

**UNIVERSITY OF KWA-ZULU NATAL**  
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**HUMANITIES)**

**CLINICAL PSYCHOLOGY**

**DISTINGUISHING BETWEEN PSYCHOGENIC AND**  
**ORGANICALLY-BASED SEIZURES: THE SEARCH FOR**  
**CRITICAL PSYCHOLOGICAL VARIABLES.**

**AUTHOR: MARLENE WELLS**

**SUPERVISOR: DOUGLAS MANSFIELD**

**CO-SUPERVISOR: PROFESSOR STEVE COLLINGS**

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**Unless specifically indicated to the contrary, this thesis is the result of my own work**

## ABSTRACT

Differentiating between organic epilepsy and psychogenic pseudoseizures is a difficult task even for experienced practitioners. Both disorders present in a similar manner and at present there are no clinical signs that distinguish between them. Iatrogenesis may occur when psychogenic seizures are treated medically and sometimes aggressively in order to control seizure activity. Quality of life is negatively impacted on in both patient groups and stigmatisation and social isolation frequently occur. Psychiatric comorbidity is associated with both epilepsy and psychogenic seizures. The primary aim of this study was to explore the possibility of finding a definitive means of discriminating between the two patient groups. This study assessed quality of life and psychiatric dysfunction in both patient groups using the QOLIE-31 and the SCL-90-R instruments, respectively. The Seizure Questionnaire was used to assess qualitative aspects. The sample (n = 19) was made up of 10 females and nine males with a mean age of 30.6 years (SD = 8.9, range 18 - 44 years). One case of mixed seizures was excluded. The sample was taken from an epilepsy monitoring unit in a hospital in Durban, South Africa. On the scales of the SCL-90-R, Anxiety showed significant difference between groups and on the QOLIE-31 scales, Energy/Fatigue, Cognitive Functioning and Overall score showed significant differences. These differences were in the expected direction as found in previous research in the literature. These trends need to be interpreted cautiously given the sample size.

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# **DISTINGUISHING BETWEEN PSYCHOGENIC AND ORGANICALLY-BASED SEIZURES: THE SEARCH FOR CRITICAL PSYCHOLOGICAL VARIABLES.**

## **CHAPTER ONE**

Psychogenic seizures and organic epilepsy present similarly and they also result in a poorer quality of life for the sufferer as compared to the general population. In the case of both intractable epilepsy and of psychogenic seizures, the patient has possibly been to many emergency rooms to receive stabilising treatment; may have consulted several specialists, and have been on different combinations of anti-epileptic drugs (AED's). For both the epilepsy patient and the psychogenic seizure patient, there is a negative impact on the personal, social and occupational areas of their lives. At present there is no definitive diagnostic technique and an estimated seven or more years is lost in moving through the medical system to find a definitive diagnosis or seizure control.

Given that in South Africa there is an estimated 1% of the population suffering from epilepsy (this is an estimate only and may or may not include the cases of pseudoseizures), research needs to evaluate ways of distinguishing between the two seizure groups as they have very different management and treatment strategies. Much time and money is invested in pursuing seizure control and in the process these individuals endure the social stigma associated with epilepsy, as well as being unable to pursue normal everyday activities. Given that both epilepsy and psychogenic pseudoseizures are prevalent during the late teens to middle years (Lancman, Lambrakis & Steinhardt, 2001) this relates to a negative impact on the work productivity of this group of persons. The mean age of the present study is 30.6 years for both epilepsy and psychogenic seizure patients.

Since management and treatment of epileptic seizures and psychogenic pseudoseizures is completely different, accurate diagnosis is critical. With organic intractable epilepsy, comprehensive assessment will precede surgery in suitable patients, and with psychogenic seizures, comprehensive assessment should lead to a referral to a psychologist and/or a psychiatrist for therapy that is suitable for the particular patient. At present no diagnostic protocol exists for psychogenic pseudoseizures despite many years of research in this area.

The two patient groups have significant interpersonal, social and occupational problems that interfere with their day-to-day living and this is exacerbated by increased levels of depression, anxiety and other psychiatric disturbances which are generally secondary to the primary seizure disorders themselves. In South Africa in particular, there needs to be more research to both delineate the problem in terms of prevalence and severity, as well as to find realistic management and treatment protocols specific to our various cultures. These matters will be discussed further in the following chapters.

In chapter two, the nature and scope of the problem is expanded on as well as definitions and nosology for both organic epilepsy and for psychogenic seizures. Prevalence and aetiology will be discussed as will the problem of iatrogenesis which stems from diagnostic uncertainty and delay. Finally, impact on the quality of life of patients with epilepsy and of those with psychogenic pseudoseizures is discussed and a rationale for this study is expanded on.

Diagnostic procedures, difficulties thereof, and confounding issues of diagnostics are addressed in chapter three, as well as a look at the presentation of seizure activity in both patient groups. Psychological assessment is also discussed in this chapter, as well as cognitive phenomena which include the commonly presented problems of memory, attention

and concentration that are prevalent in seizure patients. This chapter ends with a discussion on co-morbid psychiatric conditions.

Chapter four is concerned with research methodology, including research aims, hypotheses and instruments used in this study. The setting for the study is explained with reference to participants, and ethics. The results of this study are discussed in chapter five. In chapter six, the findings are discussed with respect to the three instruments used, namely the SCL-90-R, QOLIE-31, and the Seizure Questionnaire. The final chapter covers limitations of the present study, recommendations and the conclusion.

Throughout this paper, use will be made of acronyms and an explanation is offered here to clarify these:

V-EEG monitoring : Video-electroencephalographic monitoring

AED's : anti-epileptic drugs

PTSD : posttraumatic stress disorder

MRI : magnetic resonance imaging

MMPI : Minnesota Multiphasic Personality Inventory

WAIS : Wechsler Adult Intelligence Scales

WAIS-R : Wechsler Adult Intelligence Scales – Revised

IDD : Interictal dysphoric disorder

SCL-90-R : Symptom Checklist-90-Revised

QOLIE-31 : Quality of Life in Epilepsy Inventory-31

A special note is offered on the nosology of seizures of non-epileptic origin. Throughout the literature, there is differing opinion of what is the best terminology to use when referring to

non-epileptic seizures. These seizures have variously been referred to as pseudoseizures, psychogenic seizures, psychogenic pseudoseizures, non-epileptic seizures, hysterical pseudoseizures, functional seizures and nonphysiologic seizures. Since some of these terms have pejorative overtones it is important to be sensitive to how the patient to whom you are referring may feel about the terminology. As discussed further in Section 2.1, in this study, seizures that are not organic in origin will be referred to as 'pseudoseizures', 'non-epileptic seizures' or psychogenic pseudoseizures'.

## CHAPTER TWO

### NATURE AND SCOPE OF THE PROBLEM

No matter how they are defined and classified, both intractable epilepsy and psychogenic seizures are intrusive in the lives of the patients that suffer from them. These disorders prevent the normal participation in life events as does the accompanying psychopathology. Families of the patients feel the negative impact of these invasive disorders and the dynamics of interpersonal relationships may hold the key to manifestation and preservation of the seizures particularly with respect to psychogenic seizures.

### 2.1 DEFINITION AND NOSOLOGY

#### 2.1.1 Organic epileptic seizures

Organic epileptic seizures have been defined as a manifestation of hypersynchronous discharges of the cortical neurons which have elements of motor activity, autonomic function, sensation and consciousness, identifiable on electrographic ictal pattern (Cavazos, 2002; Gumnit & Leppik, 1991 as cited in Lancman et al., 2001; Orsini, van Gorp & Boone, 1988). This class of seizures is sudden in onset and time-limited (Lancman et al., 2001). The diagnosis of epilepsy is only given if seizures recur (Neppe & Tucker, 1992 as cited in Lezak, 1995); having one seizure does not qualify for the diagnosis of epilepsy since seizures can arise from any condition that results in excitability of brain tissue (Pincus & Tucker, 1985; Lothman & Collins, 1990, as cited in Lezak, 1995).

Organic epilepsy, as classified by The South African League Against Epilepsy, can be divided into two main categories, generalised (involvement of both hemispheres) and partial seizures (involvement of one hemisphere).

Generalised seizures :

- Generalised tonic clonic seizures (previously known as grand mal seizures). Loss of consciousness is apparent and duration is a few minutes. These seizures involve vocalisations, stiffening of the body, falling to the ground, rhythmic tightening and relaxation of muscles, the person may turn blue around the mouth as a result of oxygen deprivation, and they may salivate and be incontinent.
- Absence seizure (previously known as petit mal seizures). Blank staring and failure to respond is common. Brief loss of consciousness, chewing and twitching or blinking of the eyelids is present.
- Myoclonic seizures. Involuntary, brief and sudden muscle jerks.
- Tonic seizures. General stiffening of the muscles without jerking. Consciousness may be lost and the person may fall to the ground.
- Atonic seizures. Sudden loss of muscle tone, loss of consciousness and falling to the ground.

Partial seizures:

- Simple seizures. Consciousness is not affected. Focal motor or sensory depending on what part of the brain is affected. The person may experience an altered sense of perception – déjà vu.
- Complex seizures. Consciousness impaired. It is a non-convulsive seizure and person may display abnormal behaviour or movements.

See Appendix A .

(Information obtained from: <http://www.epilepsy.org.za/>)

Intractable (medically refractory) epilepsy has been defined and classified as failure of at least two anti-epileptic drugs (AED's) with no control of seizure activity (Engel, 2003; Passaro, 2001).

### 2.1.2 Psychogenic seizures

The definition and classification of psychogenic seizures is more problematic. Nosology is complex and many different terms have been used: pseudoseizures, nonepileptic events, nonepileptic-pseudoseizures and psychogenic seizures (Lancman et al., 2001; Martin & Gates, 2000). In this study, seizures that are not organic in origin will be referred to as either 'pseudoseizures', 'non-epileptic seizures' or 'psychogenic pseudoseizures'. When quoting the work of another author, their terminology will be used.

Psychogenic non-epileptic seizures are essentially behavioural events that resemble or mimic organic epileptic seizures of all kinds but are not organic in origin; their aetiology is linked to psychological events particularly in the patient's history (Bowman, 2001; Lezak, 1995; Rosenberg, Rosenberg, Williamson, & Wolford II, 2000; Rowan, 2000). According to Bowman and Coons (2000) pseudoseizures are paroxysmal changes in behaviour that resemble epilepsy but are without organic cause and are not accompanied by the ictal, peri-ictal and interictal electroencephalogram (EEG) changes (spikes and slowing) that characterize epilepsy of organic origin.

Psychogenic seizures are widely accepted in the literature to be of psychological origin and to represent a somatic outlet for unmanageable psychic conflict (Abubakr, Kablinger & Caldito, 2003; Barry, 1996; Benbadis, 2004; Bowman, 2001; Stevenson & King, 1987). These seizures are paroxysmal events commonly considered to be manifestations of conversion

disorder or somatization disorder (Bowman, 2001; Iriarte, Parra, Urrestarazu & Kuyk, 2003; Loring, Meador, King & Hermann, 2000). Clinical studies of subjects with pseudoseizures have found high rates of dissociative symptoms and disorders; several authors have demonstrated a correlation between these conditions and abuse or psychological trauma (Arnold & Privitera, 1996, in Reuber & Elger, 2003; Betts & Boden, 1992; Bowman, 1993; Bowman & Markand, 1996, in Bowman, 2000; Coons, Bowman & Milstein, 1988 in Bowman & Coons, 2000; Snyder, Rosenbaum, Rowan & Strain, 1994 in Bowman & Coons, 2000). Bowman (2001) describes psychogenic seizures as psychiatric illness that presents with pseudoneurologic symptoms that resemble epileptic seizures. This type of seizure poses a diagnostic challenge to the medical profession as it can mimic any type of epilepsy particularly frontal lobe epilepsy which also has bizarre manifestations (Rowan, 2000). Such bizarre manifestations include to-and-fro movements of the arms, sudden jerking movements, wild lashing movements, cycling movements of the legs, and unusual vocalizations such as barking (Rowan, 2000).

Psychogenic seizure patients are a heterogeneous group of persons and within group variation is seen with respect to emotional functioning, mental abilities, demographic backgrounds and neurological status (Lezak, 1995; Loring et al., 2000). It is a common finding that psychogenic pseudoseizure patients perform at or near normal levels on neuropsychological testing (Lezak, 1995). Reuber and Elger (2003) suggest that with respect to neuropsychological assessment of the psychogenic seizure patient, a qualitative approach would yield more useful results than a quantitative one.

Classification of pseudoseizures is still being reviewed and Rowan (2000), considers that future research may result in a multi-axial classification system that is similar to that of the

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994).

### 2.1.3 Mixed seizures

It is not uncommon for some patients to present with epilepsy and pseudoseizures (Lancman et al., 2001; Niedermeyer, 1984). Barry (1996) also noted the frequent co-existence of the two disorders, but said further that one might suspect that they have unique characteristics which have to date not been researched. Ernst Rodin (1984) made this interesting observation:

Instead of the prevailing trend to dichotomize disorders as either 'organic' or 'psychogenic', it is much more useful to think in terms of the relative contributions of organic pathology and psychogenic elements to a given symptom at a given time (p.180).

It is critical to have a thorough history and to rely on a convergence of evidence and information before diagnosing a patient as having a psychogenic seizure disorder.

### 2.1.4 Physiologic non-epileptic seizures

The following are a group of physiologic non-epileptic seizures that frequently resemble epilepsy or psychogenic seizures and can lead to an inconclusive diagnosis.

*Syncope* – syncopal attacks are fainting attacks that are either vasovagal or cardiac in origin and if of the convulsive type, can easily be mistaken for epilepsy (Rowan, 2000). In convulsive syncope there is motor activity usually clonic in type of brief duration and there may be tonic activity as well making it very similar in presentation to generalised epileptic seizures (Gates, 2000).

*Paroxysmal Movement Disorders* – these are dysfunctions of the basal ganglia such as paroxysmal kinesigenic choreoathetosis and paroxysmal dystonia which may be misdiagnosed as epilepsy (Gates, 2000).

*Migraine* – atypical migraine headaches belong to a group of pain syndromes that can be confused with epilepsy presentation (Stevenson & King, 1987). Difficulty in diagnosis arises when the headache is minor or absent, and the patient may present with paroxysmal hemiparesis, discoordination, somatosensory symptoms, language difficulty or visual symptoms (Gates, 2000).

*Sleep Disorders* – many parasomnias can be mistaken for epileptic or psychogenic seizures and polysomnography has been instrumental in providing diagnostic clarity (Gates, 2000).

*Cardiac events* – loss of consciousness and convulsive movements during intermittent arrhythmias such as ventricular tachycardia or Stokes-Adams syndrome can mimic epileptic attacks (Gates, 2000).

## 2.2 PREVALENCE

Pseudoseizures are very prevalent in neurological practice and in general medicine as well (Abubakr et al., 2003; Benbadis, 2005a; LaFrance & Devinsky, 2002). South African figures are difficult to ascertain but the prevalence of pseudoseizures in tertiary assessment centres appears to be high. The South African Epilepsy Society estimates that 1% of the population have epilepsy but they have no statistics on psychogenic seizures. According to The Society there is a real need to obtain specific statistics, something which has not been achieved up to now (Noeline de Goede, personal communication, October 2005). The National Institute of Neurological Disorders and Stroke (2004) report that in the United States of America (USA), it is estimated that 1% of the population have epilepsy – similar to the South African statistic.

The prevalence of psychogenic seizures in the hospital in which this study was conducted is estimated at 40% of the patients being admitted for evaluation (C. Bottcher, personal communication, 2005). Grieve (2003) reports estimates of up to 30% of outpatients and 50% of inpatients in South Africa may be presenting with pseudoseizures rather than epilepsy. In comparison, Alsaadi and Marquez (2005) estimate that in the USA, 20 to 40% of inpatients (hospitals and epilepsy centres) and 5 to 10% of outpatients, present with psychogenic non-epileptic seizures. These figures are confirmed by Benbadis (2005b) who states that the estimate for inpatients in the USA is 20-30% of the referrals. The estimates for inpatients presenting pseudoseizures is very similar in the two countries, but for outpatients there is a higher estimated prevalence in South Africa. Lancman et al. (2001), state that estimates of prevalence for psychogenic pseudoseizures has yet to be established since the present estimates come from patient samples that present at tertiary epilepsy centres for evaluation and do not reflect those seizure patients in the general epilepsy population. This may conceivably be the case in South Africa as well.

### 2.2.1 Age

The literature indicates that the occurrence of pseudoseizures typically begins in young adulthood (Benbadis, 2004). Generally pseudoseizures are seen between the ages of 19 to 35 years of age, although cases have been reported as young as 4 years and the oldest 77 years. Pseudoseizures also appear to peak around 19 to 22 years, and again at around 25 to 35 years (Lancman et al., 2001). Notably this disorder affects a very active and productive sector of our workforce, resulting in loss of work productivity which could negatively impact the economy.

### 2.2.2 Gender

Numerous references in the literature indicate a predominance of female patients presenting with psychogenic pseudoseizures (Alsaadi & Marquez, 2005; Benbadis, 2004; Gates, 2000; LaFrance & Devinsky, 2002; Lancman et al., 2001; Thompson, 2005). Although this high representation of females is not fully understood, more females are linked to conversion disorders which are strongly considered to be an expression of psychogenic pseudoseizures (Lancman et al., 2001). Interestingly, Freud's patients with hysteria were also predominantly female. Although gender differences were noted in a significant proportion of previous studies, a study by van Merode et al. (2004) did not find a higher proportion of females in their pseudoseizure group (n = 40).

## 2.3 AETIOLOGY

### 2.3.1 Organic epilepsy

The aetiology of epilepsy has been clearly defined in the literature as relating to past infections (meningitis; brain abscess; viral, fungal and parasitic infections; allergic reactions to infections or immunizations), brain trauma; neoplasms; congenital malformations; vascular malformations; gliomas; and genetic predisposition (Ko, 2001; Pincus & Tucker, 1985; Stevenson & King, 1987). The following table of the aetiology of seizures is given by McIntosh (in Bennett, 1992, p.24).

Table 1. Aetiology of Seizures

I.	Congenital malformations present at birth
II.	Trauma <ul style="list-style-type: none"><li>A. Birth trauma – immediate and latent</li><li>B. Head trauma in children and adults</li></ul>
III.	Neoplasm <ul style="list-style-type: none"><li>A. Associated with neurocutaneous syndromes</li><li>B. Primary brain tumors</li><li>C. Secondary brain tumors</li></ul>
IV.	Vascular <ul style="list-style-type: none"><li>A. Anoxic ischemic neonatal injury</li><li>B. Arteriovenous malformation</li><li>C. Vasculitis</li><li>D. Ischemic cerebral infarction</li><li>E. Intracerebral hemorrhage</li><li>F. Subarachnoid hemorrhage</li><li>G. Venous sinus thrombosis</li></ul>
V.	Infection <ul style="list-style-type: none"><li>A. Meningitis</li><li>B. Brain abscess</li><li>C. Subdural empyema</li><li>D. Viral infections</li><li>E. Fungal infections</li><li>F. Parasitic infections</li><li>G. Allergic reactions to infections or immunizations</li></ul>

Genetic predisposition is considered by some authors to be rare or doubtful; however the general consensus for those who consider heritability to be important is that certain seizure types are under the influence of a genetic factor whereas in others the link is less clear (Cavazos, 2002; Fawcett, Rosser & Dunnett, 2001; Lezak, 1995). Kolb and Wishaw (2003) propose that certain genotypes have a predisposition to seizures under certain environmental conditions. The major symptom of epilepsy, the paroxysmal excessive neuronal discharge, is in fact a genetic potential in every human being (Blumer, Montouris & Davies, 2004).

Epilepsy used to be conceptualised as an imbalance of excitation and inhibition in the neurons of the brain (McIntosh, 1992), but as a result of research conducted more recently it is suggested that both excitation and inhibition may participate in the generation of hypersynchronous activity (Cohen, Navarro, Clemenceau, Baulac & Miles, 2002). (See Appendix B for causes and types of epilepsy).

### 2.3.2 Psychogenic seizures

A history of childhood sexual, physical or emotional abuse are widely hypothesized as precipitating events in the manifestation of psychogenic seizures (Barry, 1996; D. Blumer, personal communication, July 22, 2004; Chemali & Meadows, 2004; Fleischer, Staley, Krawetz, Pillay, Arnett, & Maher, 2002; Grieve, 2003; Lancman et al., 2001; Rowan, 2000). Related research has shown that not only is childhood abuse significantly linked to the manifestation of pseudoseizures, but if there is recurrent abuse in adulthood, the risk is much higher for pseudoseizure presentation (Barry, 1996; Blumer, 2000; Blumer, personal communication, July 22, 2004; Bowman, 2000; Fleischer et al., 2002; Lancman et al., 2001; van Merode et al., 2004; Reuber & Elger, 2003; Torem, 1993, as cited in Bowman, 2000). Further to this, abuse in adulthood is seen in the literature as an important factor since psychogenic seizures frequently begin or recur when childhood abuse is followed in adulthood by trauma or by events that are reminiscent of childhood trauma (Blumer, 1995; Bowman, 1993; Torem, 1993, all in Bowman, 2000).

Blumer (2000; personal communication, July 22, 2004), who has researched and worked with many pseudoseizure patients, stresses the presence of pain syndromes and a history of psychological trauma and abuse commonly found in these patients. Pseudoseizures can be

conceptualised as the translating of emotions into physiological and chemical expression even though the true mechanisms for this remain unknown at this time.

Wolman (1988) described the link between the psychological and the physiological as the neuroendocrine system translating emotions into biochemical processes and translating chemistry into psychology. Wolman sees the complexity of mind-body interaction as:

Nature crosses this bridge from mind to body and from body to mind every day in a series of psychosomatic and somatopsychic phenomena. Mind and body represent two levels of transition; the mind is a higher level of transition. (p.48).

In a study by Fleischer et al. (2002), it was found that psychogenic seizures have significantly higher levels of trauma related phenomenology when compared to epilepsy patients (psychogenic seizures, n = 31; epilepsy, n = 32). They further found that the symptom profiles of the psychogenic seizure patients closely resemble those of clinical samples of patients with diagnosed Posttraumatic Stress Disorder (PTSD). Bowman (2001) found that behaviours diagnosed in some patients as pseudoseizures are actually dissociative flashbacks of trauma and cautions that patients should be screened for PTSD if there is a history of trauma. Research has for some time recognised that trauma and abuse can alter the structure and function of the brain (Cromie, 2003). Nemiah (1982, in Wolman, 1988) related psychosomatic disorders to defects in neural mechanisms and he also hypothesized that trauma could affect the functions of the hypothalamic autonomic centres in the brain. Bowman (2000) places emphasis on antecedent and concurrent life events of pseudoseizure patients as being the key to the psychic reasons for their seizures and therefore linked to treatment. She categorized these life events into three groups, (1) childhood and adulthood

trauma, (2) bereavement and losses, and (3) acute or situational stresses. Bowman conducted research into life events using structured and exploratory interviews and the results indicate that the life histories of her subjects (n = 58) were significant contributors to the onset, worsening and recurrence of pseudoseizures.

Reuber and Elger (2003) see the aetiology of psychogenic seizures as an interaction of the following predisposing, precipitating and perpetuating factors:

- (a) psychiatric disorders: somatoform or dissociative disorders, affective, anxiety and posttraumatic stress disorder
- (b) abnormalities of personality development, especially borderline personality disorder
- (c) 'organic' brain disorders such as epilepsy, and learning disability or minor head injuries
- (d) a context of social or family conflict and trauma
- (e) a history of sexual or physical abuse in childhood and adolescence.

Research needs to recognise that a temporal dimension may play a significant part in the manifestation of psychogenic seizures. In the days of Freud, Charcot, and Janet, 'hysteria' was the way (especially women) presented when psychologically dysfunctional. Psychogenic seizures may be a modern day manifestation of such dysfunction – a way of redirecting energy of the unconscious conflict, of expressing psychic energy in a physical way (G. Hayes, personal communication, May 2004). Remembering that psychogenic seizures are a commonly accepted symptom of psychological dysfunction, we need to refer to what Frosh (1999) said in the psychoanalytic tradition of the similarity of defence mechanisms and symptoms: "...the function of symptoms, too, is to avert danger, and in many respects they operate in the same way as defences, both to redirect the energy of unconscious material and to give it some form of substitutive expression". (p.66)

Bowman and Coons (2000) recognise the work of many authors who propose that conversion and dissociation are intimately connected in the somatic-dissociative spectrum of expressing distress: Betts-Boden, 1992; Bowman, 1993; Bowman & Markand, 1996; Kuyk, Van Dyk & Spinhoven, 1996; Nash, 1993; Nemiah, 1991, all in Bowman & Coons, 2000).

Another explanation for the presentation of psychogenic seizures is that of familiarity – where the patient has had the opportunity to observe epileptic seizures, or has familiarised him/herself with the symptomology and consciously or unconsciously chooses to manifest psychological discomfort this way (Bowman, 2000; Bowman, 2001; Kanner & Weisbrot, 2001).

#### 2.4 DIAGNOSTIC UNCERTAINTY AND IATROGENESIS

Presently no clinical signs are specific to pseudoseizures, despite much research in the area. There is a need for better diagnostic tools for pseudoseizures as their early detection is associated with a positive outcome (Barry, 1996; van Merode et al., 2004). There is a significant delay in diagnosis of psychogenic seizures despite the availability of video-electroencephalographic (VEEG) monitoring which would show the absence of ictal pattern during an event. During this delay, the patient will be put on AED's indicating that the suspicion for psychogenic symptoms may not be high enough (Benbadis, 2005a).

Serious iatrogenic harm may result from incorrect diagnosis when pseudoseizures are treated with AED's and more especially when high doses are used in emergency situations to stabilize apparent *\*status epilepticus* in a patient that does not have organic seizures (Barry,

1996). Iatrogenic complications are common and life threatening (Kanner, 2003; Lancman et al., 2001; Reuber & Elger, 2003).

*\*Status epilepticus* – a rapid succession of convulsive epileptic seizures without the patient regaining consciousness between events, this is a neurological emergency which if untreated may be fatal.

Mostly the diagnosis of psychogenic pseudoseizures is based on an exclusion of epilepsy, that is, the diagnosis of psychogenic origin is only one of elimination, and resulting in a low level of certainty which in turn results in a low level of comfort in communicating the diagnosis (Benbadis, 2005a; Gigineishvili, 1999). We need to be in a confident and positive position when diagnosing pseudoseizures as this is a critical indicator of positive response to entering therapy.

Psychogenic symptoms are underdiagnosed and this links to an extensive cost of diagnostic evaluation before the diagnosis of psychogenic seizures is finally made (Benbadis, 2005a). Persons with psychogenic seizures spend inordinate amounts of time and money moving through the medical system being treated for an organic condition which actually does not exist in them. In terms of lost manpower hours and invasive medical interventions, we need to arrive at a more precise and early detection of this kind of seizure.

## 2.5 NEED FOR ACCURATE AND EARLY CORRECT DIAGNOSIS

Arriving at the correct diagnosis and then sensitively imparting this to the patient is critical to positive outcomes and successful treatment for the pseudoseizure patient (Benbadis, 2005a; Iriarte et al., 2003; Lancman et al., 2001; Lesser, 2003; Reuber & Elger, 2003; Thompson, 2005). Pseudoseizures are commonly misdiagnosed as epilepsy and once this diagnosis is

given it is very difficult to undo (Benbadis, 2005a). Two major issues of concern around misdiagnosis are iatrogenesis and financial cost (Barry, 1996; Fiszman, Vieira Alves-Leon, Nunes, D'Andrea & Figueira, 2004; Kanner, 2003b; LaFrance & Devinsky, 2002; Reuber & Elger, 2003). Pseudoseizure patients are not easily diagnosed and much time and money is spent moving from one specialist to the next and undergoing diagnostic evaluation as well as frequent emergency room visits. In an emergency situation, these patients are exposed to possible iatrogenic complications as a result of complex medical procedures to stabilize them. Despite diagnostic techniques currently available, the time between manifestation of symptoms and diagnosis remain unacceptably long, Reuber & Elger (2003) have estimated this to be 7.2 years, and Benbadis (2004) puts this delay in final diagnosis at an average of seven to ten years. Giving a diagnosis of psychogenic seizures needs to be done very sensitively as this is a critical moment recognised by many authors to be an important factor in positive outcomes (Barry, 1996; Lesser, 2003).

A protocol has been developed by Shen, Bowman and Markand (1990) for managing the possible negative reactions to receiving a diagnosis of psychogenic seizures (Iriarte et al., 2003; Thompson, 2005) and although it has been positively received there is some criticism in the literature. This protocol for presenting the diagnosis attempts to address the sensitive aspects of giving a diagnosis of psychogenic causes and not one of organic causes for unexplained and distressing symptoms. Some of the suggestions contained in the protocol include explaining the seizures in positive terms, i.e. they are not organic and the need for AED's falls away, and that these patients are not 'mad' as psychogenic causes are often identified in patients with such seizures. Although Iriarte et al. (2003) and Kanner (2003a) agree with the protocol, these authors disagreed with a point Shen et al. make of the patient being able to exert some control over their seizures; the matter of voluntary control remains

controversial in the literature. Shen suggests that the events may resolve spontaneously, but adds that the sufferer may also be able to exert conscious voluntary effort to abort the attacks (Iriarte et al., 2003), and this is the point of controversy.

## 2.6 IMPACT ON QUALITY OF LIFE

Quality of life is clearly negatively impacted on by both epilepsy and pseudoseizures. Buelow and Ferrans (2001) see quality of life as a multidimensional construct encompassing the far-reaching effects of the epilepsy itself as well as the side-effects of medication, psychological sequelae of the seizures, having no control over the seizures, and also the social stigma attached to the disorder. The psychosocial and psychiatric problems associated with epilepsy are often not recognised and this impacts negatively on the quality of life of these patients (Kanner & Weisbrot, 2001). Dodrill (1984, in Buelow & Ferrans, 2001) identified certain important aspects reflective of quality of life in epilepsy: Family background; emotional adjustment; interpersonal adjustment; vocational adjustment; financial status; adjustment to seizures; medication and medical management; and overall psychosocial functioning. All these aspects link to the person's values, expectations and perspectives, thereby defining their quality of life. This evaluation, although possibly biased, belongs to the person and is the only opinion that actually counts. It is important to note that an understanding of quality of life places emphasis on the patient's perception more so than on that of the medical personnel involved in their case, and that for chronically ill patients, health status is a major determinant of their quality of life (Loring et al., 2000).

Both patient groups are restricted from driving a motor vehicle and this impacts negatively on their independence and autonomy. Lack of autonomy is further reflected in low self-esteem,

impaired social relationships and reduced occupational functioning (Iriarte et al., 2003; Loring et al., 2000; Passaro, 2001). In South Africa, it is not illegal to drive a vehicle if you have epilepsy, however the decision to drive or not rests with the patient and their doctor and is based on type and severity of seizures and degree of seizure control (The Epilepsy Society of South Africa, 2005). Loring et al. (2000) state that the paroxysmal nature of epilepsy limits the sense of well-being and important aspects of independence that are not generally associated with other chronic medical conditions. It is apparent then that quality of life is more than just the health status, but relates to the patients lived experience in every aspect of their lives.

## 2.7 RATIONALE FOR THE PRESENT STUDY

In the case of both intractable epilepsy and psychogenic seizures, the patient possibly has been to many emergency rooms for treatment, consulted several neurologists, and been on different anti-epileptic drugs (AED's). These patients may become slaves to their conditions, may be unable to drive, may lose opportunities for employment and may indeed experience significant social problems. Whether a person suffers from intractable organic epilepsy or psychogenic seizures, the effect on their lives is immense and their potential for optimal functioning is reduced, if not minimised. This effect extends to the family context as others are affected by the often intangible but very real presence of these disorders.

The management and treatment of intractable epilepsy is completely different to that of psychogenic seizures. With the former, comprehensive assessment will precede surgery in suitable patients; while with the latter, comprehensive assessment should lead to referral to psychologist and or psychiatrist for appropriate therapy. Both management and treatment

clearly depend on correct diagnosis for the appropriate measures to be implemented so that the person can resume as normal a life as is possible. It is important to carefully monitor the presentation and context of each of these seizure disorders in an attempt to identify and isolate any variables that may distinguish between them. It is apparent that psychogenic symptoms are under diagnosed, keeping the patient in the medical system and contributing to costs of extensive diagnostic workup (Benbadis, 2005b).

Persons suffering psychogenic seizures make up a significant portion of seizure patients in our country, as well as internationally. Many years are spent in and out of medical facilities and much money and time is absorbed by this, more importantly, these patients have a poor quality of life. It is imperative for research to address this issue and to explore ways of identifying these patients, implementing support systems and therapeutic interventions for them and their families as well as providing clear statistics to clarify the problem and to raise awareness for it.

The literature generally refers to the need for future research to identify the potential spectrum of cognitive profiles that exist in patients with psychogenic seizures, as this is an area of common dysfunction in both seizure types. Swanson, Springer, Benbadis & Morris III (2000) suggest that future research "...may elucidate the role of neuropsychological assessment in the diagnosis of NES by using cluster analysis to identify the potential spectrum of cognitive profiles that exists in this population" (p.134).

Clearly, accurate diagnosis is critical to the management and treatment of these two disorders that are so very different. An average of five days is required for meaningful observation and assessment of patients in an epilepsy unit; the costs incurred are very possibly out of the range

of normal medical aid benefits adding to the burden on the family of the patient. By identifying variables specific to psychogenic seizures, this research would contribute to a more specific assessment and this would simplify and shorten the evaluation period.

Although identifying distinguishing variables is critical as this would contribute to a future test battery for assessing psychogenic seizures, it is one contributing factor in a multiplicity of factors. Converging evidence is critical in attempting to understand and explain the phenomena of psychogenic presentation. Psychological dysfunction is the key to psychogenic seizures and to why they present and when and how they do. It may be that the increased prevalence of these seizures in recent times indicates that psychogenic seizures are possibly a modern way of manifesting psychological dysfunction just as hysteria was 'fashionable' in the days of Freud. Research needs to be aware of the range of factors that could contribute to the manifestation of these seizures – an assessment of psychological (dys)functioning is important in obtaining a psychological profile indicative of patients who present with these seizures. If we consider the impact of seizures on the lives of patients we can understand the necessity for research to contribute to facilitating accurate diagnosis.

Patients with epilepsy have to deal with altered lifestyles, like possibly not being able to drive, or the impact of cognitive slowing, and then the impact of social stigma attached to epilepsy. They and their disorder are seldom truly understood by laypersons. Some of the old perceptions of this disorder live on. These people have formed a consciousness of who they are in the world that is influenced by their unconscious and by the environment. The feedback they receive from these spheres provides ways of being in the world. The feedback may be misinterpreted (or itself negative), processed by misattribution and faulty perception. Added to the psychological impact of the disorder itself and the negative side effects of

AED's, the patient may well develop a negative attitude and certainly may become depressed and anxious. This is compounded by the restrictions placed on daily living and the uncertainty of the future.

For the psychogenic seizure patient the picture is no less compounded. They have been diagnosed as having epilepsy until further investigated. They have suffered seizures no less real than that of the patient with organic epileptic seizures and have more than likely been taken to an emergency department many times. Here they would possibly have received aggressive treatment in an attempt to stabilise them, measures such as high doses of intravenous anti-epileptic medication, or sometimes even general anaesthesia. Clearly iatrogenic complications may arise as a result of this, and these complications may not only cause organic illness but indeed could be life-threatening. These patients also have a conscious concept of who they are, informed by their unconscious and by the environment in which they live. The feedback that they receive once again informs how they conceptualise their space in the world and the decisions they make as to how to act and react as well as use of coping mechanisms and defences. Given that the origins of psychogenic seizures frequently point to childhood and possible current trauma, these persons are commonly manifesting a psychopathology which in itself is an indication of faulty operations and objectifications. Their interactions with others are very likely to be problematic and relationships tenuous at best. Their psychological dysfunction adds to, or is in essence caused by, the dysfunctional interactions with the environment. The effects of unnecessary AED's will significantly impact on their ability to remain at least somewhat functional.

Consciousness, awareness and the creation of self-identity defines how one behaves in the world as well as the coping mechanisms one employs to interact in this world and to defend oneself. Consciousness theories can be used to understand how the individual perceives

him/herself within the context of the unconscious contents and the external environment.

Andrewes (2001) reminds us that until recently the study of consciousness has been neglected in psychology but it is an important aspect of neuropsychological investigation. The study of conscious awareness embraces our external environment as well as our internal environment in terms of imagery and thought. Consciousness enables us to control and direct different functions. According to the Global Workspace Theory (Baars, 1997), much is now being discovered about the role of consciousness in the nervous system, how consciousness appears to be the main way in which the nervous system adapts to challenging events in the external world.

What is needed in research is deeper understanding and awareness raising of the complex and mostly difficult world of persons suffering unpredictable and invasive seizure activity of the brain.

## CHAPTER THREE

### 3.1 DIAGNOSIS

Psychogenic seizures and epilepsy have a superficial similarity making it difficult to distinguish between the two disorders without valid video-electroencephalographic (VEEG) monitoring as well as thorough assessments and the taking of a case history. To further complicate the profile, the patient with epilepsy can present with psychogenic pseudoseizures as well, making diagnosis even more challenging. (see Appendix C for semiologic details that can help to distinguish between epileptic and psychogenic seizures).

#### 3.1.1 Standard diagnostic procedures for epilepsy and psychogenic seizures

A prime part of the evaluation of patients presenting with any seizure disorder is magnetic resonance imaging (MRI) used to rule out possible lesions in the brain (Cavazos, 2002; Rowan, 2000). MRI technology uses a large magnet and a radiofrequency pulse of a certain resonance to create an image of the soft tissues of the human body. This is a safe, non-invasive procedure.

The advent of video-electroencephalographic (VEEG) monitoring has enabled the physician to accurately assess the electrical activity of the brain during ictal events. VEEG telemetry also allows the physician to match brain rhythms with behaviour and seizure activity.

Epilepsy can be definitively diagnosed and the focus located with VEEG monitoring. VEEG monitoring has long been considered the gold standard for non-epileptic seizure diagnosis (Barry, 1996; Benbadis, 2004; Bowman & Coons, 2000; Fiszman, Vieira Alves-Leon, Nunes, D'Andrea, & Figueira, 2004; LaFrance & Devinsky, 2002; Lancman et al., 2001; Loring et

al., 2000; Reuber & Elger, 2003; Rowan, 2000 Thompson, 2005). To differentiate clearly between the two disorders, it is essential to have an event and preferably two events recorded on the VEEG telemetry as epilepsy presents an ictal pattern, but psychogenic seizures do not. As discussed in Section 3.1.3, scalp electrodes do not detect seizure activity in the frontal lobes, and this is an important point to consider with respect to diagnostics.

Both organic epilepsy and psychogenic seizure patients are admitted to a specialised epilepsy unit particularly if they are unresponsive to AED's. In this unit, patients are evaluated for differential diagnosis, medication adjustment or surgery evaluation. The specialised epilepsy unit provides a safe, secure medical environment in which to observe events as they happen, and is equipped with video EEG telemetry with which the specialist can assess the electrical activity of the brain during ictal events (Lancman et al., 2001; Passaro, 2002). The epilepsy unit in which this research was undertaken is fully equipped and can observe two patients at any one time. The average observation period for a patient is five days, during which all tests, assessments and consultations are carried out. During this time the patient is taken off medication to facilitate the presentation of seizure activity for monitoring. The team of professionals that attend, monitor, and test these patients include: a neurotechnologist, a neurologist, a neurosurgeon, a neuropsychologist and if required a neuroradiologist. These specialists are called upon as needed to provide expert opinion or to carry out diagnostic procedures. In a typical unit, cameras allow patient to be viewed throughout the day by means of remote panning and infrared detectors. Patients are typically wired with a standard 10-to 20- electrode array (see Appendix D) with the use of special adhesives that allow prolonged contact with the scalp (Lancman et al., 2001). During VEEG monitoring, an opportunity exists for the neurotechnician to observe the behaviour that is presented in order to aid diagnosis. The presence or absence of responsiveness during the event can be

observed, as well as the kind of motor activity presenting. In addition the neurotechnician can attempt to alter repetitive, tonic or dystonic behaviour by intervention, as this is possible in the case of pseudoseizures (see Section 3.1.2.8 and 3.1.2.9). Pupillary reactivity and plantar responses can be evaluated (Rowan, 2000).

It is common practice in specialized epilepsy centres to use induction protocols in order to induce seizures for observation, diagnosis and classification. Although controversial due to ethical concerns, the essential principle behind provocative techniques is suggestibility (Benbadis, 2004; Reuber & Elger, 2003). Managed health care is a reality today and this restricts the stay in hospital for long term diagnostic observation and this is where provocative techniques are helpful (Lancman, et al., 2001). There are different types of provocative techniques: withdrawal of medication; sleep deprivation; saline injection; carotid alcohol pad; hyperventilation; photic stimulation, suggestion, and the application of a tuning fork to the head (Benbadis, 2005a; Lancman, et al., 2001; Barry, 1996). In the epilepsy unit where this research took place, the protocol includes: saline injection; photic stimulation; drug withdrawal; sleep deprivation; and hyperventilation (C. Botcher, personal communication, 2004).

Ultimately psychogenic seizure diagnosis is based on a process of triangulation involving the patient's history, observation of a typical seizure, and lack of physiological or neurological explanation for the seizures.

### 3.1.2 Comparison of presentation of event

Although difficult to distinguish between organic epileptic seizures and psychogenic seizures, certain ways of presenting during an event are more especially associated with either psychogenic seizures or epilepsy. Provocation by suggestion remains a reliable sign that points to psychogenic seizures. The method used to provoke the seizure is not as important as the suggestion of the possibility that a seizure may result. The following factors are monitored in clinical assessment:

#### 3.1.2.1 Trigger factors

In organic epilepsy, stress is frequently cited as a trigger, whereas in psychogenic seizures the trigger is usually in the form of an emotional upheaval like personal loss, frustration or an altercation with someone (Gates, 2000).

#### 3.1.2.2 Onset and cessation

In epileptic seizures the onset is sudden and so to the cessation of an event. With psychogenic seizures, the onset is typically gradual becoming more vigorous as it progresses and the cessation is gradual (Gates, 2000).

#### 3.1.2.3 Duration of event

Epilepsy is usually fairly discrete lasting at the most a few minutes; however *status epilepticus* may occur when there is a rapid succession of seizures without recovery of consciousness in between. Psychogenic seizures are usually longer in duration and may present resembling status epilepticus for which aggressive treatment may even prove fatal (Blumer, 2000).

### 3.1.2.4 Auras

The presence of an aura is common in epilepsy, and with focal lesions the aura can be related to the damaged area (Pincus & Tucker, 1985). In complex partial epilepsy the auras include, autonomic sensations (blushing, changes in respiration etc), cognitive sensations (déjà vu, dreamy states), affective states (fear, panic, elation, depression) and more typically, automatisms such as lip smacking and chewing (Sadock & Sadock, 2003). Auras are found in pseudoseizures as well, but they are clinically dissimilar to those in epilepsy. These auras can include unusual feelings, light-headedness, strange tastes, sensations of warmth and headaches (Lancman et al., 2001).

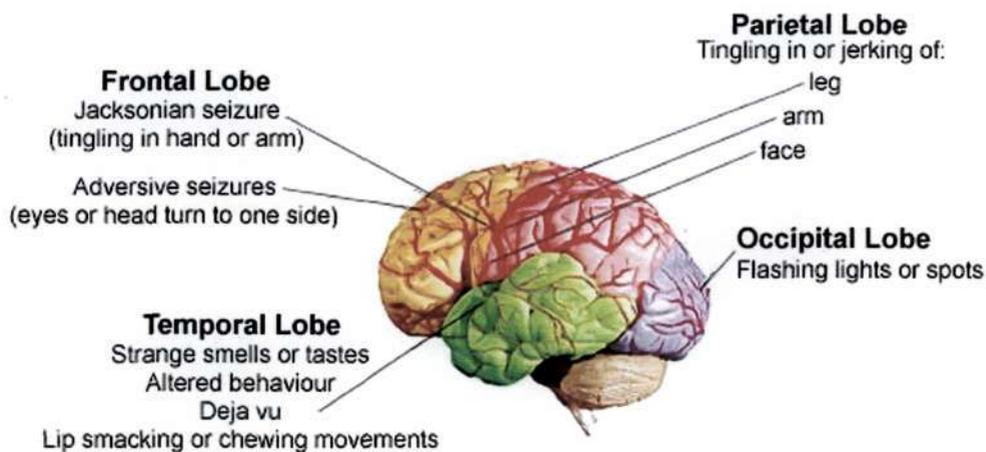


Figure 1. Brain areas and common auras and behaviour (The Epilepsy Society of South Africa).

### 3.1.2.5 Nonphysiologic progression

In epilepsy there is a distinct physiologic progression of motor activity based on anatomic and physiologic principles (Gates, 2000), as in the Jacksonian seizure where a simple motor seizure starts in one area of the motor cortex and sequentially moves along the cells thereby involving the representative body parts (Andrewes, 2001). The exception here is frontal lobe

seizures which have a bizarre presentation (Gates, 2000). In psychogenic seizures there is no distinct physiologic progression and therefore progressive involvement of body parts does not adhere to a known anatomic pattern.

#### 3.1.2.6 Pelvic thrusting

This is common in psychogenic seizures but can also be present in mesial frontal epileptic seizures (Lancman et al., 2001).

#### 3.1.2.7 Dystonic posturing

This is highly suggestive of psychogenic seizures and can range from flexion and inversion of feet to full-blown opisthotonus. There may also be twisting movements of the body (Gates, 2000).

#### 3.1.2.8 Ability to interfere with or modify motor activity

With psychogenic seizures it is possible for the neurotechnician to modify or stop motor activity by restricting a limb or changing the patient's position. This would be difficult if not impossible in organic seizures (Gates, 2000).

#### 3.1.2.9 Avoidance behaviour

If avoidance behaviour is present this is suggestive of psychogenic seizures. If the neurotechnician holds the patient's arm over their head during an event and then drops it, the arm will invariably fall to one side and avoid the face. Similarly, if a threat is present the patient will blink their eyes or move the face away (Gates, 2000).

(see Appendix C for distinguishing observations).

### 3.1.3 Difficulties with diagnostics

Although VEEG monitoring is used in the diagnostic protocol for both epilepsy and pseudoseizures, there are instances where this procedure is not successful in detection or ictal pattern or in making a differential diagnosis. Mostly epilepsy can be definitively diagnosed and the focus located with VEEG monitoring but when the epilepsy has a deep focus in the brain structures it becomes difficult to detect electrographic ictal pattern via the scalp electrodes (Lancman et al., 2001).

Scalp electrodes typically record cortical electrical activity to a depth of five millimetres within the cortical substance, therefore only reflecting surface activity (Stevenson & King, 1987). Psychogenic pseudoseizures can have a similar physiological presentation to frontal lobe epileptic seizures and further to this, VEEG recording of scalp electrodes do not detect frontal lobe epileptic seizures (Lezak, 1995; Shulman, 2000), so, in essence, we have inconclusive results for both frontal lobe epileptic seizures as well as for psychogenic seizures, as the VEEG does not distinguish between the two.

Iriarte et al. (2003) critique the use of VEEG for diagnosis of pseudoseizures because of the similar non-diagnostic result found in epileptic focus in the mesial frontal regions of the brain. There is a confounding similarity in the presentation of pseudoseizures and the bizarre presentation of frontal lobe epilepsy. There appears to be no definitive way of differentiating between the two disorders. These authors warn of the confounding issue of deep frontal lobe seizures and state that recording of epileptiform discharges at midline electrodes (Fz, Cz, Pz) (see Appendix D) should warn against premature diagnosis of psychogenic seizures as this may be an indication of epileptic seizures of mesial frontal origin which are frequently misdiagnosed as pseudoseizures.

### 3.1.4 Confounding issues in the differential diagnosis

It is critical that organic pathology is excluded with imaging studies (Benbadis, 2004) and this should form part of the primary diagnostic protocol. Non-epileptic seizures are an important alternate explanation for intractable epilepsy (Abukakr, et al., 2003), these two disorders account for the patients admitted to a tertiary epilepsy unit for further diagnostic clarity. It is essential to differentiate between dissociative states based on neurotic mechanisms and epilepsy or other organic conditions (Niedermeyer, 1984). Perhaps the greatest diagnostic challenge lies in differentiating between frontal lobe epilepsy and pseudoseizures. Frontal lobe epileptic seizures can appear bizarre and demonstrative if they involve the supplementary motor area, or they may involve a strong emotional component such as fear if they involve the cingulum, making them similar to pseudoseizures (Saygi, Katz, Marks & Spencer, 1992, Kanner, Morris, Luders et al., 1990, all in Reuber & Elger, 2003). Given the interconnections of the anterior cingulate with underlying limbic structures and areas of the frontal lobes, there could be exceedingly subtle disturbances which could manifest in problems of emotionality, information processing and self-monitoring. The study of the anterior cingulate is a rapidly expanding area of interest whose importance may have been previously unrecognised (D. Mansfield, personal communication, January 12, 2006).

Psychological and neuropsychological assessments have been used in studies attempting to discriminate between psychogenic seizures and organic epilepsy. While some studies have found reliable and consistent trends, others have not (Barry, 1996) and it seems that discrimination on this basis remains questionable.

Diagnosis of pseudoseizures is particularly challenging to the clinician even after much exposure to ictal events; nevertheless, the onus is on the clinician for correct recognition of these two types of paroxysmal events (Lancman et al., 2001; Stevenson & King, 1987).

#### 3.1.4.1 Frequency of seizures

In both intractable epilepsy and psychogenic seizures there may be a high seizure frequency. In the case of intractable epilepsy, high frequency should alert to concurrent illness or AED non-compliance (Rowan, 2000).

#### 3.1.4.2 Response to anti-epileptic drugs

A common feature to both disorders is that of non-responsiveness to AED's. Medically refractory epilepsy is unresponsive to medication and surgical intervention is indicated for seizure control. Epilepsy is considered to be medically refractory if there is failure of two or more AED's (Engel, 2003; Passaro, 2001). Engel (2003) points out that the abundance of new AED's on the market will result in a greater delay for surgical referrals since it will take so much longer to prove that seizures are unresponsive to every AED and combinations of AED's. In the case of psychogenic seizures, the mechanisms at cellular level of epilepsy are not present so the AED's are not effective or are only temporarily effective.

#### 3.1.4.3 Emotional response

An interesting phenomenon of psychogenic seizures is that of disturbed emotionality. Patients tend to show an unusual lack of concern about their seizures ("La Belle Indifference") or can be excessively emotional. Inappropriate affect is commonly associated with pseudoseizures (Benbadis, 2004) and although it is not uncommon for excessive emotion to be present in both epilepsy and psychogenic seizures, it may point to psychogenic seizures

if it is accompanied by weeping etc (Rowan, 2000). Gerald McIntosh (in Bennett, 1992) explains that emotionality in persons with seizure disorder varies considerably between individuals, but remains typical of the particular person. Commonly fear is experienced during the seizure-related psychic experience, but pleasure, sadness and vague familiarity and aggression may also be present (Andrewes, 2001).

#### 3.1.4.4 Injury

In epilepsy it is common to find injuries as a result of the seizures: tongue biting, lacerations and fractures, but in psychogenic seizures this is not common. If injuries occur this should alert as to the possible severity of the underlying psychiatric disorder (Rowan, 2000).

#### 3.1.4.5 Pain and history of abuse

Blumer (personal communication, July 22, 2004) stressed the importance of screening for pain syndromes as well as previous abuse in pseudoseizure patients. Blumer (2000) stated that a majority of pseudoseizure patients have suffered the pain of severe abuse in the past. It is no surprise then that the majority of pseudoseizures tend to be preceded, often in a crescendo (considered pathognomonic for pseudoseizures), by a prodrome of pain. Trauma causes pain, often unbearable and this is frequently dealt with by repression or dissociation (Blumer, 2000). Chronic pain is often reported by pseudoseizure patients and this is linked to somatization and psychogenic pain (Benbadis, 2004). Self-esteem may be related to the appearance of physical pain as a conversion symptom and the individual may restore lost self-esteem by suffering pain and this is linked to a belief that he/she would function well in all areas of life if not for the pain (Christie & Mellett, 1981).

### 3.1.5 Psychological assessment

Some psychological and neuropsychological assessments have been used extensively in previous studies attempting to discriminate between the two disorders. The Minnesota Multiphasic Personality Inventory (MMPI) is frequently used and in clinical studies of subjects with pseudoseizures, there have been consistently elevated scores on scales one (hysteria), three (hypochondriasis) and two (depression) with the last being at least ten points lower than the first two, resulting in the “conversion V profile” (Barry, 1996; Lancman et al., 2001; Loring et al., 2000; Swanson et al., 2000). Not all studies have found significance in the profiles of the MMPI for discriminating the two disorders. Owezarek and Jędrzejczak (2001) conducted a study with both mixed and distinct disorders using the MMPI for the purpose of presenting a personality profile and to highlight differences. Their sample was made up of three patient groups: epileptic seizures (n = 36), pseudoseizures (n = 38) and mixed (n = 32). Their findings suggest that conversion (elevated scores on scales one and three, with lower scale two) is present in both groups demonstrating pseudoseizures, but absent in the patients with epilepsy – here the ratio of scales one and three to two are reversed. This concludes that patients with mixed seizures and patients with pseudoseizures have similar profiles and therefore MMPI does not clearly discriminate between epilepsy and pseudoseizures. The decision to not repeat the MMPI on the participants in this present study is based on the fact that it has already been used significantly in previous studies and the conversion v profile has been shown to be present with pseudoseizures, but it is not definitive of this disorder.

Studies have also examined intellectual functioning using the Wechsler Adult Intelligence Scales (WAIS) and findings indicate cognitive impairment across both patient groups. Orsini et al. (1988) report that patients with general tonic-clonic seizures present with scores in the

low average to average ranges of the WAIS. Barry (1996), reports that using the WAIS-R, there are significant cognitive impairments in the pseudoseizure patient group. Dikmen and Matthews (1977, in Orsini et al., 1988) indicate the seizure frequency is inversely related to intellectual performance. In their study, patients with more than one tonic-clonic seizure in a month had intellectual scores in the low average range, whereas patients who had only one seizure in six months had intellectual scores within the average range. Other studies have shown that hemisphere of onset may have implications for intellectual functioning.

Blakemore, Ettliger and Falconer (1966, in Orsini et al., 1988), found some evidence to link left hemisphere onset to lower intellectual scores than right hemisphere onset, however the scores were all still within the average range. An important finding in the literature is that verbal IQ is relatively lower in left temporal lobe epileptic seizure patients (Ivnik, Sharbrough & Laws, 1987, in Orsini et al., 1988) and that performance IQ is lower in right temporal lobe seizure patients (Milner, 1958; Fedio & Mirsky, 1969, in Orsini et al., 1988). These findings are being researched more in recent times especially in view of the implications for epilepsy surgery (M. Roux, personal communication, 2004).

### 3.1.6 Cognitive phenomena

Individuals with epilepsy as a group have serious cognitive problems (Aldencamp, Baker & Meador, 2004; K. Grieve, personal communication, May 26, 2004). Cognitive disorders are common to both seizure groups and amongst the cognitive dysfunctions that have been cited in the literature are those of memory, attention, concentration and language (Grote, Smith & Ruth, 2001). Cognitive and psychological functions are interfered with during a seizure when the brain is electrophysiologically dysfunctional (Grote et al., 2001). Cognitive problems in epilepsy appear to have a multifactorial origin : aetiology, the seizures themselves, and the side effects of treatment, which indicates that cognitive impairment develops as a symptom

secondary to the epilepsy (Aldenkamp et al., 2004). These patients commonly experience problems with memory, attention, concentration and slowing on speeded tasks (Aldenkamp et al., 2004).

AED's have a global effect on the excitation levels in the central nervous system and this can lead to disturbances in cognition and behaviour with a wide range of possible symptoms such as sedation, distractibility, insomnia and more (Ortinski & Meador in Baker & Goldstein, 2004). Seizure frequency appears to result in decreased scores on tests of abilities and changes in intelligence test results as well, uncontrolled seizures negatively impact on many areas of cognitive functioning (Dodrill, 2004). Lezak (1995) reports that generalised seizure activity appears to correlate with more generalised cognitive deficit than is the case with focal seizures, and that increase in seizure rate will result in worse cognitive functioning in both kinds of seizures (Hirtz & Nelson, 1985, in Lezak, 1995; Shulman, 2000).

Age of onset of seizures influences IQ, and early onset is associated with lowered IQ scores (Oxbury, 2000). Intractable temporal lobe epilepsy commonly presents with significant memory problems especially verbal memory. Some patients in this group also present with impairment in executive function tasks that are sensitive to frontal lobe damage (Oxbury, 2000). Severe amnesic syndrome has been found in some patients with bilateral medial temporal lobe damage (Oxbury, 2000).

Related research has concluded that cognitive impairment does occur over time with uncontrolled epileptic seizures, more especially with generalized tonic-clonic seizures and with status epilepticus (Dodrill, 2004).

Hoepfner and Smith (in Ettinger & Kanner, 2001) state that:” The impact of epileptic activity on cognitive and affective behaviours will depend on the overlap between the localization and distribution of the epileptic activity and the anatomic and physiologic substrate of the particular behaviour under consideration” (p.284).

#### 3.1.6.1 Memory

Memory impairment has long been associated with epilepsy and research has found these impairments to be particularly associated with temporal lobe epileptic foci (Bennett, 1992; Walsh, 1994). Studies have also linked verbal memory impairment to left temporal lobe focus and nonverbal impairment to right temporal focus (Jarvis & Barth, 1984, Milner, 1975, in Bennett, 1992).

#### 3.1.6.2 Attention and concentration

Attention and concentration are seemingly affected by the type of epileptic seizure (Bennett, 1992) and sustained attention is affected by generalized seizures more than by focal seizures (Lansdell, Mirsky, 1964, Mirsky, Primoc, Marsan, Rosvold & Stevens, 1960, in Bennett, 1992). The explanation given by Mirsky et al. is that generalised seizures likely affect the central subcortical structures responsible for maintaining attention. With respect to selective attention, patients with focal seizures appear to be more impaired since focal seizures in the cortex produce inattentiveness by disrupting selective attention.

### 3.2 CO-MORBID PSYCHIATRIC CONDITIONS

Psychiatric problems are frequently associated with epilepsy, but are always present with pseudoseizures (Rowan, 2000). Increased levels of depression and anxiety are common to

both disorders (Baker & Goldstein, 2004; Betts, in Nowack, 2004; Trimble, Ring & Schmitz, 1996, in Nowack, 2004).

Psychiatric symptoms in epilepsy are the expression of at least three important processes:

- (i) an intrinsic epileptic process resulting from neurochemical and neurophysiological changes in the limbic circuit;
- (ii) an expression of the iatrogenic potential of many of the AED's used in these patients; and
- (iii) an expression of a reactive process to a chronic disorder that demands multiple adjustments (Kanner & Weisbrot, 2001).

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, text revision, (DSM-IV) (American Psychiatric Association, 2000), classifies pseudoseizures as conversion disorder with seizures, or as part of another somatoform or dissociative disorder.

Maladaptive personality traits appear to be more common in pseudoseizures than personality disorders, but when personality disorders do present, they tend to fall into the DSM-IV cluster B disorders (borderline, histrionic, and antisocial) (Bowman, 2001).

The estimated rates of psychiatric illness in pseudoseizure patients are 40% to 100% (Bowman, 2001). Mood disorders are common in both epilepsy and psychogenic seizures, and differing patterns of mood symptoms may help to differentiate between the two groups (Donofrio, Perrine, Alper & Devinsky, 2000).

Many other authors state that psychiatric disorders are common in epilepsy and quote high percentages for it – Vuilleumier and Jallon ( in Nowack, 2004) estimated that 20-30% of

patients with epilepsy also have psychiatric disturbances and that 2-9% of patients with epilepsy have psychotic disorders. The consequences of these disturbances alone will impact on the quality of life of the patient with epilepsy. Neurobehavioral disorders are significantly higher in epilepsy patients than in the general population, and Gibbs (in Nowack, 2004) found this to be especially true of patients with temporal lobe or complex partial epilepsy. Temporal lobe epilepsy is frequently linked to psychiatric disorders (Orsini et al., 1988; Stevenson and King, 1987; Walker & Blumer, 1984; Walsh, 1994).

In 1969 Flor-Henry conducted a retrospective study (n = 50) of psychiatric disorders with relevance to hemispheric dominance. The study found that temporal lobe epilepsy of the dominant hemisphere predisposes to psychosis that is schizophreniform in nature, and that psychosis associated with non-dominant hemisphere epilepsy tends to be manic-depressive in nature (Walsh, 1994). However, Schmitz, Robertson, & Trimble (in Nowack, 2004) found that in epilepsy patients, multiple interacting biological and psychosocial factors determine the risk for developing either schizophreniform psychoses or major depression.

Psychogenic seizures are considered symptomatic of psychological dysfunction and this is more simply understood if we take the psychoanalytic explanation for the function of symptoms. In this sense, the symptom, much like a defence mechanism, functions to avert danger, and redirects energy of the unconscious repressed material into some form of substitutive expression (Frosh, 1999, p.66).

The key to understanding and diagnosing psychogenic seizures must lie in identifying the psychological profiles that are common among this population. This disorder is not going to

be simply assessed for by tests and lack of electrographic ictal pattern, but will require an investigation into psychological functioning or dysfunctioning of each patient.

### 3.2.1 Mood disorders

Persons with epilepsy are more likely to suffer from affective disorders than the general population (Lezak, 1995). Mood disorders are common across both patient groups, and Donofrio et al. (2000) consider that different patterns of mood disturbance may help to differentiate between the two groups. Current understanding and research have refined our knowledge of the temporal lobes and the limbic system and it is clear that these play an important role in the emotions. Given this information and the research into epilepsy, it is more clearly understood how patients with temporal lobe epilepsy suffer frequent and specific interictal behaviour sequelae (Himmelhoch, in Blumer, 1984). Blumer emphasised the pleomorphic patterns of mood complaints in epilepsy consistent with the observations of earlier researchers and coined the term: interictal dysphoric disorder (IDD) (Barry, Leubke & Huynh, in Ettinger & Kanner, 2001, p.46). The symptoms of IDD include depressive-somatiform (depressive mood, anergia, pain and insomnia) and affective symptoms (irritability, euphoric mood, fear and anxiety).

#### 3.2.1.1 Depression

Depression is also common to both organic epileptic seizure patients as well as psychogenic seizure patients. More specifically, Gates & Rowan (2000) report that depression may be associated with epilepsy, but it is always present in psychogenic seizure patients.

Several clinical studies of psychogenic seizure patients have found a prevalence of depression (Abubakr et al., 2003; Benbadis, 2004; Bowman, 2001; Robertson, Trimble & Townsend in Bennett, 1992; Szaflarski & Szaflarski, 2004). Nowack (2004) has suggested two

possibilities for the high prevalence of depression in epilepsy patients, one being that it is a reaction to the chronic illness and the other being that it is part of the epilepsy. Related research (Mendez, Cummings & Benson, 1986 in Nowack, 2004) concluded that depression might be related to a specific epileptic psychosyndrome.

Studies have found a relation between depression and laterality, and it has been found that major depressive episodes are common in patients with left temporal lobe seizures (Lopez-Rodriguez, Altshuler & Kay, 1999, in Nowack, 2004). Patients with partial seizures of temporal lobe origin are at particular risk for developing interictal depression as this type of seizure commonly involves the limbic circuitry (Kanner & Weisbrot, 2001). Lezak (1995) similarly reports the frequent association of depression with seizures of the temporal lobe more than in any other type of seizure.

More specific syndromes or traits have been found in temporal lobe epilepsy: global hyposexuality; deepened emotionality (from intense anger to hyper religiosity); viscosity-circumstantiality; and schizophrenia-like cognitive disorder (Himmelhoch, in Blumer, 1984). Waxman and Geschwind (in Nowack, 2004) have similarly defined a collection of abnormalities in temporal lobe epilepsy which is now known as the Geschwind Syndrome.

### 3.2.2 Anxiety

Anxiety is common in pseudoseizure patients (Benbadis, 2004) and van Merode et al. (2004) hypothesize that high anxiety levels may be a core characteristic of individuals likely to develop pseudoseizures. Bowman (2001) see pseudoseizures as a somatic outlet for unmanageably intense feelings of anxiety, anger and sadness. Research conducted by Donofrio, et al., (2000) confirmed what earlier researchers had found, that there is a high

prevalence of anxiety and depression in pseudoseizure patients than in epilepsy patients.

Anxiety, and related disorders appear to be common in temporal lobe epilepsy more so than other seizure types (Gates, 2000; Lezak, 1995; Pincus & Tucker, 1985).

## CHAPTER FOUR

### RESEARCH METHODOLOGY

#### 4.1 INTRODUCTION

It was decided to use three questionnaires in this study, two being quantitative (SCL-90-R and QOLIE-31), the third being qualitative (The Seizure Questionnaire). The qualitative questionnaire was used more to provide a rich contextual background which may substantiate the findings on the quantitative ones. More especially, particular questions were isolated from the qualitative questionnaire to investigate presence of 'pain' and 'abuse', again to further substantiate findings.

#### 4.2 RESEARCH AIMS

A primary aim of this study is to attempt to identify and isolate psychological variables that may be specific to psychogenic seizures. At present no profiles are specific to either epilepsy or pseudoseizures and this makes diagnosis very challenging.

#### 4.3 RESEARCH HYPOTHESES

(a) The groups of patients with organic epileptic seizures will differ significantly from groups of patients with psychogenic seizures in terms of psychiatric status as measured by the SCL-90-R assessment instrument.

(b) Perceived quality of life as measured by the QOLIE-31 will be significantly lower in the psychogenic seizure group of patients.

#### 4.4 RESEARCH INSTRUMENTS

##### 4.4.1 The Symptom Checklist-90-R (SCL-90-R)

The SCL-90-R was designed by Leonard R. Derogatis in 1975 and is a brief, multidimensional self-report inventory designed to screen for a broad range of psychological problems and symptoms of psychopathology (Derogatis, 1983; Derogatis & Lazarus, in Maruish, 1994; Lezak, 1995). The SCL-90-R is used by clinical psychologists, psychiatrists and other professionals in mental health. It is well suited for use in research and its validity, reliability and utility has been demonstrated by more than 940 research studies (Pearson Assessments, 2004). It can be completed in less than 30 minutes, consists of 90 items and is similar to the MMPI. (see Appendix E).

The scales consist of nine primary symptom dimensions and three global indices:

##### Symptom Scales

##### Somatization :

reflects distress arising from bodily dysfunction.

##### Obsessive-Compulsive:

thoughts, impulses, and actions experienced as unremitting and irresistible but are also ego-alien.

##### Interpersonal Sensitivity:

feelings of personal inadequacy and inferiority, especially in comparison to others.

**Depression:**

symptoms of dysphoric mood and affect, lack of motivation and energy.

**Anxiety:**

nervousness, tension, trembling, panic attacks and feelings of terror.

**Hostility:**

aggression, irritability, rage and resentment.

**Phobic Anxiety:**

persistent fear response to a specific person, place object or situation.

**Paranoid Ideation:**

projective thought, hostility, suspiciousness, grandiosity, centrality, fear of loss of autonomy and delusions.

**Psychoticism:**

hallucinations and thought-broadcasting.

### Global Indices

**Global Severity Index (GSI):**

best single indicator of the current level or depth of the disorder.

**Positive Symptom Distress Index (PSDI):**

a pure intensity measure, and functions as a measure of response style.

**Positive Symptom Total (PST):**

a count of the number of symptoms the patient reports as positive, that he/she experiences to any degree.

Clinical significance is critical in measuring and reporting on constructs and as such the symptom scales chosen for the SCL-90-R have been clearly and consistently defined in the

literature, in order to avoid confusion about what is being measured (Derogatis, 1983). The three global indices of distress (GSI, PSDI and PST) each function to communicate in a single score, the level or depth of psychopathology for each individual (Derogatis, 1983).

The reliability measures for the SCL-90-R are of two types: Internal consistency (Alpha coefficient) and Test-retest. The Alpha coefficients ranged from 0.77 for Psychoticism to 0.90 for Depression. The coefficients on the Test-retest ranged from 0.80 to 0.90 which is an appropriate level for measures of symptom constructs (Derogatis, 1983).

The validity of a measure concerns what the test measures and how well it does so and in essence refers to how well the conceptual and operational definitions mesh with one another. The validity for the SCL-90-R has been examined by many studies and they have concluded that this instrument is highly sensitive to identifying the different symptom constructs in a broad variety of context both medical and clinical (Derogatis, 1983). (The University of KwaZulu Natal's registered copy of the SCL-90-R was used for this research).

4.4.2 Quality of Life in Epilepsy Inventory-31 (QOLIE-31) (Rand Health). (see Appendix F).

The QOLIE-31 is an important instrument as it provides an indication of the impact of seizures on the lives of both organic epilepsy patients, and psychogenic seizure patients. The Quality of Life in Epilepsy Inventory (QOLIE-31) contains seven multi-item scales that tap the following health concepts:

Emotional well-being; social functioning; energy and fatigue; cognitive functioning; seizure worry; medication effects and overall quality of life.

A QOLIE-31 overall score is obtained by the use of a weighted average of the multi-item scale scores and it also includes a single item that assesses overall health (Vickrey et al., 1993).

Scores on each scale are converted to *T* scores with a mean value of 50 and a standard deviation of 10. With the QOLIE-31, higher scores reflect a better quality of life and lower scores reflect a poorer quality of life.

Internal consistency reliabilities (Alpha coefficient) for the multi-item scales range from 0.77 to 0.85 and the Test-retest reliabilities (Pearson correlation coefficients) range from 0.64 to 0.89 (Vickrey et al., 1993). Both of these measures exceed the group-level comparisons of 0.70 (Nunnally, 1978 in Vickrey et al., 1993).

Construct validity was supported by correlations between the QOLIE and established measures such as the Profile of Moods (POMS) (Buelow & Ferrans, 2001).

With respect to the terminology of this questionnaire, the word *epilepsy* was replaced with the word *seizure* wherever it appeared, and this was done to prevent labelling of the patient prior to definitive medical diagnosis.

Permission was obtained from Rand Corporation for the use of the QOLIE-31 (see Appendix H).

#### 4.4.3 The Seizure Questionnaire (Dr Dietrich Blumer). (see Appendix G).

The seizure questionnaire was developed at the Epic-Care Centre (Memphis, USA) over a number of years to its present form to assess systematically the seizures and the broad

psychiatric variables of patients with seizures (Blumer & Davies, 2001). It allows for a comprehensive and expedient evaluation of patients including non-epileptic seizures. It allows for accurate research data.

The questionnaire is submitted to the patient and the patient's next of kin who are competent to answer the questions (or completed by the interviewer).

The answers are reviewed for completeness and accuracy by the interviewer, who thus obtains a complete set of data by semi structured interview of the patient and the next of kin together or separately if more straightforward responses need to be facilitated.

The Seizure Questionnaire begins with questions about the seizures, including the prodromal and post-ictal phases (questions 1-11). The second section deals with significant past and present life events (questions 12-21). The third section addresses the physical and emotional health before and after onset of the seizures and includes questions about the history of past abuse, the effects of the epilepsy on emotional life, and the influence of the menstrual cycle on seizures and on moods (questions 22-23). Then follows the important specific questions about the eight key symptoms of the inter-ictal dysphoric disorder (questions 24-32) and their course in time (question 29 addresses not a key symptom but the general lability of moods); the number of any key symptom that is troublesome by itself is circled. Two questions address psychotic symptomology (questions 33+34). This main section ends with questions about confusional episodes apart from seizures, personality traits, history of education, and religious orientation (questions 35-39). Finally there is a list of important illnesses in the family history to be reported by the patient and next of kin (question 40). On the last page the interviewer will establish a relatively detailed family tree of the patient for documentation of

illnesses as well as of social achievements (occupations) and difficulties in the family (Blumer & Davies, 2001, p.243).

Permission was obtained from Professor Blumer for the use of the Seizure Questionnaire (see Appendix H).

## 4.5 SETTING FOR THE STUDY

### 4.5.1 Epilepsy Unit.

As previously described (section 3.1.1), this research took place in a specialised epilepsy monitoring unit of a hospital. The patients were admitted on specialist referral for further diagnosis to assist in decision making for treatment. The data was collected over a period of nine months during which time the neurotechnician would contact the researcher if a patient was suitable and agreeable to partake in the study.

### 4.5.2 Preparation.

Prior to the commencement of the data collection, the researcher arranged appointments with six neurologists, one psychiatrist and one psychologist who refer patients to the epilepsy unit or worked with the patient population admitted there. The purpose of these visits was to familiarise them with the study and the ethical approval received from the hospital. These visits were also aimed at obtaining each specific professional's permission to work with their patients during the course of the research. These professionals were also invited to offer any comment or suggestion they may have during the course of the study. The comments of the eight professionals were noted. Four of the professionals commented on the large prevalence of non-epileptic seizure patients, especially pseudoseizures. Five of the neurologists cited past trauma and or abuse as linked to aetiology of pseudoseizures, one said the history of

abuse was only admitted much later in the treatment, and a further one said that recent trauma was more likely to be a cause but felt that stress and psychological dysfunction featured significantly in aetiology. Three of the neurologists felt that patients with mixed seizures would present the biggest problem for the study. The psychiatrist felt strongly that the language one uses to give the diagnosis of pseudoseizures is critical in predicting outcomes, above all one needs to acknowledge that they have a problem. This links to what was said by Shen, Bowman and Markand (1990) about how diagnosis is given (see Section 2.5). All professionals agreed that psychiatric co-morbidity, depression and low quality of life were prevalent in the pseudoseizure group.

## 4.6 PARTICIPANTS

### 4.6.1 Sample

Purposive sampling was suited to this study and the patient sample was taken from the epilepsy unit of a private hospital in Durban, South Africa. Neuman (1997) states that purposive sampling is used to identify particular types of cases for investigation and is about gaining deeper understanding more so than about generalising to the general population. Further to this, Babbie (2001) states that in some instances one may wish to study a smaller subset of a larger population where, although the members may be easily identified, it would be an unmanageable task to include all of them. Babbie (2001) adds that it is sometimes appropriate to select the sample based on one's judgement and on the purpose of the study (p. 166). When this study was designed the researcher had in mind to obtain a larger sample than was actually achieved. When the staff at the epilepsy unit were asked about expected patient numbers, they were enthusiastic but unsure since it depended on the referrals from the doctors, which were unpredictable, as well as on the patient's available funds. One important

factor realised was that managed health care and restrictions placed by various medical aids impact on the patient's ability to remain in the unit for the recommended observation period (see Section 3.1.1). The costs of the monitoring and allied costs of management by professionals can impact on patient numbers that come to the unit and on the length of stay that the medical aid may be willing to pay for, or the patient may be able to afford. Exclusion criteria had to be adhered to as well (see Section 4.6.2). The sample was ultimately chosen by the staff of the monitoring unit (see Section 4.6.3). The final sample consisted of 19 patients, ten females and nine males. Patients ranged in age from 18 to 44 years ( $M = 30.6$ ,  $SD = 8.9$ ). Patients had a mean education level of 13.0 years ( $M = 13.4$ ,  $SD = 3.3$ ) with a minimum of seven years and a maximum of 19.0 years of education ( $n = 19$ ). One patient who presented with mixed seizures was excluded from the study as this may confound the analysis.

#### 4.6.2 Exclusion criteria

It was decided to exclude persons with learning, speech or hearing disorders as this would complicate the assessment and interview. To prevent complications arising from possible early dementia, persons over the age of 55 were excluded. Given ethical issues arising from disclosure of possible sexual abuse, persons under the age of 18 years were also excluded from the study.

#### 4.6.3 Procedure

On admission to the epilepsy monitoring unit, each potential participant was given a letter of information about the research and the researcher's details. They were asked by the neurotechnician to read the contents and to make an informed decision as to whether they would be willing to participate in the study. If the patient agreed, the neurotechnician contacted the researcher and the interviews were scheduled for soon after. The researcher

then obtained verbal and written agreement from the participant. The three research instruments were administered by the researcher in a casual setting and with sensitivity to the patient's mood or tiredness as well as to accommodate hospital procedure and visits from significant others. Ample time was allocated for the participant to talk freely of their disorder or related problems and it was an informal procedure that underpinned the formal collection of data.

#### 4.7 ETHICS

The research was approved by the ethics committee of the University of KwaZulu-Natal, and permission to undertake the research was obtained from the hospital in question.

The patients' anonymity was assured and only codes were used to identify them.

Only the researcher, the neurosurgeon, and the neurotechnologist had access to the patient's true identities. Access to the data was limited to the researcher and to the research supervisor. All data were stored with the researcher in coded files.

The identities of the patients and the name of the hospital will be concealed to protect all parties concerned with this study. This thesis is to be stored at the University of KwaZulu Natal, as is customary for master's research projects.

##### 4.7.1 Informed Consent

Full verbal and written consent was obtained from all participants (see Appendix I for consent form). In order to make an informed decision about participation, the patients were given as much information on the research as possible, without divulging pre-test information particularly on pseudoseizures. This is not to say that the research involved deception, but that pre-test information may have influenced attitude and answering. The patients were

informed as to what was required of them and how the research aims to understand seizures more clearly. They were also informed that they may withdraw from the research at any time if they feel they want to. Patient consent was obtained to interview a significant other if this was possible.

#### 4.7.2 Beneficence

Harm to the participants was not anticipated, as only interviews and assessments were necessary for this study. It was recognised that anxiety and discomfort may have resulted when participants were asked to recall unpleasant events referred to in the questionnaire. Stress was kept to a minimum and when it was apparent that the interview was tiring or stressful it was continued on another day. At all times the interests of the patients were paramount. Patients were reminded that they may withdraw from the study at any time.

#### 4.8 DATA ANALYSIS

This was a single blind study and the researcher did not have prior knowledge of group inclusion/exclusion for intractable epilepsy and psychogenic seizures. Once the data had been collected, medical records were referred to for final diagnosis and comparison. The medical diagnosis was made by the attending physician or team of specialists attending the case after the monitoring period and the medical tests were complete. Analysis was performed with the use of the Statistical Package for Social Sciences (SPSS) program.

## CHAPTER FIVE

### 5.1 RESULTS

#### 5.1.1 Use of non-parametric tests.

Non-parametric tests were used to analyse the data. The reason these were used is because these tests can operate without the assumptions about the normality of a distribution which, given the small sample size, could be wrong to assume in this study. Non-parametric techniques such as the Mann-Whitney U Test allows us to compare the rank order of data with what we might expect to find across the population and thereby to conclude if there is a significant difference. Further to this, non-parametric tests require differences to be much greater if they are to be accepted as statistically significant (Rowntree, 2004). The disadvantage of the non-parametric techniques is that they do increase the risk of a Type II error (accepting the null hypothesis when it is false) than would parallel parametric techniques (Black, 2002; Rowntree, 2004). A larger sample size would considerably reduce the probability of making a Type II error and if the sample is selected randomly, the larger sample is more likely to be representative of the population being studied.

### 5.2 DESCRIPTION OF SAMPLE

Table 2 presents the sample description. There were 19 cases in the sample and 47.4% were male ( $n = 9$ ) and 52.6% were female ( $n = 10$ ). The ages of the total sample ( $n = 19$ ) ranged from 18 to 44 years with an average age of 30.6 years and a median of 31.0 years. Almost two thirds of the sample were single ( $n = 11$ ). Years of education for the total sample ( $n = 19$ ) ranged from seven to 19.0 years with an average of 13.4 and a median of 14.0. The duration

of the illness was from four months to 37.0 years with an average of 10.3 and a median of 9.0 years. Only four patients across both groups were unemployed at the time of data collection and within the non-epilepsy group ( $n = 12$ ), 83.0% were employed. The recorded diagnosis was obtained after the study from the hospital records, and for the purposes of the study the sample was divided into epilepsy ( $n = 6$ ) and non-epilepsy ( $n = 12$ ) groups. The non-epilepsy group consisted of pseudoseizures and inconclusive cases. The one mixed case (epilepsy and pseudoseizures) was excluded from further analysis as this is a potentially confounding case. The inconclusive cases may well be pseudoseizures since these may not have presented while under observation in the monitoring unit. What is known with certainty is that the epilepsy group did indeed present with measurable ictal pattern seizures on VEEG monitoring. It is possible to provoke pseudoseizures as well as epileptic seizures while under observation, but this does not always result in an event happening. The provocative techniques used during monitoring are discussed in Section 3.1.1.

The sample size is regrettably small and for this reason rigorous analysis may give rise to both Type I and Type II errors. Where no significant difference is found with such a small sample one may make a Type I error, that is incorrectly rejecting the null hypothesis of no significant difference between the two groups of epilepsy and non-epilepsy patients. Similarly, with a small sample, Type II error may occur where one says that a relationship does not exist between the groups when in fact it does, thereby falsely accepting the null hypothesis. A larger sample size would have ensured greater statistical significance for the findings and this is important to ensure in future studies.

Table 2. Summary of sample characteristics.

		Frequency	Percent
Gender:	Male	9	47.4
	Female	10	52.6
Marital status:	Single	12	63.2
	Married	7	36.8
Employed:	Yes	14	73.7
	No	5	26.3
Recorded diagnosis:			
	Epilepsy	6	31.6
	Non-epilepsy	12	63.2
	Mixed	1	5.3

### 5.3 ANALYSIS OF SAMPLE CHARACTERISTICS BY DIAGNOSIS

#### 5.3.1 Gender

The distribution of gender by diagnosis is presented in Table 3. As discussed in Section 2.2.2 previous studies have found significantly more females presenting with non-epileptic seizures, especially pseudoseizures, but possibly as a result of the small sample size this is not apparent in this study. One study by van Merode et al. (2004) did not find a higher proportion of females in their pseudoseizure group (n = 40).

Table 3. Distribution of gender by diagnosis.

	Gender	Male	Female	Total
Recorded diagnosis	Epilepsy			
	Count	3	3	6
	% within gender	37.5%	30.0%	33.3%
	Non-epilepsy			
Count	5	7	12	
% within gender	62.5%	70.0%	66.7%	
Total	Count	8	10	18
	% within gender	100.0%	100.0%	100.0%

When Pearson Chi-Square analysis was used to analyze the sample characteristics by diagnosis, there was no significant association found between gender and diagnosis ( $\chi^2 = 0.113$ ,  $df = 1$ ,  $p = 0.737$ ). Similar proportions of males (37.5%) and females (30.0%) were diagnosed with Epilepsy. The requirement of the  $\chi^2$  test is that the minimum expected count should be  $\geq 5$ , therefore no inferences can be made since 50% of cells have an expected count of less than five.

### 5.3.2 Duration of illness, age, and education

The average age of the epilepsy group ( $n = 6$ ) was 29.8 years, with a range of 18 to 44 years. The average age of the non-epilepsy group ( $n = 12$ ) was 31.9 years, with a range of 20 to 43 years. This shows very little difference in the ages of the two groups. The youngest age of onset of seizures for the epilepsy group was 1.5 years of age and the oldest was 36.0 years. For the non-epilepsy group the youngest age of onset of seizures was 16.0 years and the oldest was 36.0 years, but 58.3% ( $n = 7$ ) were 20 years and younger at age of onset with an average age of 23.4 years. The average duration of the illness for the epilepsy group was 14.2 years whereas for the non-epilepsy group it was 8.6 years with a wide range of 0.3 to 25.0 years.

There was no significant difference in the mean rank for duration of illness for the epilepsy group and for the non-epilepsy group (Mann-Whitney U 23.5,  $p = 0.241$ ) (see Table 4).

A similar result (of no significant difference) was found for age and education by diagnosis (see Table 4).

Table 4. Mann-Whitney U Test : diagnosis by age, education and duration of illness.

	Recorded diagnosis	N	Mean Rank	Mann-Whitney U	p
age	Epilepsy	6	8.7	31.5	0.241
	Non-epilepsy	12	9.9		
	Total	18			
educate	Epilepsy	6	9.2	34.5	0.887
	Non-epilepsy	12	9.6		
	Total	18			
duration	Epilepsy	6	11.6	23.5	0.241
	Non-epilepsy	12	8.5		
	Total	18			

#### 5.4 RELIABILITY OF SCALES FOR THE SCL-90-R AND THE QOLIE-31

It is important that the instrument one is using is reliable, that is, that it consistently measures what one is trying to measure. The degree of reliability of the instrument will affect and influence any conclusions drawn by the study (Black, 2002). The reliability coefficients for measuring instruments give us an indication of the reliability using a scale of 0.00 (no consistency) to 1.00 (perfect consistency) (Black, 2002). As is indicated by the following tables, the reliability for both the SCL-90-R and the QOLIE -31 were high with most of the scores being above the 0.8 that is recommended. Table 5 provides the scores for reliability on the SCL-90-R and Table 6 provides the scores for reliability on the QOLIE-31.

Table 5. Reliability of SCL-90-R subscales (n = 19) with Cronbach's Coefficient Alpha.

Subscale of SCL-90-R	Cronbach's Alpha
Somatisation	0.881
Obsessive-Compulsive	0.847
Interpersonal Sensitivity	0.835
Depression	0.894
Anxiety	0.842
Hostility	0.838
Phobic Anxiety	0.851
Paranoid Ideation	0.794
Psychoticism	0.757
Additional Items	0.823

The subscales for the SCL-90-R have been discussed in 4.4.1. Although the sample size for this study is small thus limiting the findings, the reliability of the scales in this questionnaire was high (consistently above the recommended 0.8 level). The possible reason for the lower levels on Paranoid Ideation (0.794) and Psychoticism (0.757) may be that these are especially difficult dimensions to fully examine in a single questionnaire and are more usefully explored using a clinical interview.

Table 6. Reliability of QOLIE-31 subscales (n = 19) with Cronbach's Coefficient Alpha.

Subscale of QOLIE - 31	Cronbach's Alpha
Seizure Worry	0.809
Overall Quality of Life	0.660
Emotional Well-being	0.867
Energy / Fatigue	0.739
Cognitive Functioning	0.839
Medication Effects	0.854
Social Functioning	0.764

As with the SCL-90-R, the reliability for the scales on the QOLIE – 31 was high and most were above the recommended level of 0.8. It must be noted that precoded numeric values for responses on some of the QOLIE – 31 items are in the direction that a lower number reflects a more favourable health state which is contrary to other items where a higher number reflects a more favourable health state. This necessitated the recoding of some of the items. With questions 2, 5, 6, 9, 14, 25, 26, 27, 28, 29 and 30 the scoring was reversed accordingly.

The lower level on Energy/Fatigue (0.739) may be reflective of the subjective interpretation of this item. Social Functioning (0.764) is largely dependent on individual lifestyle and what is high functioning for one person is not necessarily so for another. This dimension is imbued with personal choice and one's perception of one's space in the social world.

5.5 MEAN RANK FOR EPILEPSY AND NON-EPILEPSY BY SCALES ON SCL-90-R AND QOLIE-31

Mean rank was calculated for the scales on the SCL-90-R and the QOLIE-31 and these are presented in Table 7.

Table 7. Mann-Whitney U test for mean rank for scales SCL-90-R and QOLIE-31.

Mean Rank

Scale	Epilepsy (n = 6)	Non-epilepsy (n = 12)	Mann-Whitney U	p
SCL-90-R				
Somatisation	8.0	10.2	27.0	0.437
Obsessive-compulsive	7.3	10.6	23.0	0.250
Interpersonal sensitivity	8.4	10.0	29.5	0.553
Depression	7.7	10.4	25.0	0.335
Anxiety	5.7	11.3	13.5	0.032
Hostility	7.4	10.5	23.5	0.250
Phobic anxiety	6.8	10.8	20.0	0.151
Paranoid ideation	6.7	10.9	19.5	0.125
Psychoticism	9.1	9.7	33.5	0.820
Global Severity Index	7.1	10.7	21.5	0.180
Pos Sym Distress Index	6.9	10.8	20.5	0.151
Positive Symptom Total	7.3	10.6	23.0	0.250
QOLIE-31				
Seizure worry	12.2	8.1	19.5	0.125
Overall QOL	11.7	8.4	22.5	0.213
Emotional well-being	12.4	8.0	18.5	0.102
Energy/fatigue	13.7	7.4	10.5	0.013
Cognitive functioning	13.9	7.3	9.5	0.010
Medication effects	9.9	9.3	33.5	0.820
Social functioning	10.8	8.8	28.0	0.494
Overall summary	13.5	7.5	12.0	0.024

No significant differences in mean rank were found for gender, marital status or employment.

## 5.6 SCALES ON SCL-90-R AND QOLIE-31 BY DIAGNOSIS

When the Mann-Whitney U test was applied to the various scales of both instruments by diagnosis it was found that on the SCL-90-R, anxiety was nearing significance indicating that the non-epilepsy group were more anxious overall (Mann-Whitney U 13.5,  $p = 0.032$ ). The mean rank for the epilepsy group was 5.7 and for the non-epilepsy group was 11.4.

On the QOLIE-31, cognitive functioning was nearing significance (Mann-Whitney U 9.5,  $p = 0.010$ ). The mean rank for the epilepsy group was 13.9 and for the non-epilepsy group was 7.3. Energy/fatigue also neared significance (Mann-Whitney U 10.5,  $p = 0.013$ ). The mean rank for the epilepsy group was 13.8 and for the non-epilepsy group was 7.4.

There was no significant difference between gender and the various scores of either the SCL-90-R or the QOLIE-31.

There was no significant difference between employment status and the various scores of either the SCL-90-R or the QOLIE-31.

## 5.7 CORRELATIONS

Spearman's correlation coefficient is a non-parametric statistic which can be used when one cannot assume the data to be normally distributed. Spearman's tests first rank the data and thereafter apply Pearson's equation to the ranks (Field, 2000).

There is a significant negative correlation between Global Severity Index (GSI) of the SCL-90-R and the Overall Summary of the QOLIE-31 ( $r = -0.778$ ,  $p = 0.000$ ). The GSI of the SCL-90-R represents the best single indicator of the current level of the disorder. The Overall Summary of the QOLIE-31 represents a better quality of life if high and poorer quality of life if low. Therefore, the inverse correlation is to be expected, that is, as the GSI increases the Overall Summary score should decrease as well.

On the SCL-90-R scales, there was a negative correlation between duration of the illness and anxiety ( $r = -0.470$ ,  $p = 0.049$ ), as well as duration and hostility ( $r = -0.513$ ,  $p = 0.029$ ). This could be explained by the possibility that with a longer duration of the illness, the patient may become more accustomed to the lived experience of their illness and may present as less anxious overall as well as less likely to be hostile, which may indicate defensiveness.

There was no significant correlation between age and education level and the various scores of the SCL-90-R and the QOLIE-31.

It is necessary to take into account the small sample in this study which may have an effect on the results arrived at and that any of these results cannot be generalised to the population of epilepsy patients. However, the results commented on seem to be leading in the expected direction and looks like what one might expect to find given the evidence of previous studies and the body of literature on the subject. This indicates to the researcher that these findings are worth further investigation with a much larger sample.

## 5.8 ANALYSIS OF VARIABLES 'PAIN' AND 'ABUSE' BY DIAGNOSIS

For the assessment of the variables pain and abuse the SCL-90-R and the Seizure Questionnaire were used. On the SCL-90-R questionnaire, questions 1 (headache), 12 (heart/chest pain), 27 (lower back pain) and 42 (muscle ache) were used for assessing the extent to which respondents reported pain. These items on the SCL-90-R were rated on a 5-point distress scale ranging from 0 (not at all) to 4 (extremely). If there was a positive response to pain on any of the questions 1, 12, 27, 42 this response was coded 1 (yes) and 0 (no). Therefore for calculation purposes, 0 = no pain, and 1 = pain. On the Seizure Questionnaire, question 27 (open question on pain) was used for assessment. For the assessment of reported abuse, question 22 (respondent was asked if he or she had ever been in an abusive situation with the option to describe) from the Seizure Questionnaire was used. For both of these questions on the QOLIE-31, any positive response was coded 1, and negative response was coded 0.

Analysis of the variable 'pain' showed that 100.0% of the non-epilepsy group (n = 12) and 50.0% of the epilepsy group (n = 3) reported pain ( $\chi^2 = 7.200$ , df 1, p = 0.007). Analysis of the variable 'abuse' showed that 66.7% (n = 8) of the non-epilepsy group reported abuse as compared to 16.7% (n = 1) of the epilepsy group who reported abuse ( $\chi^2 = 4.000$ , df = 1, p = 0.046). In both of these analyses, it must be pointed out that the minimum cell frequency count was less than five – thus, no reliable conclusions can be drawn from these statistics.

There are indications from the literature (see Section 3.1.4.5) that patients with pseudoseizures tend to report pain and abuse with a higher frequency than epilepsy patients.

The current finding, while statistically problematic, does suggest some consistency with this finding.

Because of the reported high frequency of pain and abuse in pseudoseizure patients, it was decided to use these as grouping variables in the following Mann-Whitney analysis which tested for an association between pain and abuse and the scales of both the SCL-90-R and the QOLIE-31 (for pain association see Tables 8 and 9 respectively).

On the scales of the SCL-90-R (see Table 8), patients who reported pain showed higher levels of symptoms in Obsessive-Compulsive, Anxiety, Phobic Anxiety and the Global Severity Scales.

Table 8. Mann-Whitney U test for scales of the SCL-90-R associated significantly with pain.

			ranks	
	Mann-Whitney U	p	no pain (n = 3)	pain (n = 15)
Obsessive-compulsive	1.0	0.005	2.3	10.93
Anxiety	2.5	0.010	2.83	10.83
Phobic anxiety	3.0	0.017	3.0	10.80
Global Severity Index	1.0	0.005	2.33	10.93

On the scales of the QOLIE-31 (see Table 9), patients who reported pain showed higher levels of symptoms in seizure worry, energy and fatigue, cognitive functioning and the overall score.

Table 9. Mann-Whitney U test for scales of the QOLIE-31 associated significantly with pain.

ranks

	Mann-Whitney U	p =	no pain (n = 3)	pain (n = 15)
Seizure worry	2.5	0.010	16.17	8.17
Energy/fatigue	1.0	0.005	16.67	8.07
Cognitive functioning	4.5	0.027	15.50	8.30
Overall score	5.0	0.039	15.33	8.33

Although these scores reached significance, caution must once again be exercised given the small sample size.

There was no significant association between abuse and any of the scales of either the SCL-90-R or the QOLIE-31.

## 5.9 FAMILY HISTORY OF DISORDERS

Question 40 of the Seizure Questionnaire asks for a family history of the following disorders: epilepsy; migraine; stuttering; neurological disorder; psychiatric disorder; alcoholism; and drug addiction. The respondents listed the family members they knew of who suffered any of the above.

Table 10. Family members of respondents suffering disorders

	Epilepsy group (n = 6)	Non-epilepsy group (n = 12)	N
Epilepsy	1	3	4
Migraine	3	6	9
Stuttering	2	4	6
Neurological disorder	2	6	8
Psychiatric disorder	1	6	7
Alcoholism	0	8	8
Drug addiction	0	4	4

The most reported disorder was migraine followed by neurological disorder and alcoholism. In this sample, alcoholism, psychiatric disorder, neurological disorder and migraine featured highly in the families of the non-epilepsy group. This being a small sample, one cannot say confidently that this is of significance, however, in a much larger sample this may provide valuable information on any possible genetic link to pseudoseizures. Further conclusions cannot be drawn at this point for two reasons, firstly the small sample size, and secondly, the inconclusive diagnosis of the non-epilepsy group.

The most encouraging findings was the high reliability of the scales for both the SCL-90-R and the QOLIE-31. This indicates that these two questionnaires are most suitable for the populations studied. This also confirms findings in international studies which have used these instruments both in small and large studies (Kanner & Weisbrot, 2001; Loring et al., 2000; van Merode et al., 2004).

## CHAPTER SIX

### DISCUSSION

#### 6.1 FINDINGS

The research aim as stated in Section 4.2 was to attempt to identify and isolate psychological variables that may be specific to psychogenic (non-epileptic) seizures. The SCL-90-R, the QOLIE-31 and the Seizure Questionnaire were used as assessment instruments. Regrettably as a result of the small sample size, conclusive results are not possible. However, in some areas of the study, the information obtained was significant and in the direction of expected findings (from the literature and previous studies) within the population. This serves to encourage further studies with larger samples and more rigorous testing. The two quantitative questionnaires (SCL-90-R and QOLIE-31) showed high reliability in this study using the Cronbach's Alpha Coefficient. The findings on the Seizure Questionnaire provided some quantitative as well as qualitative information on the respondents, these are discussed in Section 6.1.4.

##### 6.1.1 Research hypotheses

Hypothesis one stated that it would be expected to find that patients with organic epileptic seizures will differ significantly from patients with psychogenic seizures in terms of psychiatric status as measured by the SCL-90-R. The variable, Anxiety, was seen to differ between these groups, and in the expected direction. There are concerns about the sample size, and the possibility of Type 1 errors due to multiple comparisons. Specific findings on the SCL-90-R will be discussed further on.

Hypothesis two stated that perceived quality of life as measured by the QOLIE-31 will be significantly lower in the psychogenic seizure patients. On the QOLIE-31 three scales yielded significant results as will be discussed in Section 6.1.3. Again there are concerns about the sample size and the possibility of Type 1 errors due to multiple comparisons.

## 6.2 SCL-90-R

Non-parametric tests were used in the analysis as discussed in Section 5.1.1. A significant difference was seen between the epilepsy and non-epilepsy groups on the variable Anxiety. When the T scores were examined, it was seen that the non-epilepsy group mean score (mean = 64.6) was in the elevated range (T = 60). This constitutes a clinically significant elevation. On the SCL-90-R a T score of 60, regardless of symptom dimension, will place the individual in the 84<sup>th</sup>% of the normative sample.

### 6.2.1 Anxiety

It was clear from the discussion especially with the non-epilepsy group of patients, that Anxiety was indeed prevalent. There was a sense of general anxiety about the future, about the possibility that something was very wrong with their brain, and anxiety was present in their interpersonal relationships. There were some indications of suspiciousness towards others, especially family members. In this small patient group, it was interesting to note that the female non-epilepsy patients all reported anxiety to some degree. As a group, the non-epilepsy patients had a predominantly negative self-evaluation and negative outlook on the future. One saw herself as a “sufferer” that no one understands, while another female respondent was clearly embedded in her illness and her life seemed defined by it. The literature supports the finding of Anxiety being prevalent especially in non-epileptic pseudoseizure patients (see Section 3.2.2) (Benbadis, 2004; Bowman, 2001; Donofrio et al.,

2000). High levels of Anxiety have been strongly linked with the possibility of developing pseudoseizures in a study by van Merode et al. (2004) referred to in Section 3.2.2 of this study. With respect to epilepsy and Anxiety, the literature indicates that this variable is more likely to present in temporal lobe epilepsy than in any other type (see Section 3.2.2) (Gates, 2000; Lezak, 1995; Pincus & Tucker, 1985).

Other studies that have found that the psychogenic seizure population have higher rates of psychopathology in relation to the epileptic seizure group or the general population. A study by van Merode et al. (2004) found that psychogenic seizure patients reported significantly more co-morbid psychopathology than did the non-psychogenic seizure patient group (psychogenic seizures group n = 40, and non-psychogenic seizure group n = 138). Reuber and Elger (2003) recognise the high rate of psychiatric disorders found in psychogenic seizure patients, and these authors suggest that it may be possible to regard psychogenic pseudoseizures as a manifestation of psychiatric morbidity rather than seeing it as a distinct diagnosis. Bowman (2001) reported on 16 studies of pseudoseizure patients in the United States that examined any current psychiatric illness in these patients. Bowman (2001) reports that these studies found between 43% and 100% of pseudoseizure subjects to have some kind of psychiatric illness. Her information is obtained from the National Co-morbidity Survey (NCS) of the United States.

Given the high reliability of the scales on the SCL-90-R in this study, despite the small sample, it would be recommended to use this instrument in future studies with larger samples.

### 6.3 QOLIE-31

In the analysis of the QOLIE-31, three scales showed group differences, namely, Energy/Fatigue, Cognitive Functioning and the Overall score.

#### 6.3.1 Energy/Fatigue

The non-epilepsy group presented with more fatigue and therefore lower energy levels and this was apparent in the discussions with these patients. The group as a whole had more negative expectations and cognitions, they tended to view their situations as hopeless. They appear to spend an inordinate amount of time being concerned with, and seeking medical attention for, their conditions. There was a sense across the group of not being able to cope with life's expectations and then citing lack of energy as a probable cause. Some respondents cited the drugs for seizure control that were causing their tiredness, but given their negative predisposition, one gets the pervasive sense of fatigue in this group. One female non-epilepsy patient felt that her lack of energy was linked to pain (she suffered headaches in particular). There was no conclusive evidence found in the literature on Energy and Fatigue being associated especially with non-epilepsy seizures, however, from discussion with the group, Fatigue was a common complaint and would indicate a need for assessment of this variable in a larger study.

#### 6.3.2 Cognitive Functioning

The differences found in this study between the epilepsy and the non-epilepsy group on cognitive functioning indicate that the non-epilepsy group report more problems with this variable than do the epilepsy group. However, this does not confirm what is found in the literature (see Section 3.1.6) which indicates that cognitive disorders are common to both epilepsy and non-epilepsy groups. The cognitive problems in epilepsy have been recognised

in the literature as being serious and usually concerns memory, attention and concentration (see Section 3.1.6).

### 6.3.3 Overall Score

The Overall Score is an important summary indicator for all the scales on the QOLIE-31 and the indication is, that on this instrument, the epilepsy group report a better quality of life than do the non-epilepsy group. This is apparent from discussions with the group members of both groups as well. In the epilepsy group there was a general feeling of acceptance and of wanting to make the most of their situation despite the limitations of the seizures. With the non-epilepsy group, there was a more negative perception of life and a strong need, in some cases, to be understood to be suffering.

Many previous studies have used a quality of life assessment instrument (Breier et al., 1998; Quigg, Armstrong, Farace, & Fountain, 2002; Szarflarski & Szaflarski, 2004) and of these some have used the QOLIE-31 (Buelow & Ferrans, 2001; van Merode et al., 2004; Zaroff, Myers, Barr, Luciano & Devinsky, 2004) for assessment of both the epileptic seizure group as well as the psychogenic seizure group. Breier et al. (1998) used the QOLIE-89 in their study and found that pseudoseizure patients attribute their symptoms to physical rather than psychological explanations. The QOLIE-89 is the larger version of the QOLIE-31 which is used in this current study, and the QOLIE-89 comprises both generic components and scales designed to measure specific epilepsy-related quality of life issues.

It has long been recognised that quality of life is significantly impacted on by the chronic nature of a seizure disorder of either kind. In a recent study, van Merode et al. (2004) assessed the psychological characteristics of patients with newly developed psychogenic

seizures (psychogenic seizure group n = 40, and non-psychogenic seizure group n = 138).

One of the assessment instruments in this study was the QOLIE-31 for the evaluation of the patient's quality of life, and the findings in this study showed that the psychogenic seizure patients had significantly lower quality of life compared to the organic seizure group

None of the literature considers quality of life in seizure patients to be insignificant; on the contrary the negative impact on quality of life is a point of consensus among authors.

Nowack (2004) states the danger of concentrating treatment on the actual seizures themselves, which occupy a minimal portion of the patient's life, while ignoring the many issues which negatively impact on the quality of life of these patients. Both the epilepsy patient group and the psychogenic seizure patient group present with significant quality of life problems, related to issues such as self-esteem problems, impaired social relationships and limits on work and social life activities (Buelow & Ferrans, 2001; Kanner & Weisbrot, 2001; Loring et al., 2000; Passaro, 2001).

## 6.4 THE SEIZURE QUESTIONNAIRE

### 6.4.1 Gender and marital status

Although there were more females with non-epileptic seizures in this study, caution must be exercised in considering this a significant finding given the small sample size. The literature reports an apparent preponderance of females presenting non-epileptic pseudoseizures (see Section 2.2.2) (Reuber & Elger, 2003; Rosenberg et al., 2000). Lancman et al. (2001) recognise that there is similarly a high representation of females with conversion disorder and that this disorder is strongly linked to pseudoseizures (see Section 2.2.2).

As has been discussed previously (see Section 2.3.2), pseudoseizures may be a modern day manifestation of unmanageable psychological distress. Many of the females in this study in the non-epilepsy group described themselves as irritable, emotional, frustrated and depressed. One female, now 28 years old, was diagnosed with Chronic Fatigue Syndrome at age 17, and a year later with Depression and shortly thereafter with Anorexia (from which she has now recovered). She spoke of being fearful, frustrated and of suffering “emotional depletion”. There was a general sense of dissatisfaction with life amongst this group. Relationship problems were common whether with partners, friends or family. Of the three males with a diagnosis of epilepsy, one was single and two were married. Of the three females with the same diagnosis, one was married and two were single. Four of the five males in the non-epilepsy group were single and the other was married. Of the seven females with the diagnosis of non-epilepsy, four were single and three were married. There appears to be no significant difference between the groups either in this study or the literature with respect to marital status and diagnosis.

#### 6.4.2 Age, age at onset and duration of illness

No significant difference was found with respect to age, education and duration of illness on analysis (see Section 5.3.2). The average age and range of the epilepsy group and of the non-epilepsy group were very similar in this study. Although the oldest age of onset was the same for both groups (30.0 years) the youngest age of onset was markedly different. For the epilepsy group this was 1.5 years and for the non-epilepsy group it was 16.0 years. The age of onset for the non-epilepsy group in this study concurs with the literature (see Section 2.2.1), namely that pseudoseizures typically begin in young adulthood. The duration of the illness was on average longer for the epilepsy group and less for the non-epilepsy group.

### 6.4.3 Education and employment

With respect to education and employment, four of the epilepsy group were employed and two were not at the time of interview, and the average years of education for this group was 13.0 years. Ten out of the 12 non-epilepsy patients was employed at time of the interview and the average years of education for this group was 13.8 years. There clearly is very little difference between the two groups in this respect. The males in both groups of patients were mostly satisfied with their employment status, interestingly though, five of the females in the non-epilepsy group were not satisfied and would have preferred to pursue a different kind of employment..

### 6.4.4 Causes and triggers

Question three of the Seizure Questionnaire refers to causes of the seizures: “What may have caused the seizures (birth injury, febrile convulsions, head injuries, etc.)?”. Of the six epilepsy patients, four cited head injury as a possible cause, and one of these four said it was either head injury or bacterial meningitis. One of the six patients said the cause was unknown and one cited a neonatal injury. In Section 2.3 aetiology of seizures is discussed and the three possible causes these patients have mentioned are found in the literature, namely, head injury in children and adults, meningitis and birth trauma (immediate and latent) (see Section 2.3.1).

Of the non-epilepsy patients ( $n = 12$ ), five cited head injury as a possible cause, three cited stress, two said the cause was unknown to them, one said medication was the cause, and one cited meningitis as possible cause. Past abuse is especially cited in the literature as a possible, even likely, cause of psychogenic (non-epileptic) seizures (see Section 2.3.2). Abuse was not cited as possible cause in this study and this may be because the patients had not received a

diagnosis of psychogenic non-epileptic seizures at the time of interview and may not have made the link to past abuse, if there is one. One study (Fleischer et al., 2002) found symptom profiles reminiscent of posttraumatic stress disorder patients in psychogenic seizure patients (see Section 2.3.2). It may be possible that the stress that three of the non-epilepsy patients cited was quite significant and possibly even related to trauma. Bowman (2000) in Section 2.3.2 states that one of three groups of life events, namely “acute or situational stresses” may contribute to pseudoseizures and this may be a reflection of what the non-epilepsy group are referring to by stress. With respect to head injury being a possible cause of psychogenic non-epileptic seizures, Reuber and Elger (2003) cite minor head injuries as one of a number of factors that may interact and give rise to psychogenic seizures.

Question six of the Seizure Questionnaire refers to possible triggers:” What, if anything, may bring about a seizure?”. Fourteen of the eighteen patients in the total sample (77.8%) cited stress as a trigger for seizures. The epilepsy group in this study cited stress, tension, anger, fatigue, illness, and bad diet as possible triggers. The non-epilepsy group in the study cited stress, exercise, lack of sleep, anxiety, bad diet and flashing lights as possible triggers. Stress is frequently cited as a trigger for epileptic seizures (see Section 3.1.2.1) but in non-epileptic seizures, the triggers have been identified as frustration, emotional upheaval and altercations with others (Gates, 2000). Given the frequency of stress presenting across the sample group of epilepsy and non-epilepsy patients, this would require further investigation especially amongst the South African population to see if this is a common trigger in this country.

Photic stimulation and lack of sleep are two of many induction techniques used in monitoring centres to provoke seizures for observation (see Section 3.1.1), and amongst the non-epilepsy group, flashing lights and lack of sleep were cited as triggers, and one patient in the epilepsy group cited fatigue.

#### 6.4.5 Drug and alcohol addiction

Question 38 of the Seizure Questionnaire asked: "Have you ever suffered from a drug or alcohol addiction?". All of the epilepsy group ( $n = 6$ ) answered 'no' to this question and nine of the non-epilepsy group answered 'no' as well. Two of the non-epilepsy group answered 'yes' to both drugs and alcohol and one patient answered 'no' to alcohol and 'yes' to drugs. In the literature reviewed for this study there were no studies done to evaluate the influence of drugs or alcohol on the development or maintenance of seizures either epileptic or non-epileptic. It may be a consideration in future studies to examine influence of drugs and or alcohol on the course of the two disorders.

#### 6.4.6 Interictal dysphoric disorder (IDD)

Blumer (see Section 3.2.1) identified patterns of mood complaints in epilepsy (IDD) and these are addressed in the Seizure Questionnaire (questions 24-32). The symptoms included in IDD are depressive mood, lack of energy, sleep problems, sudden moods of happiness, mood lability, irritability, anxiety and specific fears. Analysis was conducted across the sample ( $n = 18$ ) but no correlations were apparent on any of the scales relating to IDD. This may be as a result of the small sample size. However, IDD symptoms were positively correlated with Global Severity Index of the SCL-90-R ( $r = 0.695$ ,  $p = 0.001$ ) indicating that as the severity of the disorder increases, so too the symptoms of IDD would increase. This would be expected in that as the patient scores more positively on this psychiatric indicator, the more one would expect to see increased problems with mood, sleep, energy etc. The symptoms of IDD were negatively correlated with the Overall Summary Score of the QOLIE-31 ( $r = -0.778$ ,  $p = 0.000$ ). This finding may also be expected in a population where quality of life is increasing, symptoms of IDD would be expected to decrease.

## 6.5 PAIN AND ABUSE (SCL-90-R and Seizure Questionnaire)

Questions from both the SCL-90-R and the Seizure Questionnaire were used to assess pain and abuse. The results are given in Section 5.8 and to reiterate, more pain and abuse was reported by the non-epilepsy group (n = 12) than was by the epilepsy group (n = 6). The type of pain that was commonly reported by the epilepsy group was backache and seemed related to actual previous injury or occupational hazard. However, the type of pain reported by the non-epilepsy group varied and included, back, neck, shoulder, muscular and headaches (in one case, migraine). There was an eagerness to report physical pain in this group and their history of physical ailments was also substantial in comparison to the history of the epilepsy group. This would relate to the reported findings in the literature that chronic pain is frequently linked to pseudoseizures (see Section 3.1.4.5).

One epilepsy patient and eight non-epilepsy patients reported previous abuse. Details were not required to be given, but of all the cases, emotional abuse was cited most. Where physical or sexual abuse was cited, in all cases it was not ongoing and had been dealt with in the past, and in most cases therapy had been sought. There were no significant findings with respect to abuse in the present study.

## CHAPTER 7

### 7.1 LIMITATIONS OF THE STUDY

The limitations of this study clearly lie in the small number of participants ( $n = 19$ ) of which one had to be excluded because of mixed seizures which confounds the analysis. The researcher was unable to choose the sample directly. With more hospitals and monitoring units involved in a larger study this would automatically ensure larger sample size. The study would be more viable over a longer period of time, ensuring maximum exposure to potential participants. The data collection took place over nine months in the present study. Although the sample size is small, there were several studies in the literature that used small sample sizes and their findings also tended towards significant results (Abubakr et al., 2003; Quigg et al., 2002; Rosenberg et al., 2000; Wood, McDaniel, Burchfiel & Erba, 1998).

In this study, patients were placed in two groups, epilepsy (by diagnosis) and non-epilepsy (pseudoseizure and inconclusive cases). The second group could have been divided into distinct cases of pseudoseizure and inconclusive but the sample size limited the possibility of doing this. One cannot say with certainty that the inconclusive cases were not pseudoseizures, further investigation would have been recommended for these patients and a follow-up study may have clarified their diagnosis. One of the limitations of this study was that there was no follow-up with patients, especially pseudoseizure and inconclusive cases. Future research may find it possible to attain a patient sample other than from a monitoring unit in a hospital, possibly from specialists or doctors, as this would ensure a more accurate reflection of the total population of seizure sufferers. The patients entering the monitoring

unit are a distinct group who can afford medical intervention, and this does not account for the many patients who cannot.

The sample contained similar numbers of males and females, but there were only three racial groups represented. In a multicultural society like we have in South Africa, it would be important to include participants from all the ethnic groups in order to establish impact on quality of life and perception of the disorder as it is experienced by different people.

A study conducted in South Africa in 1995 by McQueen and Swartz (Swartz, 1998) on epilepsy in an Afrikaans-speaking community found that the stigma that was expected to be present as a result of the epilepsy, was actually related to the French name given the different types of seizures. This surprising finding indicated that the word *mal*, used to describe petit mal and grand mal seizures, in Afrikaans means 'mad' – this has given rise to an extremely negative belief about the disorder and entrenches the misunderstanding of it. We should aim at de-stigmatizing epilepsy and terminology (when not explained and understood) may be entrenching it.

A neuropsychological battery was not included in this study, and it is the opinion of the author that it would be important to include one in a larger study. Although some authors have found inconclusive results using neuropsychological assessment and did not achieve significant discrimination between the two seizure groups (Dodrill & Holmes, 2000; Orsini et al., 1988), it may provide a depth to the study since many functions of the brain are disrupted by seizure activity.

## 7.2 RECOMMENDATIONS

It is imperative that a larger study is conducted nationally that would include participants from different ethnic groups and sectors of society. A more comprehensive study should include a variety of tests that tap various aspects of functioning including a neuropsychological battery. In-depth interviews should be included as well as a follow-up interviews. All three questionnaires used in the present study were most suitable, reliability was high on the SCL-90-R and the QOLIE-31 (see Section 5.4), and the Seizure Questionnaire provided demographic information as well as more qualitative information about the participants lived experience of the seizure disorder.

It was clear from the discussion with the specialists prior to data collection, that there is a need for research into epilepsy and non-epileptic pseudoseizures. They all felt that more research is needed in our country since not much has been done to date and we do not have a clear picture of the prevalence and impact of these disorders. The Epilepsy Society of South Africa have expressed the need for more research and welcome it, they would assist in any way needed, they particularly need figures on prevalence.

A larger sample would allow for division of the groups into more distinct categories such as epilepsy, pseudoseizures, inconclusive and mixed cases (epileptic and pseudoseizures). A cross-cultural study will also provide insight into the perceptions of the various cultures towards seizure disorders and these need to be taken into account in any interpretation of results. A follow-up interview would be recommended since one interview followed by assessments may not have given a clear understanding of the patient's situation. This is particularly true with respect to past history of abuse and trauma which is not easily

discussed. This can be understood since they are imparting sensitive information to a stranger. One of the professionals consulted prior to data collection voiced concerns about the likelihood of patients being comfortable enough to share sensitive information at an early stage of investigation (see Section 4.5.2.).

Quality of life is an area that needs further investigation, as it is impacted on by suffering ongoing seizures of any kind. Aspects such as family background and interactions, interpersonal relationships, vocational adjustment, socio-economic status, etc, need to be carefully evaluated to understand the impact a seizure disorder has on these aspects or how these aspects may play a role in seizure presentation or maintenance. It would be more exact to follow a protocol such as the Patient Evaluation Grid (PEG) referred to in Wolman (1988) as this guide covers all the dimensions that need evaluation in these two patient groups. The PEG is essentially a bio-psycho-social model that looks at the patient in three time contexts (see Appendix J).

Longitudinal studies would provide information as to patterns and prevalence of presentation of both epilepsy and non-epileptic seizures. A study of this nature could include perceptions and management of seizures across cultures as well.

Cognitive functioning has been cited in the literature (see Section 2.7) as well as in discussion with professionals during the course of this research and it would be imperative to further investigate this aspect of the two disorders. Particular attention should be given to memory, attention and concentration since these are cited in the literature as problematic especially in the epilepsy patient group.

Awareness-raising would be important in this country, since there are many misconceptions about seizures and how to handle a person when they have one. This all stems from lack of knowledge and the families, friends and the public in general should be made aware of the aetiology, presentation and management of seizures. Many of the patients expressed the wish that others be helped to understand what they are experiencing – this can be achieved through programmes that could be run at hospitals, clinics and schools.

### 7.3 CONCLUSION

This study was important in that it served to highlight four areas where the non-epilepsy group showed significant difference to the epilepsy group and in the expected direction in terms of previous studies in the literature. Future research can use these findings to guide direction of investigation in this population group. The instruments used in this study proved to be reliable and they would be valuable inclusions in a larger study. The present study served to highlight the need for a larger national study to be done, bigger sample size and more comprehensive test battery including some neuropsychological investigation.

This study adds to the existing literature in that it is adding something to the understanding of the two disorders in South Africa. It has been said by professionals spoken to during the course of this study that more research is needed in this country as it is lacking and we have no reliable statistics on which to base our work in the field or against which to compare international findings.

In comparison to the epilepsy group, the non-epilepsy group had apparent lower self esteem, more negative self-perception and problems with social interaction and relationships. This group also suffered lower energy levels and higher anxiety. This leads to the conclusion that

the non-epilepsy group have lower quality of life than do the epilepsy group. This is not to say that the epilepsy group did not report problems, but only that by comparison the non-epilepsy group reported more and presented a more negative outlook on life. This is consistent with other findings and signifies the need to find a more definitive diagnosis of pseudoseizures and other forms of non-epileptic seizures. The present study serves to reinforce the need to continue the research into isolating psychological variables that may define non-epileptic pseudoseizures as this will expedite the treatment and management of this disorder.

What the findings of this study contribute to the reality of the patients suffering either epilepsy or non-epileptic pseudoseizures, is that firstly, there is a need to work towards finding clear diagnostic techniques so that iatrogenesis can be avoided; secondly, that the patients in both groups deserve to be understood as individuals, not as interesting neurological phenomena. They are more than just hypersynchronous firing in their brains, they are individuals who need to be understood in the context of their lives and defined by their own perception of their lived experience. With pseudoseizure patients we need to ask the question “why is this person having seizures, and why now?”. It is necessary to look at possible aetiology, presentation, maintenance and the role the seizures have in their lives. Integral to this, would be a closer look at family dynamics, the person’s coping skills, their locus of control, attribution style and perception of the self. For the epilepsy patient we need to realise that the seizures affect how they perceive themselves functioning in their world, are they limiting themselves or are the seizures doing this? In other words are they more disabled by the seizures than they need to be? Is their family dynamics locking them into a victim role? For both these patient groups, rehabilitation and therapy needs to be researched and implemented to optimise their day-to-day living and functioning in society. We must never

lose sight of the fact that we need to hear from them what they see is wrong in their lives and how they would like to change it. Each patient in this study was a unique person and although they presented similarities, the researcher was told that in a strange way she would be able to predict after a few interviews which patient had epilepsy and which patient had pseudoseizures, this proved to be true, their way of interacting was different yet similar within the group, something that could not be explained by statistics. Quality of life is an important aspect but it is subject to the perspective of the patient, and theirs is the only opinion that counts. Research needs to take this into account, the patient knows the measure of their quality of life more than any observing professional or researcher ever may and it is based on how they evaluate themselves, their abilities and their lives. Reality is constructed and multifaceted, created by the person themselves. Let us honour this. Let the research remember the uniqueness of the individual as well as the uniqueness of the collectivity. Statistics report on the variables but they fail to show the unique way that each patient is represented by that variable. We need to bear in mind the possibility that pseudoseizures may be a modern day manifestation of psychological dysfunction brought about by extreme stress and, or, reactions to traumatic experiences that are beyond the accepted realm of normal living.

Finally, in the quest to see the patients of both groups as holistically as possible, it is important that research includes both qualitative and quantitative measures as this one has done. As reported by Thomas (2003), most authors now see a combination of qualitative and quantitative measures as complimentary and not antagonistic. This profoundly broadens our view and literally puts meaning to the statistics in another dimension, that of descriptive words. Description is what is needed in terms of disseminating information on seizures of any kind to the public, family, friends of those who suffer these intrusive neurological or

psychological episodes. Through comprehensive research the knowledge of these two disorders can be broadened and the information fed back to the community so that these patients are not stigmatised, but understood and supported.

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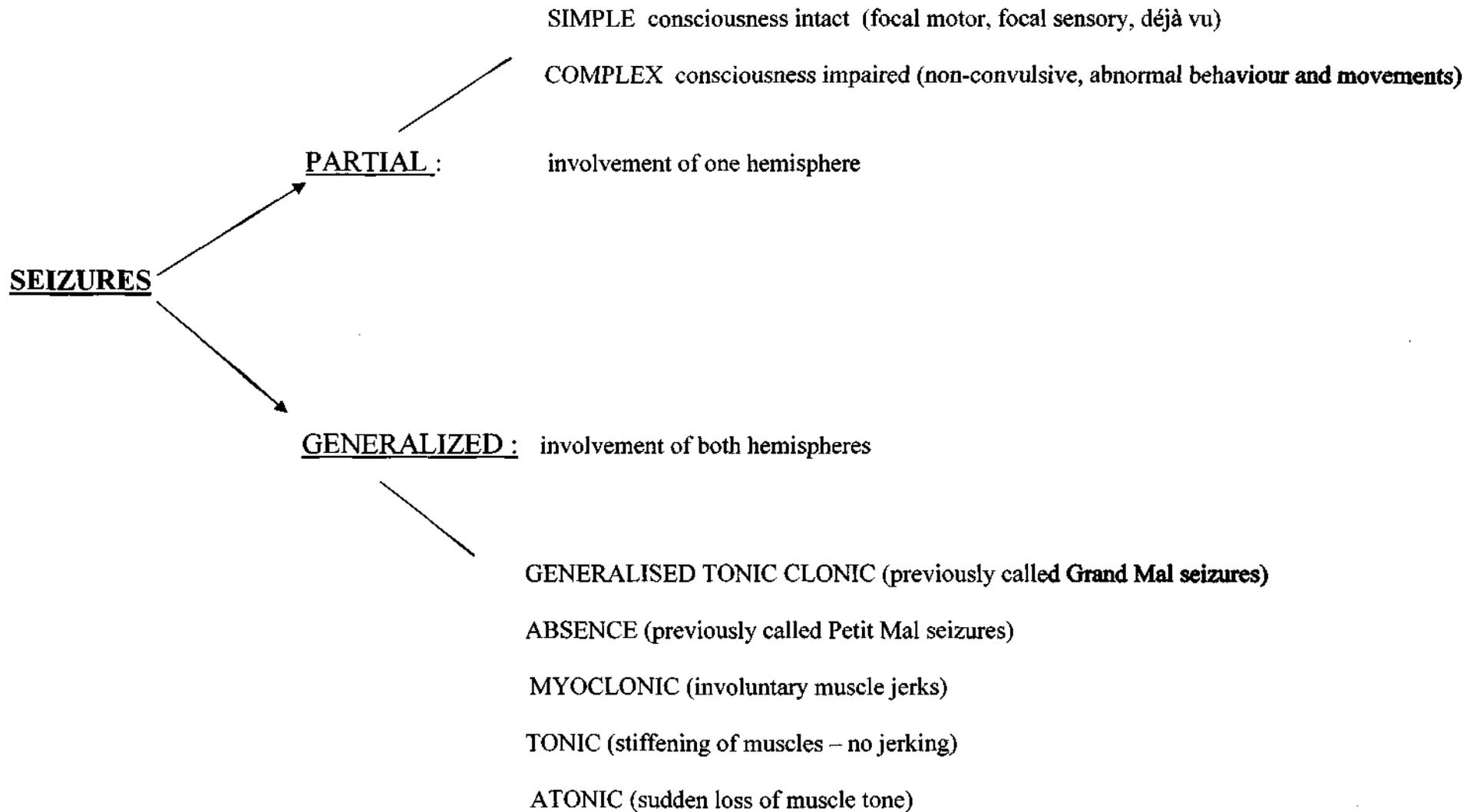
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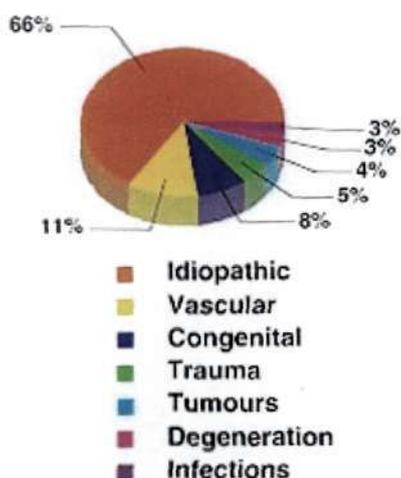
## **APPENDIX A**



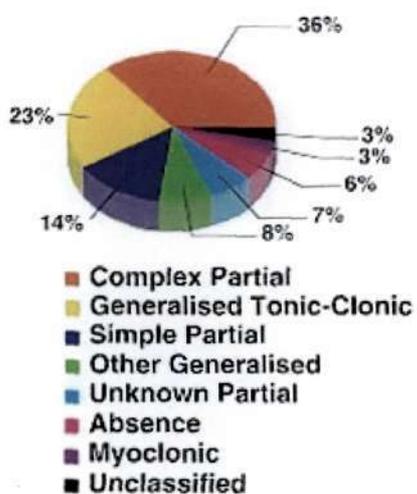
## **APPENDIX B**

The following charts are taken from the Epilepsy Society of South Africa's website (<http://www.epilepsy.org.za/index1.html>) and they give an indication of causes and types of epilepsy:

### *Causes of Epilepsy*



### *Types of Epilepsy*



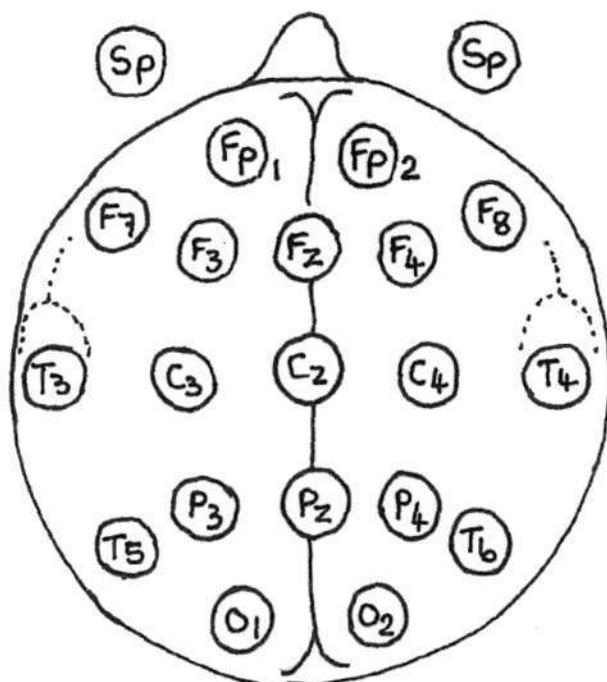
## **APPENDIX C**

Semiologic details that can help to distinguish between epileptic and psychogenic seizures

OBSERVATION	PSYCHOGENIC SEIZURES	EPILEPTIC SEIZURES
Situational onset	Occasional	Rare
Gradual onset	Common	Rare
Precipitated by stimuli (noise, light)	Occasional	Rare
Undulating motor activity	Common	Very rare
Asynchronous limb movements	Common	Rare
Purposeful movements	Occasional	Very rare
Rhythmic pelvic movements	Occasional	Rare
Opisthotonus "arc de cercle"	Occasional	Very rare
Side-to-side head shaking	Common	Rare
Tongue biting (tip)	Occasional	Rare
Tongue biting (side)	Rare	Common
Prolonged ictal atonia	Occasional	Very rare
Ictal crying	Occasional	Very rare
Closed mouth in "tonic phase"	Occasional	Very rare
Vocalization during "tonic-Clonic" phase	Occasional	Very rare
Closed eyelids	Very common	Rare
Convulsion > 2 min	Common	Very rare
Resisted lid opening	Common	Very rare
Pupillary light reflex	Usually retained	Commonly absent
Reactivity during "unconsciousness"	Occasional	Very rare
Lack of cyanosis	Common	Rare
Rapid postictal reorientation	Common	Unusual

Reuber and Elger (2003) *Psychogenic nonepileptic seizures: review and update*. *Epilepsy and Behaviour*, 4 (3), p 205-216.

## **APPENDIX D**



Electrode placement in electroencephalogram (Walsh, 1994, p 90).

The above diagram illustrates how the scalp electrodes are placed in a standard pattern and the activity between any pair of electrodes recorded as a single channel, of which there are usually about eight. The areas being analyzed at any one time may be varied by switching outputs between the pairs of electrodes. In one period of examination, eight channels might be devoted to the potential differences between: Fp2 – F8, F8 – T4, T4 – T6, T6 – O2, and the corresponding areas on the left side of the head. In a subsequent run, differences might be examined in the transverse direction: T3 – C3, C3 – Cz, Cz – C4, C4 – T4. In this way a thorough coverage of the brain can be achieved and the activity of the various areas compared. Interpretation depends on analysis of the principle characteristics of the wave activity, viz. the frequency, amplitude, form and distribution (Walsh, 1994, p 90).

The mean amplitude of the brain's electrical activity is about one hundredth that of the heart. The brain potentials are recorded in wave form from 1 to 100 Hz, with an amplitude ranging from about 5 to several hundred microvolts (Walsh, 1994, p 89).

## **APPENDIX E**

**INSTRUCTIONS:**

Below is a list of problems people sometimes have. Please read each one carefully, and circle the number to the right that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask about them.

**SEX**

MALE

FEMALE

NAME: \_\_\_\_\_

LOCATION: \_\_\_\_\_

EDUCATION: \_\_\_\_\_

MARITAL STATUS: MAR. \_\_\_ SEP. \_\_\_ DIV. \_\_\_ WID. \_\_\_ SING. \_\_\_

DATE			ID. NUMBER	AGE
MO	DAY	YEAR		

**EXAMPLE**

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
HOW MUCH WERE YOU DISTRESSED BY:					
Bodyaches	0	1	2	3	4

VISIT NUMBER: \_\_\_\_\_

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
1. Headaches	1	0	1	2	3	4
2. Nervousness or shakiness inside	2	0	1	2	3	4
3. Repeated unpleasant thoughts that won't leave your mind	3	0	1	2	3	4
4. Faintness or dizziness	4	0	1	2	3	4
5. Loss of sexual interest or pleasure	5	0	1	2	3	4
6. Feeling critical of others	6	0	1	2	3	4
7. The idea that someone else can control your thoughts	7	0	1	2	3	4
8. Feeling others are to blame for most of your troubles	8	0	1	2	3	4
9. Trouble remembering things	9	0	1	2	3	4
10. Worried about sloppiness or carelessness	10	0	1	2	3	4
11. Feeling easily annoyed or irritated	11	0	1	2	3	4
12. Pains in heart or chest	12	0	1	2	3	4
13. Feeling afraid in open spaces or on the streets	13	0	1	2	3	4
14. Feeling low in energy or slowed down	14	0	1	2	3	4
15. Thoughts of ending your life	15	0	1	2	3	4
16. Hearing voices that other people do not hear	16	0	1	2	3	4
17. Trembling	17	0	1	2	3	4
18. Feeling that most people cannot be trusted	18	0	1	2	3	4
19. Poor appetite	19	0	1	2	3	4
20. Crying easily	20	0	1	2	3	4
21. Feeling shy or uneasy with the opposite sex	21	0	1	2	3	4
22. Feelings of being trapped or caught	22	0	1	2	3	4
23. Suddenly scared for no reason	23	0	1	2	3	4
24. Temper outbursts that you could not control	24	0	1	2	3	4
25. Feeling afraid to go out of your house alone	25	0	1	2	3	4
26. Blaming yourself for things	26	0	1	2	3	4
27. Pains in lower back	27	0	1	2	3	4
28. Feeling blocked in getting things done	28	0	1	2	3	4
29. Feeling lonely	29	0	1	2	3	4
30. Feeling blue	30	0	1	2	3	4
31. Worrying too much about things	31	0	1	2	3	4
32. Feeling no interest in things	32	0	1	2	3	4
33. Feeling fearful	33	0	1	2	3	4
34. Your feelings being easily hurt	34	0	1	2	3	4
35. Other people being aware of your private thoughts	35	0	1	2	3	4

HOW MUCH WERE YOU DISTRESSED BY:

		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	
6.	Feeling others do not understand you or are unsympathetic	36	0	1	2	3	4
7.	Feeling that people are unfriendly or dislike you	37	0	1	2	3	4
8.	Having to do things very slowly to insure correctness	38	0	1	2	3	4
9.	Heart pounding or racing	39	0	1	2	3	4
0.	Nausea or upset stomach	40	0	1	2	3	4
1.	Feeling inferior to others	41	0	1	2	3	4
2.	Soreness of your muscles	42	0	1	2	3	4
3.	Feeling that you are watched or talked about by others	43	0	1	2	3	4
4.	Trouble falling asleep	44	0	1	2	3	4
5.	Having to check and double-check what you do	45	0	1	2	3	4
6.	Difficulty making decisions	46	0	1	2	3	4
7.	Feeling afraid to travel on buses, subways, or trains	47	0	1	2	3	4
8.	Trouble getting your breath	48	0	1	2	3	4
9.	Hot or cold spells	49	0	1	2	3	4
0.	Having to avoid certain things, places, or activities because they frighten you	50	0	1	2	3	4
1.	Your mind going blank	51	0	1	2	3	4
2.	Numbness or tingling in parts of your body	52	0	1	2	3	4
3.	A lump in your throat	53	0	1	2	3	4
4.	Feeling hopeless about the future	54	0	1	2	3	4
5.	Trouble concentrating	55	0	1	2	3	4
6.	Feeling weak in parts of your body	56	0	1	2	3	4
7.	Feeling tense or keyed up	57	0	1	2	3	4
8.	Heavy feelings in your arms or legs	58	0	1	2	3	4
9.	Thoughts of death or dying	59	0	1	2	3	4
0.	Overeating	60	0	1	2	3	4
1.	Feeling uneasy when people are watching or talking about you	61	0	1	2	3	4
2.	Having thoughts that are not your own	62	0	1	2	3	4
3.	Having urges to beat, injure, or harm someone	63	0	1	2	3	4
4.	Awakening in the early morning	64	0	1	2	3	4
5.	Having to repeat the same actions such as touching, counting, or washing	65	0	1	2	3	4
6.	Sleep that is restless or disturbed	66	0	1	2	3	4
7.	Having urges to break or smash things	67	0	1	2	3	4
8.	Having ideas or beliefs that others do not share	68	0	1	2	3	4
9.	Feeling very self-conscious with others	69	0	1	2	3	4
0.	Feeling uneasy in crowds, such as shopping or at a movie	70	0	1	2	3	4
1.	Feeling everything is an effort	71	0	1	2	3	4
2.	Spells of terror or panic	72	0	1	2	3	4
3.	Feeling uncomfortable about eating or drinking in public	73	0	1	2	3	4
4.	Getting into frequent arguments	74	0	1	2	3	4
5.	Feeling nervous when you are left alone	75	0	1	2	3	4
6.	Others not giving you proper credit for your achievements	76	0	1	2	3	4
7.	Feeling lonely even when you are with people	77	0	1	2	3	4
8.	Feeling so restless you couldn't sit still	78	0	1	2	3	4
9.	Feelings of worthlessness	79	0	1	2	3	4
0.	The feeling that something bad is going to happen to you	80	0	1	2	3	4
1.	Shouting or throwing things	81	0	1	2	3	4
2.	Feeling afraid you will faint in public	82	0	1	2	3	4
3.	Feeling that people will take advantage of you if you let them	83	0	1	2	3	4
4.	Having thoughts about sex that bother you a lot	84	0	1	2	3	4
5.	The idea that you should be punished for your sins	85	0	1	2	3	4
6.	Thoughts and images of a frightening nature	86	0	1	2	3	4
7.	The idea that something serious is wrong with your body	87	0	1	2	3	4
8.	Never feeling close to another person	88	0	1	2	3	4
9.	Feelings of guilt	89	0	1	2	3	4
0.	The idea that something is wrong with your mind	90	0	1	2	3	4

## **APPENDIX F**

**QOLIE**

**31**

**QUALITY OF LIFE  
IN EPILEPSY  
QOLIE-31  
(Version 1.0)**

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Patient Inventory



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The QOLIE-31 was developed  
in cooperation with the Professional  
Postgraduate Services division of  
Physicians World Communications Group,  
and the QOLIE Development Group.

**QUALITY OF LIFE IN EPILEPSY**  
**QOLIE-31 (Version 1.0)**

**Patient Inventory**

Today's Date \_\_\_/\_\_\_/\_\_\_

Patient's Name \_\_\_\_\_

Patient's ID# \_\_\_\_\_ Gender:  Male  Female

Birthdate \_\_\_/\_\_\_/\_\_\_

Have you completed this questionnaire prior to today's visit?  Yes  No

MD Name \_\_\_\_\_

---

**INSTRUCTIONS**

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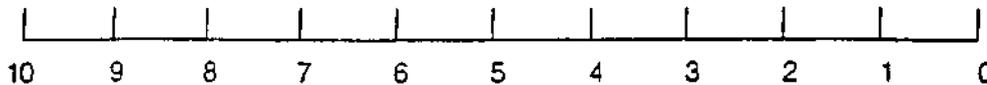
This survey asks about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3...).

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. Overall, how would you rate your quality of life?

(Circle one number on the scale below)



Best Possible  
Quality of Life

Worst Possible  
Quality of Life

(as bad as or  
worse than  
being dead)

These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous person?	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energy?	1	2	3	4	5	6
7.	Have you felt downhearted and blue?	1	2	3	4	5	6
8.	Did you feel worn out?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired?	1	2	3	4	5	6
11.	Have you worried about having another seizure?	1	2	3	4	5	6
12.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

14. How has the **QUALITY OF YOUR LIFE** been during the past **4 weeks** (that is, how have things been going for you)?\*

(Circle one number)

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5

The following question is about **MEMORY**.

	Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

This question asks about **how often** in the past 4 weeks you have had trouble *remembering* or **how often** these memory problems have interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16. Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past month** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17. Concentrating on reading	1	2	3	4	5	6
18. Concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with...

	A great deal	A lot	Somewhat	Only a little	Not at all
19. Leisure time (such as hobbies, going out)	1	2	3	4	5
20. Driving	1	2	3	4	5

The following questions relate to the way you **FEEL** about your **seizures**.  
(Circle one number on each line)

	Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21. How fearful are you of having a seizure during the next month?	1	2	3	4

	Worry a lot	Occasionally worry	Don't worry at all
22. Do you worry about hurting yourself during a seizure?	1	2	3

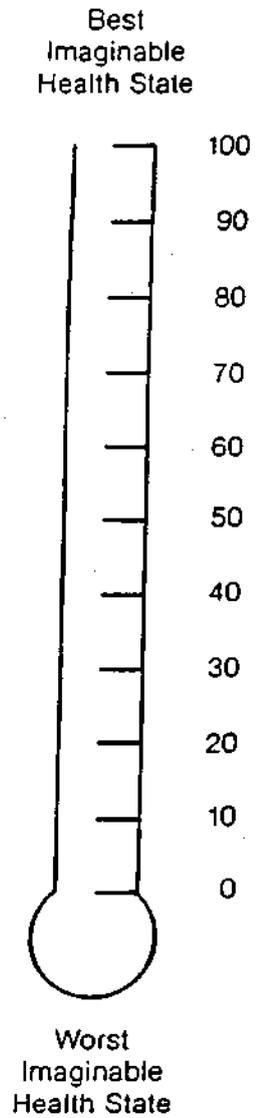
	Very worried	Somewhat worried	Not very worried	Not at all worried
23. How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4

24. How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4
---	---	---	---	---

For each of these **PROBLEMS**, circle one number for how much they bother you on a scale of 1 to 5 (5 = **Extremely bothersome**).

	1	2	3	4	5
	Not at all bothered				Extremely bothered
25. Seizures	1	2	3	4	5
26. Memory difficulties	1	2	3	4	5
27. Work limitations	1	2	3	4	5
28. Social limitations	1	2	3	4	5
29. Physical effects of antiepileptic medication	1	2	3	4	5
30. Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. Please consider your epilepsy as part of your health when you answer this question.





## **APPENDIX G**

QUESTIONNAIRE FOR SEIZURE PATIENTS

NAME OF PATIENT \_\_\_\_\_ DATE \_\_\_\_\_

DATE OF BIRTH \_\_\_\_\_ AGE \_\_\_\_\_ SEX \_\_\_\_\_

RACE \_\_\_\_\_

OCCUPATION(S) \_\_\_\_\_

EDUCATION \_\_\_\_\_

MARITAL STATUS \_\_\_\_\_

HANDEDNESS \_\_\_\_\_

ASSISTED BY \_\_\_\_\_ RELATIONSHIP \_\_\_\_\_

1. At what age did your seizures begin?

Minor (small) seizures

Major (generalised) seizures

2. Have your seizures become worse over time? If yes, in what way?

3. What may have caused the seizures (birth injury, febrile convulsions, head injuries, etc.)?

4. List your present and previous medications

present

past

---

5. How often do your minor and major seizures occur?

6. What, if anything, may bring about a seizure?

7. Describe any changes occurring regularly for hours or days before the seizures:

How long does this last before the seizure takes place?  
\_\_\_\_\_

8. What do you remember about your seizures? (include a detailed description of any aura or warning you may have)

Is this always the same?

How long does this last?

9. What do others observe at the time of a seizure?

Do others tell you that the seizures vary or do they say they are always the same?

How long do observers of your seizures tell you they last?

10. Describe what happens after the seizure is over:

How long does it take?

11. List other medical problems you may have:  
\_\_\_\_\_

12. Your years of education:

13. What type of work did you wish to persue?

14. Your work experience:

When did you work last?

15. Your present living situation:

16. Your marital history:

17. Has sex been important in your life?

18. What effect has epilepsy had on your sex life?

Since about when?

19. Do you have any close friends?

20. What effect has epilepsy had on your social life?

21. Briefly list your hobbies and other things you enjoy doing:

22. How was your physical and emotional health before onset of epilepsy?  
(list any counselling, psychiatric treatment, medication, or hospital stay)

Have you ever been in an abusive situation? If so, please describe:

23. Describe the effects of epilepsy on your emotional life:

List any counselling, psychiatric treatment, medication, or hospital stay:

*For female patients:*

How does your menstrual cycle affect your seizures?

How does your menstrual cycle affect your moods?

24. Do you have frequent depressive moods?

Since about when?

Are they present all the time or off and on?

How long do they last (hours, days or weeks)?

How often do they occur?

25. Do you often lack energy?

Since about when?

Do you lack energy all the time or episodically?

If episodically, indicate how often and how long this lasts (hours, days, weeks)?

26. Do you have trouble with your sleep?

Since about when?

How often and what kind of trouble?

27. Do you have many aches and pains? (please describe pain and location)

Since about when?

How often and for how long?

28. Do you have sudden moods of happiness?

Since about when?

How often and for how long?

29. Do your moods often change out of the blue?

Since about when?

How frequently do your moods change unpredictably (by hours, days, weeks)?

---

30. Are you often very irritable?

Do you have outbursts of temper?

Since about when?

How often do you become very irritable?

31. Do you have frequent worries (anxieties)?

Since about when?

How often do you feel worried?

32. Do you have fears of certain situations?

Since about when?

---

What fears do you have (being in crowds, being alone, or other)?

33. Do you often mistrust others?

Do you imagine things?

Since about when?

34. Do you sometimes hear or see things that are not there?

Since about when? Please describe:

35. Do you have periods of confusion or loss of memory, even without a seizure?

Since about when?

36. Do you tend to be very good-natured and conscientious?

Since about when?

37. Do you tend to be very orderly, strong on details, persistent in your actions? (please indicate which one(s) apply to you)

since about when?

38. Have you ever suffered from a drug or alcohol addiction?

About when?

---

39. What are your religious (spiritual) beliefs and practices?

Since about when?

Please list your pattern of religious practices or spiritual experiences

40. List family members who have suffered from:

\_\_\_\_\_ epilepsy \_\_\_\_\_

migraine

stuttering

neurological disorder

psychiatric disorder

alcoholism

drug addiction

Examiner : \_\_\_\_\_

Date : \_\_\_\_\_

From:

\_\_\_\_\_ The Epi-Care Centre in Memphis, USA (Ettinger & Kanner, 2001:243) \_\_\_\_\_

## **APPENDIX H**



College of Medicine  
Department of Psychiatry  
135 North Pauline  
Memphis, TN 38105  
Tel: (901) 448-6400 • Fax: (901) 448-4276

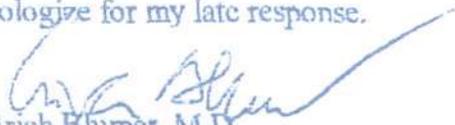
To: Marlene Wells  
Post-Grad research psychology  
University of Kwa-Zulu Natal  
Durban 4001  
Natal-South Africa

From: Dietrich Blumer, M.D.  
Department of Psychiatry  
University of Tennessee  
135 N. Pauline  
Memphis, TN. 38105

Of course, you have my permission to use our *Seizure Questionnaire*. I fax and mail you a copy as we use it daily with the space for the answers. I might just mention that the prodrome of pain to the psychogenic (startle) seizures is particularly distinct and so is the history of prior abuse or shocking trauma (often forgotten by the patient on completion of the questionnaire).

You have chosen an important topic for your research masters. I look forward to be in touch with you.

I apologize for my late response.

  
Dietrich Blumer, M.D.  
Professor of Psychiatry  
Head of Neuropsychiatry



1700 MAIN STREET  
P.O. BOX 2138  
SANTA MONICA, CA  
90407-2138

V 310.393.0411  
F 310.393.4818

November 29, 2004

Marlene R. Wells  
4 Kilburn Place,  
23 Kilburn Avenue,  
Musgrave,  
DURBAN 4001  
South Africa

Subject: QOLIE-31 Survey "Young People with Epilepsy"

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## **APPENDIX I**

PATIENT CONSENT FORM

Patient name : \_\_\_\_\_

I understand the reasons behind this research and I am a willing participant. I agree to be interviewed and assessed within the parameters of this research project. I understand that I am under no obligation to continue if for any reason I decide to withdraw.

I further understand that my identity will not be disclosed without my prior consent and that information relating to me will be treated in the strictest confidence.

I have not been offered any incentive, remuneration or other benefit in exchange for my participation.

I give permission for \_\_\_\_\_ to be interviewed with respect to this research as long as he/she is willing to participate.

\_\_\_\_\_  
Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

CONSENT FORM FOR SIGNIFICANT OTHER

Name: \_\_\_\_\_

Relationship to patient : \_\_\_\_\_

I am willing to participate in this research and I understand what the research aims to achieve. I understand that I may withdraw at any time should I decide to. I understand that all information will be treated in confidence.

\_\_\_\_\_  
signed

\_\_\_\_\_  
date

\_\_\_\_\_  
witness

## **APPENDIX J**

**PATIENT EVALUATION GRID (PEG)** (Wolman, 1988)

