 1997). Future studies are needed to determine if the practice of polypharmacy may be of greater consequence in terms of side effects that may be manifested as feeding problems and other problematic behaviors.

One potentially unavoidable problem was that of the duration of the antiepileptics used. It was clear that the participants in this study were on these antiepileptics for at least 5 months, but some were receiving their antiepileptic for a longer amount of time than others. It was impossible to control for how long each person was on their medication, if the other variables were to remain the same (such as being on only one medication). Given this limitation, it is possible that some participants may have not had enough time to develop side effects, while others may have had enough time. Despite this, the fact that virtually no significant side effects were noted, lends doubt to whether this question may have been a serious confound.

Essentially, clinicians and researchers in the field of healthcare must always weigh the benefits and costs of the treatments they choose for their clients. Given the imminent dangers that arise if a patient is subjected to seizure activity without treatment, it remains a fact that some form of proactive treatment is needed for clients with seizure disorders. Additionally, antiepileptic medications are incredibly effective when used properly. Although side effects of specific antiepileptics are evident, this study supports that possible side effects manifested as feeding problems are not frequent enough to warrant an immediate halt to the use of these antiepileptics in the MR population. However, it
must be noted that future research must attempt to address some of the issues described in this study in order to make firmer conclusions on the use of antiepileptic medications.
References


Vita

Rinita Bhalchandra Laud is a third year graduate student in clinical psychology at Louisiana State University in Baton Rouge. Rinita was born in Mumbai, India, and was raised in Houston, Texas, since the age of 2. She graduated in the top 5% of her high school and was secretary of her graduating class for two years. Rinita then attended the University of Texas at Austin and received her Bachelor of Arts Degree, with a title in Liberal Arts Honors as well. Her minor from the University of Texas was in German. She is currently under the guidance of Dr. Johnny Lee Matson, and is specializing in working with mentally retarded individuals with mental health needs.