The assessment and treatment of concerns and anxiety in patients undergoing pre-surgical monitoring for epilepsy

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ABSTRACT

The aim of the present study was to investigate the efficacy of an information package on reducing pre-surgical anxiety and concerns in patients with intractable epilepsy. Adverse psychological and social effects of temporal lobe epilepsy (TLE) are instrumental in anxiety and distress in these patients. This is brought into the hospital setting and exacerbated by the monitoring process and concomitant possibility of surgery where many patients prematurely curtailed the process at cost to themselves and the hospital.

Two experiments were conducted to identify concerns and anxieties specific to these patients and an attempt was made to reduce these concerns and anxieties. The first was a validation of a questionnaire, the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ) which identified concerns and ways of coping specific to one hundred and twenty-one temporal lobe epilepsy patients, thirty-six males and eighty-five females, average age 35.47 (SD=11.50), undergoing monitoring. An initial questionnaire was constructed from multiple sources of information. Exploratory and confirmatory factor analyses were conducted to refine the CAEMQ and determine its factor structure. Using a varimax rotation, six factors were revealed which contributed to 70.1% of the variance. 1. Information about surgery (alpha 0.86). 2. Personal concerns-family and pecuniary (alpha 0.85). 3. Information about monitoring (alpha 0.80). 4. Coping alone (alpha 0.77). 5. Denial (alpha 0.76). 6. Support from others (alpha 0.74). Test re-test reliability of the questionnaire was fully adequate with $r$ ranging from 0.86 to 0.60. An acceptable level of concurrent validity of the CAEMQ was also found when assessing the relationship between CAEMQ sub-scales and the State-Trait Anxiety Inventory (STAI- state anxiety 0.31, STAI-trait anxiety 0.28) measures. The use of the test as a measure of anxiety in surgical conditions is discussed.

The second experiment investigated the impact of a treatment information package on epilepsy patients being monitored for possible surgical treatment for temporal lobe epilepsy. One hundred patients were randomly assigned to either a high or low information preparation condition. Levels of anxiety and personality were tested soon after admission using the Hospital Anxiety and Depression Scale (HADS), the State-Trait Anxiety Inventory (STAI), Eysenck Personality Questionnaire-Revised (EPQ-R), and the newly devised questionnaire to assess specific concerns, anxieties, and ways of coping, the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ). Dispositional desire for information was assessed by the Miller Behavioural Style Scale (MBSS) to investigate whether coping disposition affected coping style strategies (as assessed by the CAEMQ) in the hospital setting. Patients assigned to the high information condition were exposed to an intervention package which included viewing a video depicting two separate interviews with patients who had undergone surgery for refractory
Dedication

This work is dedicated to the memory of my mother, Stefanie Pniewski, my brother Edward John Pniewski and my father, Edmund Pniewski.
Statement

This is to certify that

(i) the thesis comprises only my original work unless otherwise indicated in the preface

(ii) due acknowledgment has been made in the text to all other material used,

(iii) the thesis is less than 30,000 words in length, exclusive of tables, maps, bibliographies and appendices.
Preface

The information contained herein is the original work of the sole investigator. No information has been reproduced within this thesis, in whole or in part except where due reference has been made in the text.

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A special thank you to my parents who began post-war life in a new and alien land so that their children would have the chances they never had. To my father, who instilled the love of books and learning and to my mother who gave me my sense of self, of respect for oneself and others, and who faced the horrors of the Holocaust and her final battle with cancer in the same way- with dignity and strength. I thank you both for the person I am.
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CHAPTER 1

INTRODUCTION

Foreword: The aims of this thesis

Temporal lobe epilepsy (TLE) has been associated with psychological, behavioural and psychiatric morbidity (Mattson, Tibblin, Kihlgren and Kumlien, 2005; Ruber, Anderson, Elger and Helmstaedter, 2004; de Toffel, 2004; Wrench, Wilson and Bladin, 2004). These studies have shown the efficacy of surgery itself in reducing anxiety and depression as well as improving quality of life. Given these patients are already vulnerable to psychopathologies it is of interest to study and address the stressful situation of surgery for TLE patients as this is likely to exacerbate their vulnerabilities. This thesis aims to investigate the interaction between the psychological profile of TLE patients with a treatment program. The thesis has four major aims as follows:

1. To explore the personality and coping styles of patients with TLE prior to surgery

2. To develop an assessment device for the measurement of therapeutic intervention

and

3. To assess the therapy designed to reduce anxiety

Specifically, the thesis will investigate whether the administration of an information package to patients being monitored for possible surgical treatment for temporal lobe epilepsy would decrease their anxiety and depression levels. Further, dispositional desire
for information will be assessed to investigate whether the amount of information to
which the patients are exposed will increase or decrease their anxiety. The validation of a
newly devised questionnaire, the Concerns About Epilepsy Monitoring Questionnaire
(CAEMQ), will assess concerns and anxieties identified as endemic to TLE patients
about monitoring and the possible corollary of surgery.

Epilepsy monitoring involves many stressful procedures that may increase anxiety and
reduce compliance. Accurate electrographic localisation is essential to identify those
eligible for surgical treatment and this is only obtained during hospitalisation where anti-
epileptic drugs (AED’s) are gradually reduced or discontinued. This results in an increase
of epileptic seizures occurring while they are undergoing EEG monitoring so that
localisation of seizure origin can be identified. The patients face extensive testing which
entails a range of scanning techniques, neurological testing and continual EEG
monitoring for up to fourteen days. Patients are often required to be canalised to allow
injections for single photon emission computed tomography scanning (SPECT) during
both ictal and inter-ictal periods. As is evident, parts of the procedure are invasive and
electrodes can sometimes cause severe itchiness, rashes and discomfort. This often makes
the patient’s stay in hospital uncomfortable and stressful. Furthermore, there is the lack
of privacy concomitant with twenty-four hour video monitoring as well as the dislocation
from family. Finally, these stressors are compounded by the underlying distress of living
with the disease on a daily basis and uncertainty about the diagnostic and prognostic
outcomes of monitoring.
The author’s own survey of past records in two major Victorian hospitals indicates that approximately one in eight patients undergoing epilepsy monitoring remove themselves from the process prematurely, often citing stress related reasons for this curtailment. This has obvious concomitant negative consequences for their diagnostic and treatment process. This premature curtailing of the monitoring process by the patients themselves bears witness to the psychological toll this takes on these patients.

However, sources of anxiety for these TLE patients arise not only in the immediate monitoring situation but also from everyday life with the disorder. Areas of concern from which these anxieties and concerns originate will be investigated so that a more complete understanding of the profile presented by this patient population presenting for monitoring and possible surgery is obtained. This will be achieved through three main ways. First it is proposed that an identification of the concerns and anxieties during monitoring and about surgery will be attained through the design and validation of a newly devised questionnaire, the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ). Second, validated psychometric measures will identify personality attributes of the patients as well as levels of their anxieties and concerns. Third, these anxieties and concerns will be addressed and treated in a twofold procedure aimed at reducing anxiety by increasing information at the monitoring stage.

The first procedure will be through the exposure to an information package which outlines the testing procedures that the patient will undergo whilst undertaking the monitoring process. This will immediately be followed by a discussion about the package
with the researcher. The second procedure will be the viewing of a video depicting two patients, one male and one female, who have undergone the entire procedure from monitoring to surgery. These two will be viewed individually as they respond to a neuropsychologist’s invitation to relate their experiences and feelings during the entire process from monitoring to surgery and beyond. The researcher will remain with the epilepsy patients while they view the video, addressing questions and responding to comments made during and after the viewing.

1.1 The structure of this thesis

Chapter 2 describes the patient population under investigation (those with refractory temporal lobe epilepsy) with particular focus on this group’s pre-disposition to anxiety. It is argued that this anxiety arises from various sources and adds a supplementary burden to the anxiety experienced during the monitoring procedure of which the likely corollary is surgery. The uniqueness of this sub-group of epilepsy patients is established through the link between TLE and schizophrenia-like psychosis, personality traits and behavioural problems. Specifically, putative differences between TLE and other types of epilepsy have been identified in TLE patients with respect to personality changes. This has given rise to the term ‘the temporal lobe personality’. Further, schizophrenia-like psychosis has been linked with temporal lobe epilepsy, manifesting itself many years after seizure onset. Literature and research is investigated in this area to determine whether such a link is warranted by comparing the manifested symptoms and experiences of temporal lobe patients with that of schizophrenia sufferers. Finally the chapter looks at the role of stigma as a further possible source of anxiety which may be
brought to the monitoring procedure by TLE patients. The chapter posits that, due to the plethora of identified psychological and clinical problems encountered by TLE patients living with refractory epilepsy, that many of these patients are already compromised by anxiety from various sources when they arrive for the monitoring procedure which may result in the patient undergoing a temporal lobectomy. It is anxiety about both the monitoring procedure and possible concomitant surgery which is the major study of this thesis.

Chapter 3 describes the way in which epilepsy patients are deemed suitable for temporal lobe surgery. The chapter begins by identifying differences between temporal lobe patients with refractory epilepsy and those suffering other types of epilepsy. This is achieved by drawing attention to the differences in clinical features as shown in the International Classification of Epilepsies and Epileptic Syndromes between those with TLE and other types of epilepsy. The chapter then looks at the complete process, from EEG monitoring to surgery and surgical outcome in terms of either a significant reduction or complete freedom from further seizure episodes. However, it is suggested that the anticipation of surgery is yet another source of anxiety for TLE patients.

Chapter 4. In order to select the appropriate features of a treatment program likely to reduce anxiety in epilepsy patients, this chapter looks at the review studies which have investigated ways of alleviating pre-operative anxiety and depression in patient populations other than epilepsy patients. The discussion focuses on describing anxiety as identified by past research as well as identifying psychometric measures which have been
utilised to ascertain the level of reported anxiety in pre-operative patients. The discussion involves an investigation of the successful methods used in reducing anxiety and depression in patients presenting for surgery in these studies, as well as dearth of such studies pertaining to epilepsy patients.

Chapter 5 presents a rationale of a newly devised questionnaire entitled the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ). The chapter discusses the need for such a questionnaire which targets the specific concerns of epilepsy patients as well as investigating their coping strategies when they present for monitoring or possible surgery. A general discussion of other measures of coping looks at whether coping is a trait-like personality characteristic (as measured by dispositional scales) or whether it is a state-like response to a particular stressor (as measured by episodic scales). Measures of coping fall into two categories; they are either general-trait scales or situation-specific scales and the merit of developing and using the CAEMQ (an episodic scale) for this particular study is discussed. The chapter also looks at ways of coping which are utilised by people in aversive situations, including those facing surgical treatment. A model of the ways of coping is presented to aid in the understanding of the difference and interaction between coping disposition (trait) and coping style (a situation-specific coping strategy).

Chapter 6 is a brief chapter which synthesises the various areas under consideration in the major study in this thesis. It provides the rationale for each of the studies as well as presenting the hypotheses to be tested. The chapter re-iterates the idea that TLE patients
are already compromised by the capricious nature of their disorder, as well as various sources of anxiety, (as identified in chapter 2) when they arrive for long-term EEG monitoring. Added to this is the real possibility that they may be surgical candidates.

Patient coping style, mediated by coping traits, determines the effectiveness with which the patient is able to reduce their anxiety about monitoring and possible surgery in the hospital environment.

Chapter 7 reports on the first experiment of this research study. It is a validation of the newly devised questionnaire, the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ) using factor analytic techniques.

Chapter 8 reports on the second and main experiment of this research study into whether the administration of an information package to epilepsy patients presenting for monitoring shows a reduction in anxiety and depression compared to a control treatment group. It also reports on the effect this package has on attrition numbers with respect to premature curtailment of the monitoring procedure by the patient usually attributed to elevated anxiety about the procedure.

Chapter 9 is the discussion and the final chapter. It provides the general findings of the research studies within this thesis and looks at some future directions for research.
2.0 The patient profile under investigation- TLE patients with refractory epilepsy

2.1 Overview of sources of anxiety for TLE patients

Psychopathology in medically refractory partial seizures is well known and documented. Thus temporal lobe epilepsy (TLE) patients with refractory epilepsy who present for monitoring have psychological problems and personality characteristics not shared by other patient groups. It is posited that these problems and characteristics specifically identify this group.

Researchers (Betts, 1998; Hyde and Weinberger, 1997; Barracough, 1987; Bear and Fedio, 1987; Edeh and Toone, 1987; Brandt, Seidmann and Cole, 1985; Dodrill, Batzel, Queisser, and Temkin, 1980) have identified a constellation of endemic problems associated with this sub-group. These researchers draw attention to psychological, behavioral and personality problems which are found predominantly in TLE patients. Early characterization referred to a ‘temporal lobe epilepsy personality syndrome’ which may be attributed to this group of patients (Blumer, 1999; Waxman and Geschwind, 1975; Bear and Fedio, 1977). Mood disturbance such as depression (Reuber et al. 2004: Schmitz, Robertson and Trimble, 1999; Victoroff, (1996) and anxiety (Wrench et al. 2004: Manchanda, Schaefer, McLachlan et al., 1996; Trimble, Mendez and Cummings, 1997) have been found to be common comorbidities with of temporal lobe epilepsy.
One of the main stressors which affect TLE patients relates to the refractory nature of their seizures. Not only do they have to cope with the uncertainty of treatment but also the process of assessment and treatment is often prolonged. The majority of patients with epileptic seizures are usually able to control episodes with a single anti-epileptic drug. Unfortunately for the population under investigation in this thesis (TLE patients with refractory temporal lobe epilepsy), even though they have complied with prescribed pharmacological regimen, their epilepsy responds poorly to such treatment. In such cases the only option to control seizures is often through surgery (Engel 1996).

It is likely that TLE patients will have multiple influences that may increase anxiety in a hospital setting. They are not only exposing themselves to the anxiety of the monitoring procedure and its possible surgical outcome, but also arrive with a history of having contended with sources of anxiety such as the exposure to the capriciousness of the disease itself and the failure of pharmacological intervention. These factors are likely to make this particular group of patients vulnerable to further stress.

2.2 Interictal emotional and behavioural alterations in temporal lobe patients and the search for a ‘temporal lobe epilepsy personality’ syndrome

The identification of the association of TLE patients and behavioural changes began when Gibbs (1951) reported frequent behavioural disorders among patients with temporal lobe seizure foci. This association of several interictal personality changes in patients with TLE such as deepened emotions, circumstantiality, heightened religious and sexual
concerns and hypergraphia led Waxman and Geschwind (1975) to outline a syndrome with deepening of emotions as a central feature characterized by intense interpersonal contact and sustained intense affect. This early work and the prominent role of the temporal-limbic areas in the emotional system fostered the link between TLE and behavioral changes.

These earlier observations were followed by an expansion to this syndrome by Bear and Fedio (1977). Theirs is one of the most influential studies which has provided some of the most interesting work towards analyzing TLE personality. It is worth considering their theory in some depth. In a meta-analysis of literature concerning nonpsychotic behaviour changes in patients with temporal lobe epilepsy, Bear and Fedio (1977) summarised and sorted various clinical observations that the literature reported into eighteen traits. The eighteen interictal traits described by Bear and Fedio (1977) are summarized in Table 2.1.
Table 2.1 Interictal behavioural traits attributed to patients with TLE (Bear & Fedio, 1977)

<table>
<thead>
<tr>
<th>Trait</th>
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<tr>
<td>Aggression</td>
<td>Overt hostility, rage attacks, violent crime</td>
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<tr>
<td>Altered sexual interest</td>
<td>Loss of libido, hyposexualism, fetishism</td>
</tr>
<tr>
<td>Circumstantiality</td>
<td>Loquacious, pedantic, overly detailed, peripheral</td>
</tr>
<tr>
<td>Dependence, passivity</td>
<td>Emotional indifference, lack of initiative, dullness</td>
</tr>
<tr>
<td>Elation, euphoria</td>
<td>Grandiosity, exhilarated mood, bipolar disorder</td>
</tr>
<tr>
<td>Guilt</td>
<td>Tendency to self scrutiny, and self recrimination</td>
</tr>
<tr>
<td>Humourlessness, sobriety</td>
<td>Overgeneralised concern, idiosyncratic humour</td>
</tr>
<tr>
<td>Hypergraphia</td>
<td>Keeping extensive diaries, excessive detailed notes</td>
</tr>
<tr>
<td>Hypermoralism</td>
<td>Attention to rules, inability to distinguish significant from minor infraction, desire to punish</td>
</tr>
<tr>
<td>Irritability</td>
<td>Increased anger, temper</td>
</tr>
<tr>
<td>Obsessionalism</td>
<td>Ritualism, orderliness, compulsive attention to detail</td>
</tr>
<tr>
<td>Paranoia, jealousy</td>
<td>Suspicious, misinterpretation of motives/events</td>
</tr>
<tr>
<td>Philosphophic interest</td>
<td>Nascent metaphysical or moral speculation</td>
</tr>
<tr>
<td>Religiosity</td>
<td>Holding deep religious beliefs, mystical states</td>
</tr>
<tr>
<td>Sadness</td>
<td>Hopelessness, discouragement, diagnosis of depression</td>
</tr>
<tr>
<td>Sense of personal destiny</td>
<td>Egocentricity, belief in divine guidance</td>
</tr>
<tr>
<td>Viscosity</td>
<td>Stickiness, tendency to repetition</td>
</tr>
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</table>

In their study, the researchers developed two forms of the same inventory, the Behaviour Inventory (referred to as the Bear-Fedio Inventory, BFI). The first was The Personal Inventory, which was a self report given to the patient and the second was the Personal Behaviour Survey which assessed personality traits in the patient as reported by a close
friend or relative. The researchers sampled each of the eighteen traits by devising five items for each trait which the patient had to either endorse or deny. Independent ratings were obtained from two forms of the inventory, one from the patient and one from a significant other’ (e.g. spouse, parent). The questionnaire was then given to four groups: patients with left and right temporal foci, patients with neuromuscular disorders and normal controls.

Bear and Fedio (1977) found an increased frequency of all eighteen traits in patients with TLE compared with normal or neurologic controls. It was found that the self-report inventory differentiated the epilepsy patients from the other two groups on all eighteen traits. Fourteen traits differentiated the controls from the epilepsy patients on the inventories rated by significant others. They also reported that patients with right hemisphere foci were more likely to show emotional tendencies and denial and those with left hemisphere foci more likely to show ideational aberrations (i.e. paranoia) and antisocial behaviour. The researchers concluded that their findings were indicative of an interictal behaviour syndrome and that the Behaviour Inventory could measure traits and self perception biases to support this conclusion.

The identification of characteristic behavioural changes, supported by a clinical study with highly significant findings has drawn heavy criticism. Several limitations were inherent in their study. These include the small size of their groups (only forty-eight subjects comprised the two TLE and two control groups), the groups were not studied consecutively and the number, type and dosage of antiepileptic drugs (AED’s) were not
specified. Further, since a control group involving a population with seizure foci in other sites was not included in the study, the specificity of these changes to limbic areas can be questioned. Also, there was only a limited number of subjects, too few to give justice to the analysis. The omission of non-epilepsy controls must be considered or at the very least, a control group of other epilepsy foci be used. The factor analysis is not conducive to profiling as it is a method of separation not consolidation into a single profile.

Although replication studies utilizing the Bear-Fedio Inventory (BFI) have produced mixed results, there appears to be some evidence of support for the constellation of traits that they identified. Strauss (1989) summarized five studies that utilized the BFI and concluded that, “some researchers reported a behavioural pattern specific to temporal lobe epilepsy but a constant trait profile has not emerged.” (p.331). One behavioural trait which has reputedly been observed in TLE patients and has received attention is that of ‘viscosity.’ This behaviour has been described as ‘a persistent drive to sustain or prolong interpersonal contact and an inability to effectively terminate social interaction which is compounded by an inability to follow a logical stream of thought without becoming occupied with trivial or irrelevant details.’(Speirs, Schomer,Blume and Hochandel, 1992, p.121). In epilepsy literature, the term has had two meanings. One is stickiness of thought processes or enhanced interpersonal adhesiveness. Patients with this trait were described as talking repetitively, sticking to restricted topics and difficulty in ceasing conversation. The other is social cohesion. Patients with this trait are characterized by a tendency to form clinging relationships with family members and close friends. Researchers Rao,
Devinsky, Grafman et al. (1991) reported on viscosity in TLE patients. In their study they obtained self-report and observer ratings from one hundred and eighteen patients. Of these patients there were eighteen with left-TLE, twenty-one with right-TLE, twelve with absence or generalized seizures, nineteen with mixed complex partial seizures, twenty-five with panic disorders who served as a psychiatric control group and twenty-three normal controls. The researchers developed self-report and rater scales for both viscosity and social cohesiveness, which were embedded in a longer questionnaire. They reported that elevations on the viscosity scale were observed in TLE patients with left or bilateral foci with no group differences reported on the social cohesion scale.

The relationship between hypergraphia and TLE was found by a number of studies (Rodin, 1973; Mungas, 1982; Waxman and Geschwind 1975; Hermann et al. 1983; Trimble 1991). Trimble (1991) stated that, “there is some evidence that this phenomenon may appear as a state or trait in certain patients …of more interest is that the other group where hypergraphia is a recognized sign is in those with major psychoses, schizophrenia and mania.” (p.119). This was of interest because of the putative link between schizophrenia-like psychosis and temporal lobe epilepsy which is discussed later in this chapter.

The question of whether there is a set of specific characteristics associated with temporal lobe epilepsy is not settled and if there is a constellation of traits endemic to these patients, current measures have not been able to conclusively identify a ‘temporal lobe personality’. However, although not all patients with temporal lobe epilepsy are prone to
behaviour disturbance, some risk factors have been identified for some of the traits, which include an early age of onset, the presence of multiple seizure types (Hermann, Dikmen and Wilinsky, 1982), and the laterality of focus (Strauss, Risser and Jones, 1982). Strauss (1989) maintains that no firm conclusions can be posited on the relationship between emotion and epilepsy and that behavioural abnormalities are not universal in TLE patients. Instead, the emphasis needs to be on the critical variables that inhibit or promote the development of interictal behaviours in some TLE patients. These variables are identified as biological and psychosocial in origin and are not of the same form and intensity in each patient, but are dependent upon an interaction with other factors including past experience, and current psychosocial situation. Hence when a TLE patient presents for monitoring with surgery the possible outcome, it must be taken into consideration that they may be one of those prone to suffering ictal or interictal manifestations of emotions. Spiers and his colleagues (1992) have suggested behavioral alterations may not be evident in every patient with temporolimbic epilepsy, but for those in whom they are present, it is imperative that importance is placed on investigating and addressing the concerns of such patients.

Finally, personality traits are influenced by developmental and social environments, gender, intellectual status, anti-epileptic drugs and other biologic and environmental factors. These factors have not been systematically studied in epilepsy patients and their roles need to be considered in any study attempting to identify behavioural traits in TLE patients. Hence there are observed behaviour changes in TLE patients which have so far defied traditional syndrome categorization. Therefore, while studies have suggested that
temporal lobe epilepsy patients show some emotional dysfunction with suggestions of certain behaviours, the results are inconclusive.

2.3 Ictal manifestations of emotions in TLE patients

In a meta-analysis of past research on ictal manifestations of emotions in epilepsy, Strauss (1989) found that temporal lobe patients had reportedly manifested a wide variety of responses. Ictally, the most commonly reported emotion that temporal lobe epilepsy patients experience was fear (Strauss et al. 1982; Gloor et al. 1982; King and Ajmone-Marsan, 1977; Bingley, 1958). The suggested aetiology of this was that it was due to activation within the limbic system, and in particular the amygdala (Weiser, 1980; Gloor et al. 1981; Gloor, 1972). However the researchers point out that the personality of the patient, ongoing concerns and the patient’s environment are also important factor to be considered (Mattsson, Tibblin, Kihlgren and Kumlien, 2005; Gloor et al. 1982; Halgren, 1982).

It was reported by Halgren, (1978) that limbic stimulation through depth electrodes was most likely to result in the experience of fear and anxiety in those epileptic patients who scored higher on the ‘psychasthenia’ (pt) scale of the Minnesota Multiphasic personality Inventory (MMPI) - a scale which measures anxiety and stress. Additional evidence of a link between the amygdala and fear comes from investigators (Henrikson 1970; McLachlan and Blume, 1908) who have described the cessation of attacks of fear in patients who have undergone temporal lobectomy which included portions of the amygdala.
A more recent study by Cendes, Andermann, Gloor et al. (1994) investigated fifty patients with intractable TLE. Seventeen patients had a history of fear accompanied by a rising epigastric sensation as the initial manifestation of their seizure episodes. Compared with the thirty-three patients who did not experience this manifestation, the amygdala volumes of those with a history of fear were significantly smaller. The researchers concluded that ictal fear was related to the pathology of the amygdala and that it is an important substrate of temporal lobe epilepsy.

Another ictal manifestation which has received attention for many years is aggression, with the belief that directed aggression occurred as part of the epileptic seizure (Trieman, 1989). In the most comprehensive study to date on ictal aggression by Delgado-Escueta, Mattson, King et al. (1981), the researchers defined violence as the ‘directed exertion of extreme and aggressive force, which, if unrestrained, would result in injury, destruction or abuse.’ (p712). Thirteen patients with a clinical diagnosis of epilepsy were observed for evidence of aggression using a six-point rating scale ranging from no violence or aggressive behaviour to severe violence to a person resulting in injury. All forms of aggressive behaviour (which were given a rating of between two and no higher than four) occurred during complex partial seizures. On this basis, six patients had no or minimal aggression and in the remaining seven patients spontaneous, non-directed aggression was observed during the height of epileptiform paroxysms with amnesia for aggressive acts present in every case.
Devinsky, Ronsaville, Cox, Witt, Fedio and Theodore (1994) administered the Buss-Durkee Hostility Questionnaire to two groups of epilepsy patients (left temporal lobe foci and right temporal lobe foci) and compared them to normal controls. They found that the patients with left temporal lobe foci scored higher on Hostile Feelings (irritability, resentment, suspicion and guilt), the controls scored higher on Covert Aggression (indirect aggression and negativism) and the right temporal patients scored higher on Overt and Aggressive actions (physical and verbal assault). Males with right temporal lobe epilepsy scored higher than females with right temporal lobe epilepsy. They concluded that patients with TLE were not a homogeneous group with regard to hostile thoughts and actions and that lateralisation of seizure focus in temporal lobe epilepsy may alter expression of aggressive behaviour. However, other factors such as developmental environment and medications should also be considered.

Strauss’ (1989) analysis of past research led her to conclude that ictal aggression is rare and when it does occur, it is often due to the patient being restrained by well meaning people in an attempt to protect the patient. She further states that researchers have reported the ‘aggressive acts are typically unsustained, unplanned, and are not premeditated.” (p.322). It would therefore be prudent to conclude that the weight of evidence suggests that ictal aggression is extremely rare and, when exhibited, is not premeditated, is often a response to the individual’s current concern (i.e. usually freeing themselves from restraints imposed by well meaning people) and is reportedly not remembered by the patient.
2.4 Reported differences between right and left temporal lobe patients

Another area of past research, which has been mentioned earlier in this chapter, is the attention given to left and right temporal lobe patients with respect to behavioural and emotional differences (Brandt, Seidman and Kohl 1985; Svoboda, 1979; Master, Toone and Scott, 1984; Bear and Fedio, 1977). A recent paper by Andelman, Fried and Neufeld (2001) investigated the relationship of the laterality of the epileptogenic lesion to personality factors, emotional processing and the subjective experiences of quality of life (QOL) in candidates for epilepsy surgery. They found that left TLE patients showed higher levels of anxiety and lower self-estimates of the QOL than right TLE patients. The researchers cautioned that, as the high level of anxiety shown by left TLE patients may be representative of a personality trait, that it may also present a pre-surgical risk factor for those with left TLE and that appropriate intervention or counselling is suggested. Their study adds credibility to the aim of the major study of the present thesis which looks at the efficacy of an intervention package to reduce anxiety in TLE patients presenting for monitoring.

Other behavioural differences have been noted in temporal lobe epilepsy patients between those who have right temporal lobe epilepsy and those with left temporal lobe epilepsy (Svoboda, 1979; Master, Toone and Scott, 1984; Bear and Fedio, 1977). In 1979 Svoboda summarised the work of Mc Intyre, Pritchard, and Lombroso (1976) and Bear and Fedio (1977) with respect to psychiatric tendencies associated with temporal lobe seizures which appeared to differentiate between right and left- sided seizures. These differences are shown in Table 2.2.
An inspection of Table 2.2 shows that a patient with a seizure disorder involving the left dominant hemisphere (the area primarily in charge of processing language) may have a tendency to be more introspective, reflective and contemplative. Further, the patient may become deeply concerned that external events influence his life and may catastrophise when faced with failure. The right temporal lobe seizure patient is described as more emotive with displays of anger, sadness and elation. Strict adherence to rules and impulsivity are also attributed to these patients. Also, left temporal lobe patients may be more prone to develop a thought disorder than a mood disorder whereas a mood disturbance is more likely to be attributed to a right temporal lobe seizure patient.
<table>
<thead>
<tr>
<th>Left temporal lobe</th>
<th>Right temporal lobe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SELF DESCRIPTION</strong></td>
<td></td>
</tr>
<tr>
<td>Emphasises faults</td>
<td>Exaggerates good qualities</td>
</tr>
<tr>
<td>Minimises strengths</td>
<td>Denies disapproved behaviours</td>
</tr>
<tr>
<td>Tarnishes own image</td>
<td>Tries to build a good image</td>
</tr>
<tr>
<td><strong>ORIENTATION</strong></td>
<td></td>
</tr>
<tr>
<td>Introspective and contemplative</td>
<td>Gregarious and impulsive</td>
</tr>
<tr>
<td>Intellectual ruminations</td>
<td>Externalised emotion</td>
</tr>
<tr>
<td>Religious pursuits</td>
<td>Anger</td>
</tr>
<tr>
<td>Philosophical interests</td>
<td>Sadness</td>
</tr>
<tr>
<td>Sense of personal destiny</td>
<td>Euphoria and elation</td>
</tr>
<tr>
<td>Feels events control life and destiny</td>
<td>Repetitious and talkative about details</td>
</tr>
<tr>
<td><strong>REACTIONS</strong></td>
<td></td>
</tr>
<tr>
<td>Verbal expression of ideas</td>
<td>Non-verbal reactions</td>
</tr>
<tr>
<td>Excessively detailed speech and language</td>
<td>Emotional with wide swings</td>
</tr>
<tr>
<td></td>
<td>Aggressive (amnesia for event/denied)</td>
</tr>
<tr>
<td><strong>EMOTIONAL PROBLEMS</strong></td>
<td></td>
</tr>
<tr>
<td>Thought disturbances</td>
<td>Mood disturbances</td>
</tr>
<tr>
<td>Catastrophic fears and despairs</td>
<td>Manic depressive</td>
</tr>
<tr>
<td>Paranoid schizophrenia</td>
<td>Impulsive</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>Aggressive</td>
</tr>
</tbody>
</table>

However, since the pivotal study by Bera and Fedio (1977) the reported differences between left and right temporal epilepsy patients have met with little or mixed success being either partially confirmed or directly refuted (Master, Roone and Scott, 1984; Mungas, 1982; Rodin and Schmalz, 1984; Rodin, Schmaltz and Twitty, 1984). Also, since a control population seizure foci in other sites was not used, the specificity of these tendencies in the two limbic regions can be questioned. Hence the search for a distinction
between right and left foci epilepsy patients through the use of current psychometric measures such as the Behaviour Inventory has proved inconclusive and perhaps it is more a measure of some specific areas of maladjustment in these patients rather than a measure to distinguish left and right foci patients.

2.5 Schizophrenia and TLE patients

The association between epilepsy and schizophrenia-like psychosis has attracted attention as to the question of the exact nature of association of these two disorders. A very early report by Glaus (1931), based on a small number of patients (seven cases out of six thousand where a double diagnosis had been made), suggested that epileptiform seizures occurred rarely in schizophrenia and considered the possibility of epilepsy occurring before the psychosis. Of the eight cases, four patients whose epilepsy had been controlled for many years were diagnosed with schizophrenia. Two cases showed an improvement in epilepsy frequency when the schizophrenia developed and one case of a combination of the two disorders was diagnosed. Glaus (1931) reportedly observed either simultaneous or successive association between the two disorders in epilepsy patients. Although the successive cases suggested some kind of antagonism, he concluded that the two disorders did not significantly influence each other.

However, in 1934 von Meduna, (cited in Trimble, 1991) examined the brains of both epileptic and schizophrenic patients noting that changes in epilepsy were opposite to those of schizophrenia with the loss of few neuronal cells but with clear gliosis. From this he hypothesized that there was hypofunction of the glia in schizophrenia and and
hyperfunction in epilepsy. The suggestion of an antagonism between epilepsy and schizophrenia was made in 1930 by Nyiro and Jablonsky who posited that the process of schizophrenia worked against the epileptic process. They based this on their observation that there was a much higher number of cured epilepsy patients who had developed schizophrenia (16.5%) compared to those who had previously had epilepsy only (1.05%).

This interest in the antagonism between seizures and psychosis was renewed when Landolt (1953) used the concept of ‘forced normalisation’ after being faced with the puzzling observation that the EEG’s of epilepsy patients who had been diagnosed with schizophrenia often looked less pathological. He described the term thus, “Forced normalization is the phenomenon characterized by the fact that, with the occurrence of psychotic states, the EEG becomes more normal or entirely normal as compared with previous and subsequent EEG findings.’ (p. 114). Later studies (Wolf, 1988; Palkinas et al. 1987; Currie, Heathfield, Henson et al. 1971) supported this observation as well as emphasizing the prevalence of temporal lobe association with this phenomenon. For instance, Palkinas et al.’s (1987) study involved seven patients who had no psychiatric history and whose psychiatric manifestations emerged after seizure control was achieved through anticonvulsant therapy. Their EEG’s abnormal before therapy, normalized during psychotic episodes.

Another interesting finding with respect to onset of schizophrenia-like psychosis in epilepsy patients was first reported by Glaus (1931) who noted that psychosis associated with temporal lobe epilepsy had been diagnosed much later than the onset of epilepsy.
Specifically, he found that epilepsy occurred between the ages of six and thirty-five with a mean of seventeen years, whereas schizophrenia-like psychosis appeared between the ages of twenty-two and forty-two, with a mean of thirty-one years. Recent research in this area by Kanner, Stagno, Kotagal and Morris, (1996) has reported the onset of postictal psychosis in patients after having seizures for a mean of more than ten years and Kanemoto, Kawasaki and Kawai, (1996) also reported a lengthy latency period before the onset of psychosis with patients in their study having had epilepsy for a mean of more than twenty years.

Other early studies (Hill, 1953; Pond, 1957; Slater and Beard, 1963), also suggested that specific psychiatric conditions such as schizophrenia develop in association with temporal lobe epilepsy. However, Bartlett (1957) posited that there was no evidence to support the hypothesis that schizophrenia was more or less likely to occur in temporal lobe epilepsy patients than in the general population. Slater and Beard (1963) repudiated this suggestion and reported that the incidence of focal epilepsy patients who had developed schizophrenia-like psychosis was ‘much greater than chance expectations would permit’ (p. 98). They maintained that the psychosis experienced by epilepsy patients was due to “a stage in a dementing process” (p.149). Pond (1957) found that patients with complex partial seizures developed psychotic states which closely resembled schizophrenia. Such a condition was most likely to appear gradually with the onset of middle age and resemble a paranoid schizophrenic state. This was observed to occur when the seizures were diminishing in frequency, either through treatment or spontaneously.
2.6 Schizophrenia-like psychosis in epilepsy—is it schizophrenia?

Results from recent studies suggest that when reference is made to temporal lobe psychosis and schizophrenia that it is not one and the same thing, as was suggested by earlier studies. However, due to the similarities of symptoms displayed with respect to schizophrenia, studies have been devoted to investigating brain morphology in schizophrenia patients and comparing these with TLE patients (Briellman and colleagues, In Press; Barr et al., 1997). These studies suggest that the manifest clinical features in the two patient populations are not indicative of the same disorder in both groups but are two different types of psychoses. Briellmann, Hopwood, Ward, Kalinas, Bekovic and Jackson (In Press), found differences in the hippocampus between schizophrenia patients and TLE patients with and without postictal psychosis. Specifically, all TLE patients showed hippocampal abnormalities which were well defined, whereas those with schizophrenia showed only subtle abnormalities of the hippocampus. TLE patients without postictal psychosis showed a focal-side hippocampus which was shorter and atrophy diffusely distributed. TLE patients with postictal psychosis revealed the focal-side hippocampus as larger with less atrophy. The researchers also found evidence of underlying temporal lobe dysplasia in post ictal psychosis patients. These were less frequent in those without postictal psychosis. The researchers posited that this may account for the different brain morphology and clinical feature in the post ictal psychosis patients.
Other literature and studies (Trimble, 1991; Slater and Beard, 1963) devoted to closer examination of the comparison between schizophrenia patients and temporal lobe patients have also concluded that the two disorders are not one and the same. In most studies, the term ‘schizophrenia-like’ psychosis is used to describe the symptoms of TLE patients rather than the word ‘schizophrenia’. This is because the observed clinical features were in many ways quite different between the two groups of patients. In an early study, recognised as the forerunner in the study of psychoses among epileptic patients, Slater and Beard (1963), reported that even though many of the usual symptoms of schizophrenia had been exhibited by TLE patients, that the combination of symptoms shown by these patients differed from the usual schizophrenic patterns. Specifically, they reported that catatonic states were rare in the TLE patient, they were more friendly and co-operative, were less suspicious of hospital staff, and the loss of affective response did not occur as early and was not as marked in the TLE patient as was evident in the schizophrenic patient. Also, unlike the schizophrenia patients, TLE patients were able to function in a normal ward and were able to maintain interpersonal relationships. As Trimble (1991) notes, “the (TLE) patients retained affective warmth and this was one of the characteristic distinguishing features between the schizophrenia-like psychoses of epilepsy and process schizophrenia.” (p135). Further, after a psychotic episode, unlike those with schizophrenia, the TLE patients acknowledge that the hallucinations are not real, indicating a stability of the mind in these patients.
2.7 Ictal, postictal and interictal psychoses

More recent studies have focused on the distinction in psychosis during ictal, postictal and interictal periods (Sachdev, 1998; Kanemoto, Talenchi, Kawasaki and Kawai, 1996). Kanner and colleagues (1996) reported that postictal psychosis was observed in 6.4% of patients being monitored while Kanemoto et al. (1996) reported a figure of 10%. Kanner et al. (1996) also indicated that there was a non-psychotic period of between twelve hours and three days after the seizures had ceased. Symptoms of psychosis included clouding of consciousness, delusions, hallucinations as well as affective symptoms such as mania and depression. Resolution is usually within three days but can last up to a month (Savard et al. 1991). The resumption of anti-epileptic drugs when EEG-monitoring has been completed aids in this resolution.

Sachdev’s (1998) article describes each type of psychoses; ictal, interictal and postictal. Ictal psychosis is described as brief lasting from a few hours to a couple of days. Initially resembling delirium, ictal behaviour may be prolonged postictally where presentation includes a wide range of perceptual, behavioural cognitive and affective symptoms often with automatism involving oral activity, picking at clothes and paucity of speech. Symptoms may include hallucinations and thought disorder in clear consciousness with maintenance of insight indicates that it is not of a true psychosis. Brief interictal psychosis is usually self limiting, lasting from days to weeks. Their description is one of an alternating psychosis. That is, a brief psychosis alternating with periods of increased seizure activity such that the two appear antagonistic. Paranoid delusions and auditory hallucinations are characteristics of interictal psychosis and multiple other features such
as insomnia, anxiety and feelings of withdrawal mark the onset of the psychosis. Unlike ictal and postictal psychoses, this type of psychosis can be ameliorated by the occurrence of one or more seizures. Postictal psychosis is the term given to brief psychotic episodes following a cluster of seizures. Occurring in close proximity with seizures, they are often noted in patients who are undergoing video-EEG monitoring after withdrawal from anti-epileptic drugs (Kanner, Stagno, Kotagal et al. 1996; Kanemoto, Takenchi, Kawasaki et al. 1996; Savard, Andermann, Olivier et al. 1991).

The study by Kanemoto et al. (1996) focused on three sub-groups of TLE patients who had been diagnosed with psychosis. Specifically, they divided the sample into those with postictal, interictal and chronic psychosis, and found that the interictal and chronic patients reported similar clinical symptomology which simulated schizophrenia. However, those in the postictal group manifested psychosis which was quite different from that of schizophrenic psychosis. Specifically, those with postictal psychosis exhibited grandiose and religious delusions with elevated moods or feelings of impending death, fusion of the body with the universe, reminiscence and diplopia. They did not exhibit schizophreniform psychotic traits such as perceptual delusions or voices commenting as did those in the interictal and chronic psychosis group whose psychoses simulated schizophrenia. They concluded that brief interictal psychosis manifests when seizures are controlled or infrequent. Periods of brief psychosis alternate with periods of increased seizure activity, thus appearing antagonistic and, unlike postictal psychosis, this psychosis can be ameliorated by the appearance of one or more seizures. Kanemoto, et al. (1996) reported that postictal psychosis ‘is almost always associated with TLE’
(p.1201) specifically to a particular subset of TLE patients, those with unilateral (left-side) mesial temporal sclerosis.

Kanner Stagno, Kotagal et al. (1996) cautioned that because there was a recognised temporal relationship between psychosis and a preceding increase in epileptic activity, that TLE patients presenting for monitoring are especially at risk. Kanner et al.’s study was the first to have estimated the incidence of post-ictal psychiatric events during prolonged video-EEG monitoring. They reported an annual incidence at their clinic of 7.8%. In their study they found that, over a period of eighteen months, thirteen patients presenting for monitoring met the criteria for a post-ictal event. Of the thirteen, six had experienced more than one post-ictal psychotic event prior to the monitoring study. Seven experienced their first event during monitoring. The researchers suggested that video-EEG monitoring facilitated the occurrence of these events. The potential precipitant was the increase (or ‘flurries’) of seizures following discontinuation of antiepileptic drugs. Thus, as the anti-epileptic drugs are tapered to allow the epileptogenic abnormalities to become apparent on the EEG’s, frequent epileptic seizures may ensue. As Kanner et al. (1996) caution, “Prevention of a post-ictal psychotic event becomes even more important among patients undergoing presurgical evaluation with intracranial electrodes in whom psychotic symptoms can result in self-harm and the premature termination of the procedure.” (p.343). Thus patients undergoing prolonged video-EEG monitoring are at increased risk of experiencing postictal events due to the ‘flurries’ of seizures which may to be experienced by some patients at this time. A knowledge of this likelihood by the patient can be seen as another area of concern in
these patients, in particular those who have already experienced such events prior to monitoring.

Hence studies such as those by Sachdev (1998) and Kanemoto et al. (1996) were the first to distinguish between the three subtypes of TLE psychosis sufferers. Unlike other studies, these two studies distinguished between those patients manifesting schizophrenia-like psychoses and those with other types of psychoses. Previous studies had referred to all epilepsy patients with psychoses as manifesting schizophrenia-like psychoses without differentiating between this and other types of psychoses. Hence studies like Sachdev’s (1998) and Kanemoto et al.’s (1996) are of particular as they may assist in further clarification of the specific relationship between the type of psychosis and the sufferer.

Patients with resistant TLE, the focus of the present study, who present for monitoring are at risk of postictal psychosis and are also possible candidates for epilepsy surgery. Hence it is possible that a number of these patients will benefit from an intervention package which addresses anxiety and concerns these patients and the package is therefore warranted.

2.8 Suggested aetiology for schizophrenia-like psychosis in TLE patients - a model of possible pathophysiological mechanisms

A recent article by de Toffel (2004) maintains that ‘today, psychopathology in medical refractory partial seizures is well-known.’ Psychiatric co-morbidities are observed postictally (postictal psychoses and depression) and interictally (depression, anxiety and
psychotic states) and in relation to adverse psychiatric events of some new anti-epileptic drugs. Research by Hyde and Weinberger, (1997) supports earlier studies in that they report that patients with epilepsy develop schizophrenia-like psychosis at a rate exceeding that expected if the two disorders were independent. They further found that patients with schizophrenia are more prone to seizures than the general population and argued that this vulnerability to seizures may either be due to the neuropathological substrate of schizophrenia itself, which the authors suggest emanates from the mesial temporal lobe, or to the pharmacological treatment which lowers the seizure threshold.

In a study by Barr, Ash, Bilder, Degreef, and Lieberman, (1997), the researchers compared the features of three groups (first episode schizophrenia (FES), TLE and controls) directly with measures of the brain using magnetic resonance (MR) morphometry. The study measured ventricular and hippocampal volumes in 32 patients with first-episode schizophrenia, (FES), 39 patients with temporal lobe epilepsy-21 left and 18 right- (TLE), and 42 healthy controls. The results showed that both the FES and the TLE patients had significantly larger ventricular volumes than the controls. However, the FES group showed significantly larger temporal horns while the TLE group had larger frontal horns. With regard to the hippocampal volume, the FES group showed reduction in this area, which was comparable only to the left TLE group.

In 1998 Sachdev indicated that temporal lobe epilepsy may be associated with schizophrenia-like psychosis through a common underlying structural brain damage such
as cortical dysgenesis or diffuse brain lesions. Temporal lobe epilepsy and psychosis have a different age of onset where the psychosis manifests many years later. This onset may be dependent upon the age of epilepsy onset and where the epilepsy may be a catalyst for underlying dysgenesis, ‘setting the stage’ for the psychosis.

In his analysis of past research into the aetiology of the association between schizophrenia-like psychosis and epilepsy, Sachdev (1998) synthesises the various hypotheses. He did this through the presentation of a composite working model seen in Figure 2.1 which shows a possible pathway of association between seizures and psychosis.

Sachdev suggested that, according to this view, epilepsy patients who develop schizophrenia-like psychosis have a lesion which makes them vulnerable to the psychosis. This lesion may be neuro-developmental, leading to cortical dysgenesis. Alternatively, it may be acquired through trauma, hypoxia or infection. The area of the brain implicated is the limbic structure with the abnormality causing seizures at an early age. The seizures’ continuous subcortical activity act either as modifiers or exacerbators to the expression of psychosis. He thus hypothesised an antagonism between the two disorders. Further, he indicated that psychosocial factors, antiepileptic medication and lobectomy are also implicated as possible precipitators of schizophrenia-like psychosis.

Figure 2.1. Possible pathophysiological mechanisms for the association between
Sachdev (1998) suggests that epilepsy and psychosis may be the result of brain trauma where seizures modify the presentation of the psychosis and vice versa, producing a clinical picture of both an affinity and an antagonism between the two disorders. He maintains that this outcome is due in part to the view that epilepsy is not a static process and causes neurochemical and structural changes to the brain before and after the development of seizures.

Sachdev (1998) also suggested that the association of the two disorders may also be attributed in part to pharmacological effects of anticonvulsant and antipsychotic drugs with the latter type of drug reportedly inducing seizures in 5% of patients treated with therapeutic doses of clozapine. Other researchers, (Wolf, 1990; Matsuura, 1999) have also suggested links between AED’s and schizophrenia-like psychosis in TLE patients. Wolf, (1990), in his study of 611 patients, noted an association between a reduction or control of seizure episodes, (forced normalisation), in temporal lobe epilepsy, and the
advent of psychosis. He suggested the possible role of anticonvulsant drugs in this process. He also drew attention to a possible connection between social factors and psychosis, noting that social factors augmented biological features. Specifically, patients were unable to cope with impending psychosis and seek help prior to florid manifestation due to their lack of independence and social isolation.

Like Wolf (1990) and Sachdev (1998), Matsuura (1999) also drew attention to medication as a possible factor in the genesis of psychosis in his retrospective study of two groups of epilepsy patients; those whose drug regimen had been changed, and those whose regimen remained the same. Forty-four patients (twenty-seven who did not undergo a change in medication, and seventeen whose medication was altered) were investigated for first onset of psychosis. Medication was altered by either adding another antiepileptic drug (seven patients) discontinuing medication (six patients) or overdosing on medication (four patients). Twelve (71%) of the patients in the ‘altered medication’ group developed psychoses with a temporal relationship between the first episode of psychoses and changes in seizure frequency. Only four (15%) of those in the ‘no change in medication’ group developed psychoses in association with seizure changes. The researcher concluded that alterations in medication through additional drugs, abrupt discontinuation or overdose may provoke psychoses.

In conclusion, this additional burden of a possible connection between schizophrenia-like psychosis and epilepsy in some temporal lobe epilepsy sufferers requires acknowledging in this population of patients when they present for monitoring. It is likely that concerns
about possible surgery as well as the real possibility of psychosis during the monitoring procedure as medication is reduced, would be stressors prompting anxiety in such patients.

2.9 The role of stigma and predisposition to clinical depression in TLE patients

The way in which epilepsy patients perceive themselves as functioning members of society determines their vulnerability to distress and a tendency to psychological problems such as depression. Further, it is not unreasonable to suggest that patients feel stigmatised due to their perceptions being anchored in what they understand as the commonly held view of epilepsy amongst those in society. This feeling may be a source of anguish for them. Jacoby (1994) studied the nature and extent of stigma in a group of epilepsy patients in remission. She dichotomised stigma into two types; enacted stigma, which refers to instances of discriminatory behaviour in response to the epilepsy and felt stigma, which refers to the perception of tacit or implied attitudes of others who devalue them as an individual and avoid their company shame of having epilepsy and fearing enacted stigma. Although only a minority of patients reported either type of stigma, both types of stigma were negatively correlated with the length of time that the patients had been seizure-free. That is, those patients that had been seizure-free for four years reported more enacted and felt more stigma compared to those who had not had seizures for six years.

Hermann, Witmann, Wyler, Anton and Vanderzwagg (1990), using a factorially derived measure of felt stigma, derived by Ryan, Kempler, and Emlen, (1990) found a
significant relationship between psychopathology and felt or perceived stigma amongst temporal lobe patients. Ridsdale, Robins, Fitzgerald, Jeffrey and McGill, (1996) found that epilepsy patients who experienced the most frequent seizure episodes over a six month period were at greater risk of felt stigma and depressive episodes than those who had reported no more than one episode in six months.

Hermann and colleagues’ (1990) study suggested that epilepsy is more than a neurological disorder and that the role of psychosocial factors in predisposing patients with epilepsy to distress needed attention thorough research. Their study utilised a 30-item version of the General Health Questionnaire (GHQ) to predict psychiatric distress. The responses revealed that enacted stigma (actual instances of discriminatory behaviour in response to an individual’s epilepsy), poor adjustment to epilepsy (fearful of seizures because of ensuing embarrassment and resentment because their lives have been ruined by the disease), the number of stressful events in the preceding twelve months and vocational difficulties were significant predictors of depression in epilepsy patients.

Dawkins, Crawford and Stammers (1992) found that not only do epilepsy patients suffer psychosocial difficulties which are experienced by others with neurological disorders, but also experience additional stressors which are associated with epilepsy. These included the inability to obtain a license, not gaining employment in a preferred field, and not knowing when a fit may occur with the concurrent embarrassment of experiencing a fit when out in public. The researchers suggested that many epilepsy sufferers contended with a myriad of stressors associated with epilepsy stigma and
discrimination, social exclusion and employment difficulties, suggesting that sufferers of epilepsy have been made to feel different and humiliated in ways that were never imposed on victims of most other disorders. This in turn caused sufferers to feel inadequate, embarrassed, ashamed and vulnerable to depression.

Victoroff, Benson, Grafton, Engel and Mazziota (1994) found that of the fifty-three patients in their study with intractable complex partial seizures, 62% (32) had a history of interictal depressive disorders. They further found that 30% (16) of the fifty-three met the criteria for at least one major depressive episode (MDE). In this latter finding a history of MDE was reported as being more prevalent in those people with left-sided temporal lobe epilepsy. These findings were based on the use of a structured clinical interview which tested for depressive disorders as identified using DSM-III criteria. A history of depressive disorders was very frequent in their population of subjects with medically intractable complex partial seizures. However, a greater lifetime prevalence of both depressive disorders and major depressive episodes was found in patients with left-sided ictal onsets. The researchers concluded that their study added further support to the suggestion that neurobiologic variables are implicated in depressive disorders in patients with complex partial seizures. They posited that metabolic changes may reflect dysfunction in the limbic network subserving mood.

In conclusion, researchers focussing on the social consequences of epilepsy and have reported that the disorder bears a substantial stigma (Jacoby, 1994; Ryan, Kempler and Emlen 1990; Hermann et al. 1990; Ridsdale et al. 1996) and that there is a clear
relationship between complex partial seizures and levels of depression (Victoroff et al. 1994; Dawkins et al. 1992). Hence it is not unreasonable to suggest that some patients with complex partial seizures, presenting for EEG-monitoring in the hospital setting, will be more vulnerable to the rigours of the monitoring procedure due to the possibility of stressors such as stigma and depression which they bring with them to the procedure.

2.10 Concluding remarks

As is evident, temporal lobe epilepsy patients are a unique group of people who present at monitoring with problems endemic to this group that have already compromised them over a long period of time. They may therefore be vulnerable to the rigours of the monitoring process which is further compounded by the real possibility of temporal surgery. As noted earlier in this chapter, this group of patients is vulnerable to the commonest forms of psychiatric morbidity with epilepsy. A few of the patients experience schizophrenia-like psychosis and some report perceived stigma for the label they carry. The present thesis will address the anxiety which these patients experience during the monitoring procedure, an aim which is warranted given that studies have pointed to the relationship between seizure frequency and clinical depression and anxiety.

2.11 Summary
This chapter introduced the population under investigation in the major study of this thesis. This population is representative of patients deemed suitable for consideration for epilepsy surgery and forms a sub-set of a larger group of patients with chronic refractory epilepsy. It was argued that refractory temporal lobe epilepsy patients, who present for long term EEG monitoring, are a unique group of patients with problems endemic to this group. The chapter then looked at research that investigated the comorbidity of epilepsy with schizophrenia, which reported that the onset of psychosis occurred in temporal epilepsy patients many years after the onset of epilepsy, often occurring as seizure frequency was diminishing. The two disorders were investigated for similarities in brain morphology and trauma as well as the incidence of vulnerability to one disorder occurring in conjunction with the other. Researchers have identified three types of psychosis; ictal, interictal and postictal where the former two more closely resemble schizophrenia and the latter does not. Speculation as to the genesis of this psychosis was discussed and it was concluded that the psychosis of schizophrenia and that of epilepsy were not indicative of the same disorder. The chapter argues that TLE patients, who are already compromised from various anxiety-provoking sources, are vulnerable to the procedure which accompanies the monitoring procedure.

It was reported that these patients are different to other sufferers of the disorder in that, unlike patients with other types of epilepsy, this group is not only targeted for surgery but also has a plethora of psychological, behavioral and emotional problems which distinguish them from the other sufferers of the disorder. Further, putative differences between left and right temporal lobe patients were investigated with reference to current
research, in particular the finding suggesting that left TLE patients have a higher susceptibility to anxiety.

The chapter concluded by looking at research into the roles of stigma and depression in epilepsy patients. It was found that perception about stigma, (which was dichomomised into ‘felt’ and ‘enacted ‘stigma), and vulnerability to depression were correlated highly with the incidence of seizure episodes. This gives credibility to the present study in that TLE patients are more likely to experience a higher prevalence of seizure episodes than those with other types of epilepsy due to the refractory nature of their seizure type and the intervention package in the present study is designed to attempt to reduce anxiety and depression during the monitoring procedure.
CHAPTER 3

3.0 Ascertaining epilepsy patients’ eligibility for temporal lobe surgery

3.1 Utilisation of the classification of seizures to identify potential surgical patients with temporal lobe seizures

Surgery is not routinely used to treat epilepsy. Typically, this disorder is managed with medication. However, for a sub-group of patients with refractory temporal lobe epilepsy, surgery is the only option to reduce seizure frequency (Wiebe, Warre, Blume, et.al. 2001; Engel 1999; Engel 1994; Sperling, O’Connor Saykin and Plummer 1996). Researchers have argued for earlier rather than later surgical intervention for these patients (Kwan and Brodie, 2002; Engel, 1999; Herman, Wyler and Soames 1992). They have suggested that the organic, behavioural and psychosocial sequelae of chronic epilepsy, together with many years of failed treatment with anti convulsant drugs be addressed with earlier surgical intervention. Most of these patients have had epilepsy since the first decade of life and many have had intractable epilepsy since adolescence. Hence, it is argued that, if
surgery is delayed, there is the associated risk that irreversible psychosocial consequences of the prolonged illness are likely to eventuate.

Therefore there has been a recent move towards considering surgery sooner rather than later, preferably with surgical intervention taking place early in the course of the disorder to prevent the self-perpetuating progression by interrupting its progress through this earlier effective therapeutic intervention (Mattson et al. 2005; Aydemir et al. 2004; Wiebe et al. 2001; Hermann, Wyler and Somes, 1992; Engel, 1996).

An aid in determining patient’s suitability for resective epilepsy surgery is initially dependent on the identification of seizure-type and epilepsy-type using current seizure classification (Table 3.1). The classification, together with the diagnosis that the patient has been identified as medically intractable, as well as other clinical measures such as electroencephalography (EEG), magnetic resonance imaging (MRI) and single photon emission computed tomography (SPECT), is used in patient selection. The source of the seizure is identified, and then it is determined whether removal of the source will reduce or stop the seizures without detriment to the patient (Bourgeois, 1992). It is usually patients with complex partial seizures who are especially targeted for monitoring in order to assess their suitability for surgery.

To appreciate the type of patient presenting for monitoring in hospital, it is necessary to place temporal lobe epilepsy (TLE) patients in context with sufferers of other types of epilepsy through a brief overview of this classification of epilepsies and epilepsy
syndromes. The development of the classification saw terms like ‘psychomotor’ (Cairns, 1974) made inadequate. This was due to the observation that researchers were using the words ‘psychomotor’ ‘temporal lobe’ and ‘complex partial’ as equivalent entities. However, as Strauss (1989) pointed out, many patients with a focus in the temporal lobe may never have the clinical manifestations of a psychomotor seizure and patients with a psychomotor or complex partial attacks may not have a temporal lobe focus. The classification of seizures provides a distinction between seizures without a focal onset (generalized seizures) and those with a focal onset (partial seizures). Briefly, generalised seizures involve discharge through many brain structures. The principal feature of generalized seizures is that both hemispheres of the brain are involved. A division is acknowledged between grand mal and absence seizures in the overall classification of generalized seizures (Table 3.1). Partial seizures are of two types. Those of elementary symptomatology (simple partial) have no impairment of consciousness whereas those with complex partial seizures may be accompanied by such alterations. Hence, clinical features of seizures may include disturbances of consciousness, motor function or sensation. Presentation depends on whether the focus is diffuse (generalized) or focal (partial).

3.2 Classification of seizures

In 1981 the Commission on Classification and Terminology of the International League Against Epilepsy, CCTLAE (Dreifuss, Bancaud, Henriksen, Rubio-Donnadieu, Seino and Penry, 1981) presented a system of classification according to seizure type. The International Classification of Epileptic Seizures (1981). This was superseded in 1985 by
the Clinical and Electroencephalographic Classification of Epileptic Seizures (Dreifuss et al. 1985), shown in Table 3.1 and supplemented in 1989 with the Classification of Epilepsies and Epileptic Syndromes (Dreifuss et al. 1989) shown in Table 3.2

Table 3.1 Clinical and Electroencephalographic Classification of Epileptic Seizures (1985)

<table>
<thead>
<tr>
<th>1. Partial seizures</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Simple partial seizures</td>
</tr>
<tr>
<td>1. With motor symptoms</td>
</tr>
<tr>
<td>2. With somatosensory or special sensory symptoms</td>
</tr>
<tr>
<td>3. With automatic symptoms</td>
</tr>
<tr>
<td>4. With psychic symptoms</td>
</tr>
<tr>
<td>B. Complex partial seizures</td>
</tr>
<tr>
<td>1. Beginning as simple partial seizures and progressing to impairment of consciousness</td>
</tr>
<tr>
<td>a. With no other features</td>
</tr>
<tr>
<td>b. With features as in 1. A. 1-4</td>
</tr>
<tr>
<td>c. With automatisms</td>
</tr>
<tr>
<td>2. With impairment of consciousness at onset</td>
</tr>
<tr>
<td>a. With no other features</td>
</tr>
<tr>
<td>b. With features as in 1. A. 1-4</td>
</tr>
<tr>
<td>c. With automatisms</td>
</tr>
<tr>
<td>C. Partial seizure evolving to secondarily generalised seizures</td>
</tr>
<tr>
<td>1. Simple partial seizures evolving into generalised seizures</td>
</tr>
<tr>
<td>2. Complex partial seizures evolving into generalised seizures</td>
</tr>
<tr>
<td>3. Simple partial seizures evolving to complex partial seizures to generalised seizures</td>
</tr>
</tbody>
</table>

11. Generalised seizures

A. Absence seizures

1. Absence seizures
2. Atypical absence seizures

B. Myoclonic seizures

C. Clonic seizures

D. Tonic seizures

E. Tonic-clonic seizures

F. Atonic seizures

111. Unclassified epileptic seizures

The classification of seizures was empirically based on both the visible manifestations of the seizure and the electroencephalography (EEG). The pathology, anatomical cause and
underlying physiology are ignored. Basically, three main categories are recognised: partial seizures which are subdivided into simple and complex and generalised seizures which are subdivided into convulsive and non-convulsive and unclassified.

### 3.3 Classification of epilepsy by seizure syndrome

In 1987 Dreifuss, Martinez-Lage, Roger, Seino-Wolf and Dam put forth a proposal to include a classification of seizure syndromes to supplement the International Classification of Epileptic Seizures (1985). They defined a syndrome as a constellation of signs (defined as observations by a physician/friend relative of the patient which indicate the presence of abnormal functioning of a bodily system) and symptoms (defined as the complaints made by the patient or elicited from clinical history). The signs and symptoms combined to become classified as syndromes and became recognised as clinical representatives of illness (Trimble, 1991).

This supplement to the ICES was due to an acknowledged limitation of the ICES. Specifically, the classification was confined to a description of seizure types, whereas terminology used between doctors and hospital staff focused on description of syndromes. A syndrome was defined as ‘an epileptic disorder characterised by a cluster of signs and symptoms customarily occurring together: these include such items as type of seizure, etiology, anatomy, precipitating factors, age of onset, severity, chronicity, diurnal and circadian cycling and sometimes prognosis.’ (Commission on Classification and Terminology of the International League Against Epilepsy, CCTILAE, 1989, p.389). Hence some of the epileptic disorders were syndromes with a common aetiology and
prognosis while others were considered syndromes with a common aetiology still to be determined.

The diagnosis, treatment and prognosis of seizure disorders are dependent on the correct identification of the type of seizure and type of epilepsy and this has resulted in the two currently accepted classifications which are the International Classification of Epileptic Seizures, 1985 (Table 3.1) and the International Classification of Epilepsies and Epileptic Syndromes, 1989 (Table 3.2).

Classification by seizure type and classification by seizure syndrome are both based on clinical and electrophysiologic data and both maintain a basic dichotomy between partial (focal, localised) and generalised epileptic disorders. For instance, in Table 3.1 partial seizures are further classified into those that are simple partial, complex partial and partial with secondary generalisation whereas in Table 3.2 they are classified predominantly on their motor manifestation with the epilepsies divided into idiopathic and symptomatic types.
Table 3.2. Classification of Epilepsies and Epileptic Syndromes. 1989

1. Epilepsies related to localisation (focal, local, partial)
   A. Idiopathic (with age related onset)
      1. Benign childhood epilepsy with centrotemporal spikes
      2. Childhood epilepsy with occipital paroxysms
   B. Symptomatic.
      1. Chronic progressive epilepsia partialis continua of childhood
      2. Cryptogenic (presumed to be symptomatic but of unknown cause), classified according to the following:
         3. Type of seizure (see Table 3.1)
         4. Anatomical location (e.g. temporal lobe epilepsy)
         5. Cause (in symptomatic epilepsies)

2. Generalised epilepsies
   A. Idiopathic (with age related onset, in order of age)
      1. Benign neonatal and neonatal familial convulsions
      2. Benign myoclonic epilepsy in infancy
      3. Childhood and juvenile absence epilepsy
      4. Juvenile myoclonic epilepsy (impulsive petit mal)
      5. Epilepsy with grand mal (generalised tonic-clonic seizures on awakening)
      6. Epilepsy with seizures precipitated by specific modes of activation
   B. Cryptogenic or symptomatic (in order of age)
      1. West’s syndrome (infantile spasms)
      2. Lennox-Gestaut syndrome

3. Epilepsies and epileptic syndromes of undetermined type (focal or generalised)
   1. Neonatal seizures
   2. Severe myoclonic epilepsy in infancy
   3. Epilepsy with continuous spike-and-wave discharges during sleep
   4. Acquired epilepsy aphasia (Landau-Kleffner syndrome)

4. Special situation-related epileptic syndromes
   1. Febrile convulsions
   2. Isolated seizures or isolated status epilepticus
   3. Seizures due to acute metabolic or toxic factors (e.g. alcohol, drugs, eclampsia, and nonketotic hyperglycemia)

Thus, epilepsy is currently classified in two divisions (types and syndromes) resulting in two distinct classifications of an International Classification of Epilepsy (ICE), 1989. One division, types, defines the major classes by separating the seizures into two types, specifically as to whether they are localised (partial or focal) in origin or primarily generalised. The other division, syndromes, separates epilepsies into those of known aetiology (symptomatic or ‘secondary’ epilepsies) from those that are idiopathic (primary) and those that are cryptogenic. The authors of the ICE (1989) define idiopathic
epilepsies as having no other underlying cause other than hereditary predisposition with age-related onset and well-defined EEG characteristics. Symptomatic epilepsies and syndromes have an underlying known or suspected disorder of the central nervous system. Cryptogenic epilepsies are presumed to be symptomatic but their aetiology is unknown.

3.4 Temporal lobe (complex partial) seizures - the focus of this study

The temporal lobe contains a number of important areas connected with language, memory and mood. Its structure is varied due to the presence of both neo-and allo-cortex. Seizures originating from the temporal lobe have a distinctive and highly varied phenomenology (Cockerell and Shorvon, 1996). The classification of syndromes recognizes two main areas from which temporal lobe seizures originate; the amygdalohippocampus and the lateral temporal cortex. The main types of seizures arising from the temporal lobe are complex partial, simple partial and complex partial with secondary generalisations. The main distinction between the simple and complex seizures is that there is no loss of consciousness with simple partial seizures. Currie, Heathfield, Henson, and Scott, (1971) noted that regional localisation in temporal lobe epilepsy has had more attention devoted to it and was worked out in more detail due to the prevalence of this type of epilepsy. The areas of discharge have been linked to the overt sensations and symptoms that these patients experience which are very distressing and often embarrassing.
There are two main types of partial seizures: the simple partial seizure (with elementary symptomology) and the complex partial seizure (with complex symptomology). Simple partial seizures are localised in one hemisphere of the brain rather than beginning all over the brain simultaneously and are often referred to as focal seizures. During a simple partial seizure, patients commonly experience a variety of psychic, gustatory, olfactory and automatic symptoms. Olfactory or gustatory symptoms are suggestive of medial temporal lobe involvement and may take the form of bad smells or tastes (Lesser, Luders, Dinner and Morris, 1987). Hence focal seizures begin in one hemisphere involving a single function, which then successively spreads to involve larger areas of the brain and an increasing number of functions become involved as the attack progresses. Simple partial seizures may often also produce symptoms such as *deja vu* or *jamais vu* as well as memory flashbacks, depersonalisation, feelings of unreality and alterations of an object’s apparent size or shape (Gloor, Oliver, Quesney and Aldermann, 1981). As noted earlier, sensory symptoms may affect any sense modality with either somatosensory phenomena or any of the senses of vision, audition and in particular, olfaction.

During complex partial seizures the patient experiences impaired consciousness and these seizures are characterised by the following three common manifestations. The first is experienced at the onset of the seizure and is referred to as an *aura*. Although an *aura* heralds the onset of a seizure, it may be missed because it wasn’t recognised or its duration was too brief (Svoboda, 1979). However, the ensuing attack (or ictum) is quite apparent with the patient at the very least, confused or at most, unconscious. The second involves automatisms which involve stereotyped, repetitive, involuntary movements such
as lip smacking, chewing, picking at objects, scratching and gesturing (Wiebe et al. 2001). The whole body may be involved or repetitive movements may be confined to one part of the body. For example, if a seizure emanates from the superior temporal gyrus, auditory sensations are experienced. If originating in the more posterior part of this area, these sensations will be accompanied by dizziness or vertigo. If the discharge is from the hippocampus, indescribable feelings and perceptual illusions are reported. This may include subjective feelings such as forced, repetitive thoughts, mood alterations, hallucinations or déjà vu (the latter predominantly in right temporal lobe patients). A broader range of effects is described by those with amygdalar epilepsy which include nausea, facial pallor or flushing, fear, panic, dilation of pupils and hallucinations (Currie et al. 1971). The third is postural changes where the patient sometimes appears catatonic or exhibits a frozen posture.

The clinical features of complex partial seizures are summarized and outlined in Table 3.3. The table also shows the criteria by which patients are identified with temporal lobe epilepsy. The clinical features depict the adverse sensations that the patient experiences during the episode. This often ends with disorientation, recent memory deficit, amnesia for the event and dysphasia if the language area is involved (Engel, 1996).
### Table 3.3  The Syndrome of Temporal-Lobe Epilepsy (Engel, 1996; p.650)

<table>
<thead>
<tr>
<th>History</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher incidence of complicated febrile convulsions than in other types of epilepsy</td>
</tr>
<tr>
<td>Family history of epilepsy is common</td>
</tr>
<tr>
<td>Onset in latter half of first decade of life</td>
</tr>
<tr>
<td>Auras that often occur in isolation are common</td>
</tr>
<tr>
<td>Infrequent secondarily generalised seizures</td>
</tr>
<tr>
<td>Seizures that often remit for several years until adolescence or early adulthood</td>
</tr>
<tr>
<td>Seizures that become medically intractable</td>
</tr>
<tr>
<td>Interictal behaviour disturbances can develop, most commonly depression</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical features of seizures</th>
</tr>
</thead>
<tbody>
<tr>
<td>An aura is usually present. The most common is epigastric, often with other autonomic or psychic symptoms, including emotion (e.g. fear). Olfactory or gustatory sensations can occur. Auras usually last several seconds.</td>
</tr>
<tr>
<td>Complex partial seizures often begin with arrest and stare, oroalimentary automatisms and complex automatisms are common. Posturing of one arm may occur contralateral to the ictal discharge. The seizure usually lasts one to two minutes.</td>
</tr>
<tr>
<td>The postictal phase usually includes disorientation, recent memory deficit, amnesia for the event and dysphasia if seizures begin in the language-dominant hemisphere. This phase lasts several minutes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neurologic and laboratory features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologic examination usually normal except for memory deficit.</td>
</tr>
<tr>
<td>Unilateral or bilateral independent anterior temporal EEG spikes with maximal amplitude in basal electrodes.</td>
</tr>
<tr>
<td>Extracranial ictal EEG activity only with symptoms of complex partial seizure: usually initial or delayed focal rhythmic onset pattern of 5 to 7 per second.</td>
</tr>
<tr>
<td>Usually temporal lobe hypometabolism on interictal single-photon-emission tomography with flurodeoxyglucose, often involving ipsilateral portion of the thalamus and basal ganglia.</td>
</tr>
<tr>
<td>Usually temporal lobe hypoperfusion on interictal single-photon-emission computed tomography and characteristic of hyperperfusion and hypoperfusion on ictal single-photon-emission computed tomography.</td>
</tr>
<tr>
<td>Usually memory dysfunction specific to the involved temporal lobe on neuropsychological testing and amnesia with contralateral intracarotid injection of amobarbital.</td>
</tr>
<tr>
<td>Hippocampal atrophy usually visible on MRI</td>
</tr>
</tbody>
</table>

### 3.5  Surgery for seizures - presurgical evaluation and surgical outcomes

Unfortunately, complex partial seizures, unlike other types of epilepsy, are resistant to anticonvulsant drug treatment and the standard treatment for intractable complex partial seizures is surgery (Augustin Novelli, and Mattson, 1984; Engel 1987). The source of the seizure has to be identified and it must then be determined whether the removal of the source will cease seizures without detriment to the patient. Table 3.4 shows proposed indications for resective surgery.
Table 3.4 Proposed indications for resective surgery. (Cockerell and Shorvon, 1996, p. 69)

<table>
<thead>
<tr>
<th>Proposed Indications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intractable seizures</td>
</tr>
<tr>
<td>Resectable structural abnormality as identified on MRIs</td>
</tr>
<tr>
<td>Confirmation that seizures arise from a visible lesion</td>
</tr>
<tr>
<td>Over 20% of seizures arising from the contralateral lobe</td>
</tr>
<tr>
<td>Intelligence quotient &gt; 70</td>
</tr>
<tr>
<td>No significant psychiatric morbidity</td>
</tr>
<tr>
<td>No medical contraindications</td>
</tr>
<tr>
<td>Age &lt; 45 years</td>
</tr>
</tbody>
</table>

Only patients with seizures identified as arising bilaterally and from a defined focus are suitable for surgery. Presurgical evaluation involves tests that localise the epileptic source with the aid of interictal EEG as well as long-term (usually 7-14 days) video EEG monitoring to capture the ictal electrical activity and clinical symptoms, with the use of both invasive and non-invasive procedures. EEG uses twenty different scalp electrodes which records cerebral activity. Each electrode records the postsynaptic potential from millions of neurons and is an invaluable tool in the diagnosis and management of epilepsy. (Niedermeyer, and Lopez de Silva, 1982). Figure 3.1 shows the typical placement of electrodes on the scalp prior to EEG monitoring.

Figure 3.1 Electroencephalography montage showing the typical placement of electrodes on the scalp (Cockerell and Shorvon, 1996, p.75)
Magnetic resonance imaging (MRI) helps identify structural abnormalities and positron-emission tomography (PET) is used to reveal areas of abnormal blood flow. Neuropsychological testing is also carried out at this time. Cortical mapping to identify areas to be resected includes an intracarotid injection of amobarbital (the Wada test) to identify the language dominant hemisphere and laterality of memory function. (Engel, 1996).

Long term video monitoring is usually performed on an inpatient basis before any surgical treatment is begun for three main reasons. The first is to verify that the events are epileptic, the second is to characterise the seizure semiology (onset and signs) and the
third is to identify electrographically the site of the ictal onset (Engel, Burchfiel, Ebersole, 1993). To achieve these aims, the patient has scalp and sphenoidal electrodes attached whilst their medication is reduced and they are put under 24 hour observation until enough seizure activity is procured. Often up to 14 days of EEG monitoring is necessary to record a sufficient number of seizures.

For a few patients in whom neuroimaging is inconclusive, the use of invasive EEG is required. This involves deep insertion of inert electrodes into the cerebral hemisphere to locate seizures that originate in deep structures and not revealed by surface electrodes alone (Murro, Park and King, 1993). For temporal lobe epilepsy sufferers whose lives have already been compromised in many ways due to the nature of the disease, entering hospital for possible brain surgery would be daunting enough. However, the monitoring process, although mostly non-invasive, would also be anxiety provoking, thus adding to the range of problems which are specific to this patient population. Figure 3.2 shows one type of surgical resection for temporal lobe epilepsy. Patients with this type of surgery may have resection up to 6.5 cm of the anterior lateral nondominant temporal lobe and 4.5 cm of the dominant temporal lobe. The mesial resection encompasses the amygdala and a minimum of 1.0 cm to 3.0 cm of the hippocampus. The extent of the resection is guided by the functional mapping of this area (Weibe et al. 2001).
Researchers (Wiebe, Warren, Blume et al. 2001; Engel 1987; 1996) draw attention to the positive outcomes of surgical resection for epilepsy patients. Wiebe et al.’s (2001) study investigated the efficacy and safety of surgery in forty temporal lobe epilepsy patients. These patients were compared with forty patients who were treated with antiepileptic drugs (AED’s). The results were obtained a year after surgical treatment was completed.
They reported that, compared to medical therapy for patients with poorly controlled temporal lobe epilepsy, surgery improved a patient’s quality of life through the control of seizures, rates of employment and improved school attendance in such patients. Engel (1987; 1996) reported that anterior temporal lobectomy (ATL) was an effective surgical treatment for refractory complex partial seizures in temporal lobe epilepsy (TLE) with up to two thirds of selected patients rendered seizure-free. Further, most of the remaining patients reported a marked reduction in seizures and a very small number with little or no improvement.

3.6 Summary

It is evident that temporal lobe epilepsy is an epilepsy-type which is not only intrusive in the everyday life of the sufferer by its capriciousness, but the problems it causes extend well beyond the experience of the symptoms of the disease. For patients who are deemed suitable for surgery, anxiety about the procedures leading up to surgery, as well as the surgery itself are likely to be further stressors to these patients already compromised by the disease. An intervention addressing fears and concerns about both procedures at the time of monitoring is likely be of benefit to such patients.
4.0 Alleviating pre-operative anxiety through psychological intervention

Temporal lobe epilepsy (TLE) is usually a chronic condition with an onset in childhood so that patients presenting for monitoring and possible neurosurgery are likely to have lived with their disease for many years. This has, in turn, adversely affected many areas of their lives for a long period of time. It has been indicated earlier (Chapter 2) that they may be more likely to be affected by psychological distress such as depression and anxiety and in a small proportion, of schizophrenia-like psychosis. A study by Aydemir, Ozkara, Canbey and Tekcan (2004), evaluated changes in intractable epilepsy patients in terms of quality of life, depression, anxiety, stigma and impact of epilepsy before and after surgery. Their study investigated twenty pre-surgical patients and twenty-one patients who had already undergone the surgery. Post-surgical patients reported as significantly better on the QOL Questionnaire than the pre-surgical patients. In this latter group the impact of epilepsy levels were found to be higher where seizure frequency, comorbidity and anti-epileptic medication affected health related QOL negatively. It is reasonable to contend that pre-surgical patients may be more vulnerable to invasive procedures and present with concerns and anxieties, which are specific to this sub-group of epilepsy patients.

Reuber, Anderson, Elger and Helmstaedter (2004) examined the course of depression and anxiety in TLE patients treated with surgery and antiepileptic drugs or by medical means alone. Depression improved due to seizure control and is more commonly
achieved by surgery than by medication alone. For the patient entering the monitoring process, this type of information, which suggests that depression in TLE patients is caused by pathological epileptic activity, may assist in a reduction in anxiety about the procedure itself. It is posited that pre-monitoring psychological intervention, which focuses on alleviating stress at this time, would greatly benefit these patients.

There are a number of studies which have shown the efficacy of alleviating pre-surgical stress through psychological intervention (Beddowes, 1997; de L’Horne, Vatmanidis and Careri, 1994; Hartfield, Cason and Cason, 1982). Some of the benefits to the patient have been that intervention reduces anxiety prior to the procedure, hastens recovery, and lessens the amount of medication sought post-surgically (Milgrom and Burrows, 2001; Johnston and Vogele, 1993; Suls and Wan, 1989). Various successful interventions have been used on patients confronted by different types of surgery, from elective minor day surgery to cardiac catheterisation. However, regardless of the type of surgery, anyone facing a surgical procedure will experience apprehension. As Autton (1968) stated, “There is no such thing as a minor operation to a patient.” (p. 3). A number of studies investigated the efficacy of various forms of psychological intervention to reduce pre-surgical stress during stressful medical and surgical procedures in populations other than epilepsy. They have reported the success of a variety of such interventions. These have included procedural information (Beddowes, 1997), visual information, relaxation training and emotion-focused intervention, (de L’Horne et al. 1994), stress inoculation procedure, (Wells, Howard, Nowlin et al. 1994), and cognitive behavioural approaches (Miller, Shoda and Hurley, 1996). An investigation into effective interventions which
have been utilised in patient populations other than TLE patients, could be applicable in addressing pre-monitoring anxiety in TLE patients. This as an area which has received sparse attention.

4.1 Stress inoculation

Stress inoculation training, which was devised by Micenbaum and Cameron, (1983), has been utilised to help individuals cope with stressful events in which anxiety or pain arise. The medical notion of inoculation is used to convey the idea that the patients are exposed to manageable amounts of the stressful event that do not overwhelm their defenses, thereby reducing stress through preparation. Wells, Howard, Nowlin and Vargas, (1986) investigated the utility of stress inoculation on pre and post surgical distress. They used the procedure on patients who were to have invasive surgery within the following week, with an expected recovery period of three days. The twenty-four patients in the study were administered the State- Trait Anxiety Inventory, STAI (Speilberger, Gorusch, and Lushene, 1970). Twelve were then randomly assigned to the stress inoculation program and twelve to the control group which received standard hospital preparatory instructions. Stress inoculation involved the patients in a program designed to self monitor and identify physical cues, which indicated that the patient was feeling anxious about the impending surgery. The patients were taught skills to identify and monitor cognitive and physical cues of stress (i.e. negative self-statements, increased heart rate) and were given ways to overcome these feelings through deep breathing, muscle relaxation, pleasant imagery and substituting negative self-statements for positively
reinforcing self-statements. These patients were encouraged to practice the procedure a few times a day prior to surgery and whenever they experienced stress cues. On the day prior to surgery, all twenty-four patients were asked to complete the STAI. It was found that there was no significant difference between the two groups at pre-intervention, but one day prior to surgery, those in the treatment group reported a decrease in their state anxiety whereas the control group reported an increase. Post-surgically, those in the treatment group were rated by physicians to require a significantly lower usage of analgesics as well as obtaining significantly lower scores than those in the control group on the Hospital Anxiety Scale which is a measure of anxiety specifically related to hospitalisation. The researchers concluded that the stress inoculation procedure was useful in reducing pre and post-operative distress as well as reducing the amount of pain medication required post-surgically.

4.2 Social and educational intervention

Two other types of intervention successfully utilised were social and educational intervention. Peterson (1991) investigated the efficacy of these two interventions on patient anxiety before cardiac catheterisation. On the day of catheterisation, seventy-two patients were administered the STAI and then randomly selected to a social intervention group, an educational intervention group and a control group, with twenty-four patients in each group. In the social intervention group the researcher chatted to the patient about the patient’s life, interests or any topic that evolved from the conversation. The patient was told that the purpose was to ‘pass the time’ and the topic of the up-coming catheterisation was not introduced by the researcher but if the patient had questions
relating to it, they were addressed. In the educational group the researcher discussed the procedure in the form of sensory information via a pamphlet, which explained the cardiac catheterisation. For the thirty minutes it took the researcher to administer the interventions, patients in the control group were left alone to interact with the hospital environment, after which the STAI was re-administered to all three groups. It was reported that both the social and educational intervention groups had a significant drop in anxiety levels between initial assessment and post-intervention assessment. Hence both types of intervention were as effective in this group of patients. Those in the control group showed no change in anxiety levels between first and second assessment times. Peterson (1991) concluded that interventions such as the support of a concerned individual before an invasive procedure, or sensory/procedural information about the course of the procedure, could minimise anxiety in patients.

4.3 Information about surgical procedure

Epilepsy patients have identified the need for more information about surgery as one factor to help ease their anxiety (Lannon, 1993; Buck, Jacoby, Baker et al. 1996). Buck et al. (1996) received responses from six hundred and seventy-seven epilepsy patients on a postal questionnaire which asked the patients to indicate what they felt they required from health professionals about their disorder. The researchers reported that epilepsy patients placed great importance on receiving adequate information about their condition and that the lack of information provision was a source of anxiety and concern to a significant proportion of patients.
Beddows (1997) investigated whether information about elective surgery, given one week prior to the procedure, would reduce anxiety on the day of surgery. The information was presented in the patient’s own home, as this was a non-threatening environment and patients were more likely to assimilate the information. Beddows maintained that, on admission, patients are highly anxious and that information given at that time may be easily forgotten or misunderstood. Her study selected a sample of forty surgical candidates for hernia and varicose vein operations. Twenty patients were visited at home by the researcher where she administered the STAI. The procedure and possible investigations that would occur the following week in hospital were then discussed and questions the patient raised were addressed. The control group of twenty patients were asked to respond to the STAI by mail. On admission to hospital, all patients underwent the necessary pre-operative procedures such as assessment by doctors, and blood samples taken if required. When all the tests had been completed the researcher administered the STAI to all patients in the study. Beddows (1997) reported that anxiety increased in both groups following admission to hospital, but that those in the control group showed a significant increase compared to those in the experimental group. She concluded that procedural information reduced surgical stress and alleviated anxiety.

4.4 Sensory information
Another type of information about surgery which has been utilised is sensory information (Hartfield, Caron and Caron 1982; Luck, Pearson Maddern, et al. 1999) The premise is that an increase in anxiety is experienced by a patient about to undergo an invasive procedure when there is no prior experience (schema) available to imagine what the procedure will entail. Therefore, responses such as unnecessary heightened anxiety during the procedure may be experienced. Sensory intervention aims to reduce the gap between anticipated experience and reality so that more realistic expectations are formed and available coping mechanisms activated, concomitantly reducing anxiety.

Varying interpretations of the word ‘sensory’ have yielded diverse interventions. Some researchers (Hartfield, Cason and Cason, 1982) have used the word ‘sensory’ literally, as pertaining to all the senses (sight, touch, smell and taste) while others (Luck, Pearson, Maddern, and Hewett, 1999) have used it to mean visual information such as that received through audiovisual aids or a pamphlet which described the surgical procedure and outcome. For example, Hartfield, Cason and Cason (1982) examined the effect of procedural and sensory information on anxiety levels in twenty subjects awaiting barium enema. All patients were administered the STAI and then ten patients were randomly selected for the sensory information group. This involved the researcher in discussing and describing sensory input during the event, such as what the patient may physically feel, see, hear or smell. The ten patients in the procedural information group were only given a general description of the clinical procedure by the researcher. There were no significant differences between the groups before the medical procedure. Following the barium examination, both groups were again given the STAI and the researchers reported
that subjects receiving sensation information reported significantly less anxiety at the post-procedure assessment than the patients receiving the procedural information. The researchers concluded that “sensory information may reduce emotional responses by decreasing the incongruency between what individuals report they expect to feel and what they report is actually felt.” (p.205). Therefore, through exposure to the sensory intervention, the patients were able to reappraise the threatening event, thus forming a more realistic image of it, resulting in a reduction of anxiety about the procedure.

4.5 Audio-visual information

Luck Pearson, Maddern and Hewett (1999) investigated the efficacy of giving audiovisual information about colonoscopy to patients one week before the procedure. One hundred and fifty patients completed the STAI. Seventy-two patients were then randomly assigned to the video-viewing group. The remaining seventy-eight did not receive this exposure. The video showed the purpose of the procedure, procedural details and potential complications which could arise from the procedure. Following the viewing, all patients in the study were required to complete a knowledge questionnaire as well as re-administering the STAI.

The researchers reported that the two groups were similar with regard to age, sex and educational attainment. There was no significant difference between the two groups in the initial STAI assessment, but patients who watched the video were significantly less anxious before the colonoscopy than those who had not been exposed to the video. Those in the video group also scored higher in the knowledge about colonoscopy procedure
questionnaire than the no video group. It was concluded that patients preparing for colonoscopy would benefit from viewing an information video about the procedure, which increased knowledge about the procedure, and decreased anxiety in these patients.

4.6 Cognitive-behavioural interventions

In a meta-analysis of pre-surgical information, researchers de L'Horne et al. (1994) suggested that it is likely that interventions which serve to reduce discomfort and distress in patients pre-surgically are likely to carry over into the post-surgical stage. Their article was based on an analysis of research on patient preparation for invasive surgical procedures. Without psychological intervention before such procedures, patients experience emotional reactions such as anxiety, (which stem from the fear of pain, uncertainty about the surgical outcome and fear of medical procedures), depression, anger and unrealistic expectations about post-operative recovery.

L’Horne and colleagues (1994) favoured cognitive-behavioural preparation at the pre-surgical stage. This involved refocusing attention, using self-statements, videos, and information about the invasive procedure. This type of psychological preparation was strongly suggested by the authors who stated that, “It can be said quite forcefully that for clinicians to ignore psychological factors in preparing adults for surgical and invasive medical procedures, causes unnecessary suffering and adds to the economic costs of surgery and hospitalisation.”(p.6). They maintained that cognitive-behavioural preparation, targets, and has real benefits for, both pre and post surgical outcomes. Specifically, pre-operatively, such preparation reduced anxiety and fear, and post-
operatively, the patients used their preparation in coping strategies to reduce anxiety and pain.

4.7 A meta-analysis of psychological preparation for surgery—which is the best intervention?

In their meta-analysis of psychological preparation for surgery, Johnston and Vogele (1993), investigated a range of pre-surgical psychological interventions in order to establish exactly which benefits are achieved through these interventions. They distinguished between two different outcome variables in the studies they investigated; those which assessed the effect of psychological interventions on patients in the period immediately following surgery, and those which assessed such interventions on pre-operative benefits. Studies that reported on post-surgical outcomes looked at the effect of interventions on pain, medication, distress, length of stay in hospital, perceived helplessness during the procedure, whereas those that reported pre-surgical outcomes investigated the effect of interventions on anxiety and information or knowledge about the procedure prior to medical procedure. Johnston and Vogele’s (1993) meta-analysis focused on research which studied the effect of interventions on post-surgical outcomes. They found that there were eight post-surgical outcomes (negative affect, pain, pain medication, length of stay in hospital, behavioral recovery, clinical recovery, physiological indices and patient satisfaction with care), all of which responded favourably to ‘procedural information and behavioural instructions’. The researchers concluded that these interventions have been successful not only in affecting post-surgical outcomes, but also found to be effective in reducing pre-surgical anxiety. This
supports the conclusions of research investigated earlier in this chapter that reported on successful pre-surgical interventions, and which can be listed under the umbrella of ‘procedural information and behavioural instructions.’ Specifically, Luck et al. (1999) reported on the success of procedural information through the use of a video, in Peterson’s (1991) study the ‘educational group’ was exposed to procedural information through a pamphlet and interaction with the researcher about the surgery, and Wells, Howard, Nowlin and Vargas (1986), effectively used a stress inoculation technique, which employed a course of instructions to reduce pre-operative anxiety.

4.8 The present study—rationale for utilising pre-monitoring intervention with epilepsy patients

The rationale for the use of an intervention package with epilepsy patients presenting for monitoring was derived from the investigation into the successful use of psychological preparation for surgery in other surgical populations. It is maintained by researchers Johnston and Vogele (1993) and Horne et al. (1994), that pre-surgical preparation has a two-fold effect on the patient. It not only relieves pre-surgical anxiety and fears, but also ‘filters’ post-operatively to reduce length of stay in hospital and lessens the amount of post-operative pharmacology. For the epilepsy patient presenting for monitoring and possible concomitant surgery, an intervention to reduce their anxiety and concerns at this time would be beneficial to the patient. Further, if such psychological preparation filters through post-operatively, then the epilepsy patient would also be benefited. Further, depending on the type of therapy, this may help them cope with changed life conditions. This is because TLE patients, whose seizures, after many years, have finally been
significantly reduced or eliminated, will be faced with situations for which they have not been prepared.

It has been noted that significant gains do not automatically follow successful TLE surgery (Bladin, 1989, Herman, Wyler and Somes, 1992) where ‘success’ is usually determined by the significant reduction or cessation of seizures. This success may in itself bring new adjustment difficulties, and, as noted by Herman et. al. (1992), patients with learned behaviours over many years of epilepsy may be difficult to change. Also, attitudes and expectations of family and friends may change, as well as the taking on of new responsibilities, and the need to make up for lost time and missed opportunities all contribute to the post-operative adjustments to be made. Hence, if pre-surgical intervention alleviates anxiety and concerns in these patients not only throughout the procedure, but also beyond the procedure itself, then their post-operative assimilation into family and social life may be made a little easier through such intervention.

4.9 Paucity of studies on pre-surgical psychological interventions for epilepsy patients

In an investigation of the research on psychological interventions which benefit patients presenting for invasive medical or surgical procedures, it is evident that there are many which have been successful in reducing pre-surgical anxiety. Unfortunately, to date, epilepsy patients have not been exposed to these interventions. The only study which has focused on pre-surgical epilepsy patients is Lannon (1993) study where a programme, developed to address psychosocial concerns and evaluation of readiness for surgery, was
implemented. To devise such a programme, the researcher assessed whether epilepsy patients were satisfied with existing support during monitoring and pre and post surgery. Patients were informally asked questions specifically about the procedure, and it was found that patients were appreciative of the level of information, but desired more written materials and visual aids to reinforce this information. Further, patients expressed the usefulness of talking to someone who had undergone the procedure. “Seeing a healthy, functioning person does far more to allay a surgical candidate’s fears than all the reassurances the professionals can give them.” (p.71). Lannon’s (1993) programme involved a three-staged process, with procedural information and emotional support paralleling the patient’s progress through the steps leading up to the surgical option. The information and support was given during the monitoring stage, the confirmation of surgical candidature stage and at the final stage, the day of surgery. Patients’ concerns, feelings and anxieties were addressed and questions about any part of the process were answered. Lannon’s (1993) paper suggests that epilepsy patients may benefit from emotional support, written materials, visual aids and exposure to a patient who has been through the procedure successfully.

Given that epilepsy patients’ situation is unique in that they have lived with the disorder for many years, and the concomitant psychosocial and physical stressors that they contend with on a daily basis, it is posited that they would benefit from interventions which have been successfully utilised with other patient populations, as well as implementing those suggested by Lannon (1993) in a formal study.
4.10 Summary

This chapter investigated research into pre-surgical psychological interventions which have been shown to reduce anxiety in patients facing invasive medical or surgical procedures. Interventions such as stress inoculation, social and educational interventions, procedural information about the surgery or procedure, sensory information, audio-visual information and cognitive-behavioural instructions were discussed. A meta-analysis of interventions found that procedural information and behavioural instructions were the most successful in eight surgery outcomes. The chapter concluded by drawing attention to the lack of research into such interventions for epilepsy patients. It was noted that the only paper to date which has looked at this issue indicated that emotional support and procedural information may be utilized to reduce pre-surgical anxiety in this population of patients. Successful interventions used in patient populations other than epilepsy may be implemented at the monitoring stage to investigate the efficacy of such interventions on TLE patients.
CHAPTER 5

5.0 Epilepsy patients, monitoring and the coping process

When epilepsy patients are placed in a monitoring situation, they enter a procedure which is quite daunting and, bearing in mind that they have arrived in hospital with a background of a constellation of problems endemic to the condition of epilepsy, the process they encounter may pose its own threat to their psychological functioning. This can only add to the anxiety and concerns with which they already contend on a daily basis. Therefore an investigation into the ways in which these patients are likely to cope in the hospital situation will identify the areas in which health professionals may be able to assist epilepsy patients so that their distress is minimised.

5.1 The expectation of an aversive event- anticipatory threat

Coping refers to strategies which are utilised by the individual when s/he is confronted by an aversive event or threat. These strategies are accessed to minimise the anxiety and concomitant adverse physiological and psychological aspects of the threat. Alternatively, they may engage in defensive, deceptive cognitions even in defiance of reality to ameliorate the adverse aspects of the threat. Threat involves the anticipation of future harm and is dependent on cognitions such as individual perception of the event, past memory (if any) of a similar or same event, and available coping strategies to enable the individual to cope with the threat (Lazarus, 1966).
When epilepsy patients present for monitoring, they may be very concerned and ruminate about what they believe will occur during the process, and, with little or no information about the procedure, may exaggerate the threat of what is going to occur. Lazarus, (1966) maintains that the threat of an aversive event is inferred from ‘antecedent conditions and responses’ (p.30). Its two main characteristics are that threat is anticipatory and future-oriented and that it is brought about by ‘cognitive processes involving perception, learning, memory, judgement and thought.’ (ibid; p.30)…In effect, threat arises from present cues about future harms…(and)…psychological stress… is incurred from these cues.” (p.32). Lazarus (1966) goes on to say that most of the stress reaction to an aversive event occurs when the individual is anticipating harm during the initial stage of the aversive event.

Folkman and Lazarus, (1985) identified three stages to an aversive event and used an examination as the example of an aversive event. The three stages were identified as the anticipation stage (just prior to the exam), the impact (sitting the exam) stage and the post impact (exam results) stage. Folkman and Lazarus (1985) indicated that the individual’s coping strategies during the three stages changed over the period of time that they were exposed to the aversive event depending on what stage in the process the individual was facing. These different stage-dependent coping strategies were incorporated into Folkman and Lazarus’ (1988) Ways Of Coping Questionnaire. Hence threat, and the cognitions it evokes, mediates the coping process that is activated with the individual utilising different coping strategies during the various stages.
5.2 Coping - is it a trait or a state? A consideration prior to the development of a new coping scale for epilepsy patients

In the selection or development of a coping scale the issue of whether coping is a state or a trait must be considered. That is, whether coping should be conceptualised as a trait-like personality characteristic or as a state-like response to a specific aversive event. Steed (1996) states that ‘coping was originally conceived in terms of defence mechanisms as formulated in psychoanalytic theory…conceptualised as a style or trait…that operates over the life span.’ (p.193). Most trait measures evaluate coping along single dimensions that address confronting-avoiding or defensive styles. Some examples include Byrne’s (1964) measure of repression-sensitisation, Goldstein’s (1959, 1973) measure of coping-avoiding, and Miller’s (1980) monitoring-blunting.

However, Folkman and his colleagues (Folkman, Lazarus, Dukel-Schetter, et al. 1986; Folkman and Lazarus, 1985) critisised such an approach, indicating that, to measure coping along a single dimension underestimates the complexity of coping strategies across time and events. They define coping as “the cognitive and behavioural efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual.” (Folkman et al. 1986, p.141) They proposed a model of coping as a process which can change across time and situations, rather than viewing coping as a stable trait organised hierarchially from less effective to more effective characteristics. For instance, a person may use different coping styles and resources when confronted by a similar event across two or three different time spans. The
researchers did acknowledge, however, that there is both change and stability in coping, in that it would be possible to assess how a person usually responds or typically would respond to a certain stressful encounter. The psychometric properties of their Ways of Coping Questionnaire (1988) exemplifies a process approach to coping, looking at how a person thinks and what he does during an aversive situation in the anticipation stage, the impact stage and the post-impact stage. So that not only may there be a change in coping strategies between two similar aversive events at different times, but also different coping strategies within the process of one aversive event.

5.3 Coping as process-oriented

Folkman and Lazarus (1985) found that coping strategies changed over a period of time in subjects who were exposed to a stressful encounter. The encounter (an exam) was described as a ‘dynamic, unfolding process, not as a static, unitary event’. (p.150) As noted earlier, they identified three stages to the process; the anticipation stage (just prior to the exam), waiting stage (waiting for the results) and the post results stage (receiving the results). Likewise, Mechanic (1962) found that students experienced greatest anxiety prior to an exam, noting that there was a difference in coping strategies between the threat (the anticipatory stage) and confrontation (the exam-writing stage). As Lazarus (1966) states, ‘The distinction between threat and confrontation points the researcher toward these specifically different psychological processes and reactions.’ (p. 40) and by extension to the different coping strategies employed at these different stages.
5.4 Ways of Coping Questionnaire- a measure of coping processes

Folkman and Lazarus (1988) developed an empirically based 8-factor model of coping strategies from their Ways of Coping Questionnaire (Folkman-Lazarus Coping Scale), specifically, confrontive coping, distancing, self-controlling, seeking social support, accepting responsibilty, escape-avoidance, planful problem solving and positive reappraisal. These were further divided into three categories, namely problem-focused coping, emotion- focused coping and a combination of problem and emotion focused coping. Problem-focused coping refers to efforts utilised to manage or alter the source of stress and emotion-focused coping refers to efforts utilised in regulating stressful emotions (Folkman and Lazarus, 1988; Ludwick-Rosenthal and Neufeld, 1993). Folkman and Lazarus (1985) reported that both problem-focused and emotion-focused coping were utilised in the anticipatory stage but markedly decreased in the waiting stage.

Folkman and Lazarus’ (1984) measure addresses coping processes (what the individual thinks and does within the context of an aversive encounter and how these thoughts and actions change as the encounter unfolds) and differs from the trait or disposition approach, which attempts to identify what the person usually does or is most likely to do. When considered as a process, coping is seen as changing according to the continuous appraisals and re-appraisals of the person-environment relationship (Folkman, Lazarus, Dukel-Sheetter, DeLongis and Gruen (1986). These changes are driven by outwardly directed efforts in an attempt to change the environment or inwardly directed efforts to
change the understanding of an event. They can also be driven by environmental changes independent of the individual.

With respect to epilepsy patients, according to this approach, the expectation would be that different coping strategies would be employed by these patients at the commencement of monitoring compared with those utilised during the process itself. For this reason, items in two scales of the newly devised Concerns About Epilepsy Monitoring Questionnaire (CAEMQ), which is the subject of the first experiment in this thesis, were tailored to investigate whether patients’ coping strategies support Folkman and Lazarus’ (1986) contention that different types of coping strategies are employed at different stages in the process of an aversive event.

5.5 Coping as trait-oriented- monitors and blunters

As noted earlier, coping can also be thought of in terms of a stable dispositional trait which could mediate the patient’s coping strategies and personality characteristics need to be considered. Lazarus (1966) posited that, “the important role of personality factors in producing stress reactions requires that we define stress in terms of transactions between individuals and situations, rather than of either one in isolation.”(p.5). This connection between the individual and the situation is based on the individual differences not only in coping strategies at different stages in the aversive event but also on dispositional traits which the individual brings with him/her to the situation.

Specifically, Miller (1980) found that when individuals were presented with an aversive event (e.g. a dental procedure), that predictability (knowledge) about the procedure
sometimes decreased, and sometimes increased stress and anxiety. She proposed the “Blunting Hypothesis” which specified the conditions under which predictability did or did not reduce stress and this was extended to account for individual differences in those that preferred predictability in an aversive situation (i.e. monitors) and those who did not (i.e. blun ters). Monitoring and blunting were representative of two different strategies for coping in an aversive situation and had foreseen repercussions if the traits were not considered when offering information about such a situation. “If the two groups are forced into their non preferred condition, (i.e. unpredictability for monitors and predictability for blun ters), they will show increased stress.” (Miller, 1980, p. 157).

Miller (1980) posited that ‘blunting’ involved the employment of strategies which ‘blunted’ the psychological impact of an aversive event and included both positive and negative cognitive strategies. For instance, positive strategies included distraction, self relaxation, and reinterpretation whereas negative strategies included denial, detachment and intellectualisation (Vaillant, 1977). This latter strategy of intellectualisation to cope with an aversive event has been studied and found to reduce the level of subjective arousal associated with stressful events (Lazarus and Alfert, 1964; Speisman, Lazarus, Mordkoff, and Davidson. 1964). For example, subjects in Lazarus and Alfert’s (1964) study were shown a film which included painful and gory scenes about a native American Indian initiation ceremony into manhood which involved crude surgery on parts of the adolescent’s body while a commentator intellectualised the aversive scenes with comments such as, “As you can see, the operation is formal and the surgical technique, while crude, is very carefully followed.” In order to deny its stressful aspects,
the commentator pre-empted scenes by saying, “You will soon see that the words of encouragement offered by the older men have their effect and the boy begins to look forward to the happy conclusion of the ceremony.” (p.196, Lazarus and Alfert, 1964).

When an individual engages in positive cognitive strategies in order to blunt the impact of the aversive event, s/he can use strategies such as distraction to think of other things, relaxation by utilising calming thoughts or reinterpreting the event in a positive light. In this way anxiety is reduced and the individual can cope with the aversive event with lessened arousal.

The negative strategies of denial and detachment also serve to keep anxiety at bay and this is achieved through denial of the aversive event and detachment from it; as though it is not happening at all. There is no attempt to deal with it in any positive cognitive way and the whole aversive event is coped by psychological withdrawal from it. However, this denial may eventually be detrimental to the patient as it deflects any information which would allow the patient to modify expectations about the event. For instance, the patient may deny any fears about possible pain during a surgical procedure, and, without appropriate information as to the expected discomfort, the resultant experience could prove to be distressful. Although blunting strategies can reduce the individual’s initial arousal in an aversive situation, Miller (1980) suggested that strategies such as reinterpretation and relaxation may be more adequate as arousal-reducing strategies than denial and detachment. This was due to the fact that reinterpretation and relaxation attended to threat relevant information processing. This in turn enabled the individual to discriminate changes in the unfolding process of the aversive situation. On the other
hand, an individual who engaged in denial and detachment was not privy to such information about the aversive event which would, in turn, increase their distress. Miller (1980) exemplifies this by suggesting that if an aversive event which was out of the individual’s control suddenly became controllable, then the blunter using reinterpretation and/or relaxation would be in a position to utilise a controlling response. However, the individual who has ‘tuned out’ from external information will not input the changes and will not be able to benefit from the situation.

Miller (1980) devised a psychometric measure, The Miller Behavioral Style Scale (MBSS), in order to distinguish blusters from monitors. Based on the assumption that people respond to an aversive event in two distinct ways, (either by seeking as much information as possible to offset anxiety, or by distraction and minimal information), the measure asks patients to respond to hypothetical life-threatening situations. The four situations depicted involved a possible imminent plane crash, a terrorist attack in a public building, a job loss situation and a visit to the dentist. Using this measure, Miller and Mangan’s (1983) study divided gynaecological patients who were about to undergo coloscopy into monitors and blusters. Half of the patients in each group were exposed to voluminous information about the procedure and half were given the usual level of information offered on admission to hospital. It was found that blusters were less aroused with low information and monitors were less aroused with high information. They concluded that variations in coping style interacted with and determined the impact of information. Therefore, for blusters, anxiety decrements occurred when information was not imposed on them and, conversely, monitors showed some reduction in anxiety.
when they were exposed to information. However, it was found that anxiety reduction did not occur immediately after the information was given, but that the information needed to be assimilated and ‘worked through’ in order that the reduction could be observed.

Another study by Peterson (1991) used a modified version of the MBSS on seventy-two patients who presented for cardiac catheterisation. The researcher investigated whether the thirty-seven blunter s and forty-five monitors in the study had different levels of anxiety when faced with this procedure. The ‘job loss’ and ‘aeroplane crash’ scenarios were omitted from the measure as the researchers felt this might add to their distress before an invasive cardiac procedure. It was found that monitors had a significantly lower mean anxiety level than bluters. It was also found that, after an intervention package, either social or educational, was given randomly to forty-eight patients (twenty-four in each group), that the two groups had a significant decrease in anxiety, (measured by the State Trait Anxiety Inventory, STAI) compared to the remaining twenty-four control patients. The bluters in the two experimental groups had a higher mean drop in anxiety post-intervention than the monitors but this was found to be not significant. Peterson (1991) concluded that although bluters had higher anxiety levels than monitors, they were as amenable to intervention as monitors. Even though bluters deny anxiety by utilising distractions such as watching television, reading or ignoring available information, their anxiety was able to be reduced by social and educational intervention even though the intervention involved informational material.
Miller (1980) had earlier suggested that monitors were those who could not distract effectively and therefore reduce their anxiety. Unlike Peterson, (1991), she found that monitors rated higher on both anticipatory fear and tension than blunders but responded with lower rates on both measures after being presented with information about the aversive event. Hence, according to Miller, (1980, 1983, 1987, 1988) predictability has been sometimes found to increase anxiety and sometimes to decrease it. This discrepancy is dependent upon individual traits in those that prefer information and those who do not prefer information in such a situation. However, as Peterson (1991) has found, giving information to blunders is as beneficial (if not slightly more so) for them as is the exposure to the same information for monitors.

The two issues of whether blunders or monitors are more anxious about an aversive event, and whether it is detrimental to give blunders information about the event has relevance to the monitoring procedure. Epilepsy patients do not need added distress to what they already bring with them when they present for monitoring for possible surgery on their brain. Procedural and outcome information about monitoring need to be targeted appropriately so that further anxiety is not created. To this end, the issues about monitors and blunders needs further investigation.

5.6 Epilepsy monitoring and the coping process

Epilepsy patients presenting for monitoring and possible surgery face an aversive situation which will activate their coping strategies, which in turn are mediated by many factors. Figure 5.1 shows how the threat of the monitoring procedure prompts an
appraisal of the threat and the activation of different types of coping strategies which are dependent upon past experience and personality type (with specific interest in whether the patient is a monitor or a blunter).

Miller, Somerton and Brody, (1987) suggested that the way in which patients are treated when they enter a hospital environment needs to be sensitive to the coping disposition of patients so that psychological distress can be reduced.
Further, in Lazarus and Folkman’s (1985) study, the researchers concluded that, because coping was a process and that different coping strategies would be activated during the different stages in that process, that there is a need to identify which coping strategies are used at which stage. ‘Problem’ and ‘emotion-focused coping’ and ‘distancing’ are used in the three stages identified by the researchers. However, the type of coping strategy used by monitors and blunters in the population of temporal lobe patients presenting for monitoring is necessary in order to identify whether and how much intervention is necessary to lessen these patient’s distress during the monitoring process.

5.7 Paucity of measures which are epilepsy-specific

The only psychometric measures specifically designed to assess epilepsy patients of which the author is aware, are Dodrill and Batzell’s (1980) Washington Psychosocial Seizure Inventory (WPSI) and Cramer, Perrine, Devinsky and Meador’s (1996) Quality of Life in Epilepsy (QOLIE-10) which was derived from their more comprehensive QOLIE-89. The WPSI is the first self-report measure utilised for the evaluation of psychosocial functioning in adults with seizure disorders. It was developed to assess current psychosocial functioning in these patients and was welcomed due to the paucity of such tests which target patients with seizure disorders. The QOLIE-10 is a brief questionnaire which screens aspects of health-related quality of life for people with epilepsy, covering general and epilepsy-specific domains in its items. Specifically, the items are grouped into three scales; epilepsy effects (memory, physical effects and psychological effects of medication), mental health (energy, depression, and overall quality of life), and role functioning (seizure worry, work, driving and social limits). It is
administered to provide information at initial assessment or follow up of problem areas not usually covered in routine clinical visits of patients with epilepsy. It differs from the QOLIE-89 which was developed to assess quality of life in a general population with epilepsy (Devinsky, Vickrey and Cramer, 1995) and the QOLIE-10 is used for screening quality-of-life issues in epilepsy patients in clinical practice.

In clinical settings the key information which is routinely gathered covers seizure frequency and severity and adverse effects of antiepileptic drugs (AED’s), but patients’ perceptions of their concerns with epilepsy entail additional parameters such as the effects of the disease on daily activities and functions. Specifically, issues such as the ever present possibility of recurrent seizures, compliance with medication, restrictions on drinking alcohol, special requirements for a driver’s licence approval and reporting on job and insurance applications are regarded as life long concerns. The usefulness of screening questionnaires such as the QOLIE-10 has been noted (Nelson, Landgraf, Hays, Wassan and Kirk, 1990), especially in the improvement in communication and the raising of concerns between the clinician and the patient. In order to improve the specificity of information, generic questionnaires need to be tailored to specific populations, in this case, people with epilepsy, with items reflecting problems typically expressed by that population (Vickrey, Hays, Graber, Rausch, Engel and Brook, 1992; Wagner, Bungay, Bromfield and Ehrenberg, 1993; Smith, Baker, Dewey, Jacoby and Chadwick, 1991). It is therefore pertinent to develop a measure which taps into the concerns and anxieties which are likely to accompany TLE patients to the monitoring procedure. These will not
only reflect concerns about the procedure itself but also fears about the possibility of temporal lobe surgery.

5.8 Summary

This chapter began with the proposal that epilepsy patients present at the monitoring process with a myriad of problems endemic to that population. The threat of the monitoring process, which is new to the majority of patients, will in itself add to the stress and anxiety which they already experience. The chapter then looked at the responses to an aversive event in the light of past research and literature which identifies ways in which individuals cope in an aversive situation. Coping was then discussed as both a trait (personality characteristic) which is stable across time and situations, and a state (a transitory experience of an unpleasant emotional state, with feelings of tension, apprehension and concern). As a trait, a dichotomous coping measure such as the Miller Behavioral Style Scale (MBSS), which identifies people as monitors and blunters, was investigated. It was noted that research is divided as to whether blunters are more or less anxious when confronted by an aversive event and whether it is detrimental to give information to blunters. Coping was discussed in the light of being a process in itself which embraces three main stages and that, even though the stages are consistent across different times and situations, the coping skills employed are not necessarily consistent. The chapter then discussed the relevance of coping style to epilepsy patients during the monitoring procedure, which is seen as an aversive event. As such, it can be viewed as having three stages and coping strategies can be identified at the various stages. A model of the perceived threat, appraisal of the threat, and major mediators relevant to possible
responses by epilepsy patients in the monitoring process was presented to bring together the main ways in which epilepsy patients may respond to the monitoring process. A brief review is presented of the few available tests specifically for epilepsy patients that are existent today. The chapter concluded by suggesting that coping styles, strategies, resources and capabilities need to be identified when patients present for monitoring so that any anxiety and concerns are addressed when the epilepsy patient arrives. It was suggested that this may be achieved by the development of a questionnaire specifically targeting epilepsy patients when they present in hospital for the procedure.
CHAPTER 6

6.0 Rationale and hypotheses in the main studies of this thesis

The rationale for the main study in this thesis was prompted by the paucity of research into interventions which reduce anxiety and depression in temporal lobe epilepsy patients who present for long term monitoring in hospital. Further, these patients arrive with the knowledge that this process may eventuate in elective surgery and this is likely to increase their distress. As has been indicated, within the population of individuals presenting in hospital, there is likely to be a range of problems which have been identified as endemic to this group (see Chapter 2). Already compromised by their disease over many years, patients present in the hospital setting receiving little else but the usual hospital information. A sense of a lack of control, which exacerbates anxiety in patients (Ludwick-Rosenthal and Neufeld, 1993), together with specific concerns and anxieties about the monitoring process and possible surgery, are likely to have a detrimental effect on these patients. Specifically this may be linked to the observed premature curtailing of the procedure in some of the patients. This termination causes a regretful loss of patients who absent themselves from the monitoring process, a process that researchers Kilpatrick, Cook, Kaye et al. (1997) have found successfully identifies candidates for temporal lobe surgery. Hence an intervention package, which aims to reduce anxiety at this time by imparting information about the monitoring procedure, as
well as showing visual evidence of the success of temporal lobe surgery, may alleviate anxiety in these patients.

The central research question of this thesis is whether the intervention package will be successful in reducing anxiety and concerns of patients during monitoring about the monitoring process as well as possible surgery. Based on previous research into interventions which have been shown to be effective in reducing anxiety and concerns in pre-operative patients on a range of surgical procedures other than temporal lobectomy, (De L’Horne et al. 1996; Miller, Shoda and Hurley, 1996; Wells, Howard, Nowlin et al. 1994), the current thesis seeks to address the lack of such research into epilepsy patients. Specifically it was decided that the intervention be composed of both procedural and sensory information about the monitoring procedure. These are two intervention strategies which have been utilized by a number of previous studies (see Chapter 4) and have been identified as effective in reducing pre-operative anxiety. In the current thesis, the first intervention involved exposure to procedural information in the visual format of a pamphlet (see Appendix 3). The second intervention provided sensory information which was presented as a video recording of two people (one male, one female) who discussed their experiences of the video EEG-monitoring procedure and their post-surgical recovery from temporal lobectomy with a neuropsychologist. During both interventions, patients were able to address any questions regarding either procedure.

Further, it has been suggested that personality factors are important mediators in information transfer (see Chapter 5). Therefore, the characteristics of individuals
identified as monitors and blunters were considered. Specifically, the study investigated the premise that anxiety is heightened in those individuals who are identified as blunters and are exposed to information about an aversive event.

This main study gave rise to two other experiments. One was the validation of a newly-devised questionnaire, the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ) and comprises the first of three studies in this thesis. The rationale for the development of this questionnaire was twofold. The first was the attempt to identify the types of concerns which may increase anxiety in TLE patients during and about the monitoring procedure and possible surgery. It was derived from and is intended solely for use in epilepsy patients arriving for monitoring.

The second rationale for this questionnaire was driven by the observation that there is, in general, a scarcity of epilepsy-specific psychometric measures. Despite the wealth of research into psychological preparation for other surgical procedures, to date it appears there are few papers which have focused on the issue of fears and concerns specific to epilepsy patients presenting for monitoring in hospital with the possibility of undergoing surgery. Nevertheless, Lannon’s (1993) paper, which was reviewed in detail in Chapter 4, gave a descriptive outline of a support program provided for epilepsy patients pre and post surgery. Briefly, her paper discussed the implementation of a program which was conducted by an epilepsy nurse specialist, and involved information and emotional support for patients and their families during various stages of surgical treatment for
epilepsy. The report is largely anecdotal and while useful, does not outline patients’ concerns in any comprehensive way.

This thesis is composed of two studies. The first is the validation of the newly-devised questionnaire, the CAEMQ. The second (main) study investigated the efficacy of an intervention package designed to reduce anxiety and depression in epilepsy patients presenting for monitoring.

The main study examined the following hypotheses. Specifically, it was hypothesized that those patients who received the intervention would show a significant decrease in anxiety and depression at post-intervention assessment compared to those who did not receive the package. The intervention was also expected to reduce the number of patients leaving the procedure prematurely which was occurring due to elevated levels of distress in these patients. It was further hypothesized that monitors would be more anxious than blunters at initial assessment. It was also anticipated that monitors would show less post-intervention anxiety compared to blunters.

CHAPTER 7
Experiment 1. Validation of the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ)- a measure of the concerns of epilepsy patients presenting for surgery

The Concerns About Epilepsy Monitoring Questionnaire (CAEMQ) is a screening questionnaire with items targeting concerns and anxieties which are endemic to epilepsy patients during the monitoring procedure and which reflect their fears not only about the monitoring procedure but also about possible surgery. Monitoring and surgery are interlinked not only because the former is a necessary precursor of the latter but also that both procedures, as noted earlier, are anxiety-provoking. Further, it is likely anxiety about the initial procedure is likely to produce anxiety about the following possible surgery. Questions regarding surgery as well as monitoring were included because it is necessary to assume that the patients may be going to surgery. Thus questions about both procedures are required to identify their anxiety and concerns about monitoring and surgery.

In selecting items, consideration was given to the patient’s internal resources (cognitions and coping styles) and external sources (money, social support, from significant others and health professionals). Another source of item identification was from an examination of previously published scales; Ways of Coping Questionnaire (WCQ; Folkman and Lazarus, 1985); Coping Responses Inventory (CRI: Moos, 1992) Coping Inventory for Stressful Situations (CISS: Endler and Parker, 1990), and the COPE (Carver, Scheir and Weintraub, 1989).
Selection of item content was also guided by research which reported that a lack of information about surgical procedure caused uncertainty and anxiety and that in studies where such information had been disseminated, patients invariably reported less anxiety (Thompson, 1981; Johnson, 1983; Leventhal, Brown, Shachan and Engquist, 1979). Hence two major concerns were identified and were assimilated into the Concerns About Epilepsy Monitoring Questionnaire (CAEMQ). One was the lack of information about the process and its possible outcomes and the other was the need to identify the ways in which patients cope at this time so that appropriate support could be given when they enter the monitoring process. Researchers de l'Horne and colleagues (1994) have suggested that patients presenting for invasive treatment cope with the demands of the situation according to their coping resources and capabilities. There is therefore a need to identify what the coping strategies and styles of patients entering the monitoring process are and whether their coping resources can be aided so that their distress is minimised.

7.1 A Guiding Conceptualisation of Coping

As reviewed in Chapter 6, coping was originally conceived in terms of defence mechanisms as formulated in psychoanalytic theory and which resulted in coping being conceptualised and measured as a style or trait which operates over a life span. Examples of this include field dependence- independence (Witkin, Goodenough, and Oltman, 1979), repression- sensitisation (Byrne, 1964) and monitoring-blunting (Miller, 1987). Lazarus and Folkman (1984, 1985) argued that such dichotomous approaches underestimate the complexity and variability of actual coping efforts. These researchers
defined coping as the “constantly changing cognitive and behavioural efforts to manage specific internal and/or internal demands that are appraised as taxing or exceeding the resources of the person.” (1984, p.114). The first study is guided by this definition as it is consistent with theories supporting a relationship between the person and the environment in a specific stressful encounter.

As indicated, the purpose of the current research was to develop and validate a measure of the ways in which epilepsy patients respond and cope with the process of diagnostic monitoring. In particular there was an aim to include previously identified areas which had predicted anxiety in hospital settings. One of the methods used to obtain items in the sub-scales of the CAEMQ was through clinical work with epilepsy patients presenting for monitoring. Patients were asked to identify areas of concern in the hospital setting as well as general concerns about their epilepsy. Their responses were collated and those which were identified as most common to the greatest number of patients were used in the CAEMQ. A further source was from an examination of previously published scales; Ways of Coping Questionnaire (WCQ; Folkman and Lazarus, 1985), Coping Responses Inventory (CRI, Moos,1992), Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1990) and the COPE (Carver, Scheir and Weintraub,1989). The items were also guided by research which reported that lack of information about the procedure caused uncertainty and anxiety and that in studies where such information had been disseminated, the patients reported less anxiety (Thompson, 1981; Johnson, 1973; Leventhal, Brown, Shachan and Engquist, 1979). In selecting items, consideration was
also given to internal sources (i.e. cognitions and coping styles) and external sources (i.e. money, social support from significant others and health professionals).

Five dimensions were originally identified using these sources. These included (1) levels of discomfort experienced while in hospital, (2) the needs of epilepsy patients with respect to information about monitoring and surgery, (3) their support network and anxieties related to hospital care and expenses, (4) “Coping”- their style of coping at the present time, and (5) “Ways of Coping”- techniques to reduce anxiety. The “Coping” and “Ways of Coping” scales were influenced by Folkman and Lazarus’, (1984) Ways of Coping Questionnaire in that items in the two scales of the CAEMQ tap into problem-focused, emotion-focused and distancing coping strategies. Each dimension had between six and twenty items resulting in a total item pool of fifty-eight items. In generating the items, directionality was varied and the questionnaire was worded so that patients would find questions unambiguous and easy to understand. The development of the CAEMQ is described in terms of an investigation into the factorial structure of the questionnaire and its assessment in terms of reliability and validity. The validation was carried out before the second assessment in the main study so as not to bias the process of validation.

7.2 Method
7.2.1 Subjects

One hundred and twenty-one patients with epilepsy who were being monitored and assessed for their epilepsy as part of the temporal lobe epilepsy programs at two acute general hospitals were invited to participate in the study. All patients gave voluntary consent to be involved in the research. Exclusion criteria were; age below 17 years or above 70 years, confounding neurological impairment or previous hospitalisation for a psychiatric disorder. There were 90 females and 31 males in the study with a mean age of 35.4 (11.9 SD) years. The mean age of onset of epilepsy was 17.5 (13.9 SD) years.

7.2.2 Materials

The National Adult Reading Test (NART), (Nelson & O’Donnell, 1978) was used to test adequate reading ability and intelligence levels. The NART consists of 50 words listed in order of increasing difficulty. The subject reads the list aloud and the number of errors made is recorded. The manual reports a split-half reliability (Cronbach Alpha) for the NART of .93. No data of inter-rater reliability have been reported, although a pilot study (O’Carroll, 1987) suggests that this is quite high.

The State- Trait Anxiety Inventory (STAI), (Speilberger, Gorusch, Lushene, Vagg & Jacobs, 1983) was of value to this study as it assesses patients’ level of transitory anxiety and their perceived general level anxiety. The STAI is a 20-item self-report questionnaire utilising a Likert scale. Extensive reliability and validity for this measure are provided by Speilberger,(1983)
The Hospital Anxiety and Depression Scale (HADS), (Zigmond and Snaith, 1983) was used to tap levels of anxiety and depression of patients. The HADS is a 14-item self-assessment scale of anxiety and depression specifically designed for use with hospital populations. Patients rate their feelings of anxiety and depression on a 4-point Likert scale and the test demonstrates satisfactory reliability and validity for measuring the existence and severity of clinical depression and anxiety in this population. Concurrent validity coefficients range between .54 and .79; internal consistency estimates range between .90 and .93; and test re-test reliabilities range between .89 and .92 (Zigmond and Snaith, 1994; 1993).

Concerns About Epilepsy Monitoring Questionnaire’s (CAEMQ) format included an initial request for demographic information regarding marital status, number of children, projected length of stay in hospital, age, age at onset of epilepsy episodes and educational level achieved. Patients rated the 58 items on a 5-point Likert Scale, one extreme being “not at all” while the other being “very much so”. (see Appendix 1 for a copy of the CAEMQ)

The areas covered in the questionnaire together with sample items for each area follow:

Patient Comfort. The interest here was in identifying how comfortable the patient felt at the present time and whether they felt that they would remain in hospital until the completion of the tests. Sample items selected to evaluate these areas were, "How strongly do you feel that you could leave the hospital before your assessment and monitoring is complete?", “Do you find the tests and observations uncomfortable?”
**Information.** An idea of whether the patient felt the need for more information regarding their epilepsy, monitoring, surgery and the after effects of surgery prior to attending the hospital was deemed to be of great importance. Sample items evaluating this area included, “Would you have liked more information about what was going to happen to you during monitoring?” “Would you like more information about how you would feel after the operation?”

**Emotional Support.** The patient’s support network was seen as an important area to survey and questions inquired whether significant others such as family, hospital staff or someone who had undergone a similar experience would be appreciated as part of the support network at the time of hospital stay. Sample items asked, “Would you like further support from your family?” “Would you like support from someone who has had a similar experience to yourself?”

**Concerns.** The items in this area related to anxieties that the patient may be experiencing in hospital. These anxieties referred to pecuniary concerns, separation from family members, safety of surgery and physical and mental well being after surgery. Questions directed to evaluate this area included “Do you have concerns about the safety of surgery?” “Are you concerned about your hospital expenses?”

**Coping.** A patient’s coping strategies were investigated, using items which represented emotion focused coping; “Do you have difficulty coping at this time?” problem focused coping; “Do you cope better by forming a plan of action and following it?” and distancing; “Do you cope better by pretending everything is okay?”

**Ways of Coping.** A patient’s ability to reduce concerns either through using techniques such as relaxation, positive thinking, more information and perception of situational
control, or ignoring the situation, was evaluated. Sample items included: Would you like to reduce concerns by using certain techniques such as relaxation exercises?” “Would you like to reduce your concerns by having more information?”

The final section of the CAEMQ consisted of three questions presented as visual analog scales where the respondent indicated their position with a cross along a line to indicate how they felt about staying in hospital. Specifically, the questions assessed the degree to which the patient felt that s/he would leave the hospital and the monitoring process before its completion. The three questions were as follows:

A) I feel happy to stay in hospital and want to leave hospital
   I

B) I don’t feel anxious about staying in hospital and want to leave hospital
   I

C) I don’t feel upset about staying in hospital and want to leave hospital
   I

7.3 Results

7.3.1 Construct Validity of the Concerns About Epilepsy Monitoring Questionnaire
A preliminary principal components analysis with varimax rotation was performed on the CAEMQ response from an initial pool of seventy subjects which yielded a Kaiser-Meyer-Olkin value of .5912. A six-factor solution appeared to be most interpretable on this analysis which accounted for 51.5% of the variance. The six factors and their respective eigenvalues were Concerns and need for Information about surgery (7.16), Personal Concerns (6.21), Information about Monitoring (3.17), Coping Alone (2.92), Denial (2.16) and Support from others (2.03).

A final and confirmatory principal components analysis with varimax rotation was performed on the CAEMQ after one hundred and twenty responses to the questionnaire had been collected. Kasier’s (1970, 1974) measure of sampling adequacy, an indicator of good factorability, was met with a Kaiser-Meyer-Olkin value of .6144 (Tabachnik and Fidell, 1989). Once again, a six factor solution appeared to be most interpretable. The resulting six factor solution accounted for 70.1% of the variance and confirmed the presence of the six factors in the initial analysis. Eigenvalues of greater than two were used as a more conservative criterion than Kaiser eigenvalue of one, due to there being more than fifty variables and too many common factors (Cattell, 1970). Table 7.1 presents the eigenvalues and variance for each component. Variables are well defined by a seven component solution and communalties appear reasonable.

Table 7.1  Showing the factor structure of the six subscales of the CAEMQ and the percent variance contributing to this solution.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Eigenvalue</th>
<th>%Var</th>
<th>Cum%var</th>
</tr>
</thead>
<tbody>
<tr>
<td>1   Concerns and information about surgery</td>
<td>7.23</td>
<td>37.6</td>
<td>37.6</td>
</tr>
<tr>
<td>2   Personal concerns-family and pecuniary</td>
<td>6.60</td>
<td>12.0</td>
<td>48.1</td>
</tr>
</tbody>
</table>
The factor that accounts for the largest proportion of the variance appears to reflect concerns about the need for information about surgery. The second factor relates to personal concerns, in particular those associated with having enough money to pay the hospital account as well as being concerned about how the family is coping at home. Factor three combines the need for information about both the treatment of epilepsy with respect to medication and monitoring procedure to be given before arrival in hospital. The fourth factor reflects the ways in which the patients used positive coping skills to deal with their episodes. The fifth factor reveals a coping strategy employed by the patient where denial of the problem to be dealt with is indicated. The sixth factor appears to be identifying people from whom the patient would appreciate support whilst they are being monitored.

Using these factors as a guide, six new CAEMQ subscales were developed relating to:

1. Concerns and Information about Surgery (Factor 1)
2. Personal concerns - family and pecuniary (Factor 2)
3. Information about Treatment and Monitoring (Factor 3)
4. Coping Alone (Factor 4)
5. Denial (Factor 5)
6. Support from significant others (Factor 6)

The final CAEMQ has thirty-five items loaded on seven factors. Of the remaining twenty-three items in the original questionnaire, six failed to load on any subscale and the remaining seventeen items loaded only one or two variables on each of eight factors resulting in too many common and poorly defined factors. These were omitted from
further analysis. Subscale CAEMQ scores were calculated by obtaining the mean score on the items included in that subscale. The transformed means and standard deviations for the subscales were calculated and are presented in Table 7.2 below.

Table 7.2. The transformed means and standard deviations for the six subscales of the CAEMQ

<table>
<thead>
<tr>
<th>measure</th>
<th>mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>surgery</td>
<td>1.98 (.25)</td>
</tr>
<tr>
<td>personal</td>
<td>1.43 (.33)</td>
</tr>
<tr>
<td>monitor</td>
<td>1.72 (.31)</td>
</tr>
<tr>
<td>copalone</td>
<td>1.76 (.24)</td>
</tr>
<tr>
<td>denial</td>
<td>1.34 (.30)</td>
</tr>
<tr>
<td>support</td>
<td>1.34 (.27)</td>
</tr>
</tbody>
</table>

7.3.2 CAEMQ Subscale Internal Consistency

In order to assess the internal consistency of the subscales, Cronbach Alpha reliability estimates were calculated for each of the scales. The resultant scales and their items (with the loadings for the respective factors being placed in brackets) and their internal consistency (Cronbach Alpha) values are shown in Appendix 2.

7.3.3 Concurrent Validity

The concurrent validity of the CAEMQ was assessed using psychometric tests which are clinical measures of anxiety and depression as a criterion. The tests included the State Trait Anxiety Inventory (STAI) (Speilberger, Gorusch, Lushene, Vagg and Jacobs, 1983) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond, and Snaith, 1983). The STAI was of value to assess the concurrent validity of the CAEMQ as it
measures patients’ level of transitory anxiety and their perceived general level of anxiety. The HADS was deemed an appropriate instrument to use to assess the concurrent validity of the sub-scales of the CAEMQ as it taps patients’ levels of anxiety and depression who are placed in the hospital environment. Pearson Product- Moment correlations are reported between the standardised clinical measures of anxiety and the related subscales of the CAEMQ in Table 7.3 below.

Table 7.3. The Pearson-product moment correlation between the standardised tests and the CAEMQ subscales

<table>
<thead>
<tr>
<th>measure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>hadsa</td>
<td>.47</td>
<td>.40</td>
<td>.53</td>
<td>.31</td>
<td>-.08</td>
<td>-.15</td>
<td>.05</td>
<td>.18</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>hadsd</td>
<td>.34</td>
<td>.46</td>
<td>.31</td>
<td>.16</td>
<td>-.19</td>
<td>.19</td>
<td>.17</td>
<td>.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>stais</td>
<td>.70</td>
<td>.16</td>
<td>-.22</td>
<td>-.14</td>
<td>.09</td>
<td>.31</td>
<td>.25</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>stait</td>
<td>.28</td>
<td>.23</td>
<td>-.22</td>
<td>-.14</td>
<td>.08</td>
<td>.15</td>
<td>.18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>personal</td>
<td>.17</td>
<td>.01</td>
<td>.22</td>
<td>.23</td>
<td>.41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>monitor</td>
<td>-.01</td>
<td>-.08</td>
<td>.23</td>
<td>.41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>copalone</td>
<td>-.24</td>
<td>.04</td>
<td>-.14</td>
<td></td>
<td>.08</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>denial</td>
<td></td>
<td></td>
<td></td>
<td>.14</td>
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<td></td>
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</tbody>
</table>

The correlations between the CAEMQ subscales and the anxiety scale on the HADS test were non significant. The highest correlations were obtained between the CAEMQ subscales of Support and STAI-State anxiety measure \( (r = .31, p< .05) \) and Personal and STAI-Trait anxiety measure \( (r = .28, p<.05) \) . The two CAEMQ subscales, Monitor and Surgery were correlated \( (r = .41, p< .001) \) and an inspection of their items indicates that both scales are tapping into the patients’ concerns regarding the need for more information about surgery and the monitoring procedure in order to reduce their anxiety.
Table 7.4 shows the correlations between the CAEMQ subscales and standardised psychometric tests.

<table>
<thead>
<tr>
<th>subscale</th>
<th>measure</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>support</td>
<td>STAI-state</td>
<td>.31</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>personal</td>
<td>STAI-trait</td>
<td>.28</td>
<td>&lt;.05</td>
</tr>
</tbody>
</table>

7.3.4 Test- retest reliability

A subsample of one hundred subjects used for concurrent validity were tested twice on the CAEMQ (mean test-retest interval of four and a half days). The following reliabilities were noted for the subscales of the CAEMQ. Surgery (.86, p< .05), Personal (.84, p<.05), Monitoring (.83, p<.05), Coping Alone (.77, p<.05), Denial (.76, p<.05) and Support, (.73, p<.05). See Appendix for the internal consistency of these scales (Alpha ranging from .86 to .73).

7.3.5 Discussion

This study sought to address the need for a well validated, reliable measure of the concerns of epilepsy patients presenting for monitoring and possible surgery. The aim was to develop a measure that could identify the concerns of this group of patients who have specific needs that require attention especially in the area of reducing anxiety concerning monitoring procedure and surgery. The results in relation to the psychometric and structural properties of the CAEMQ are encouraging. Initial results provide evidence
that the CAEMQ has both satisfactory reliability and validity. The division of the CAEMQ into six subscales of patients’ concerns appears justified. Satisfactory results were obtained with respect to internal consistency, concurrent validity and test-retest reliability.

The content of the scales reveals many features that may influence the way we approach patients who present for monitoring and possible surgery and has implications for their psychological well being at this time. The surgery scale would give an indication of whether the patient felt the need for more information regarding surgery and monitoring procedure. Questions on the personal scale would tap into whether the patient had concerns regarding present and future finances or anxieties regarding how other family members are coping at home. The copalone scale identifies whether the patient is utilising a combination of ‘problem focused’ and ‘emotion focused’ coping strategies (Folkman and Lazarus, 1985) during the monitoring process. The support scales would reveal whether the patient is using the help and advice of significant others and whether more support from these parties is required. The denial scale would inform as to whether the patient is using ‘distancing or avoidant’ coping strategies (Folkman, Lazarus, Zdunkel-Schetter, 1986) to contend with the monitoring procedure.

The internal consistency estimates for all subscales are encouraging. Tabachnick and Fiddell (1989) propose that internal consistencies of .70 or better are highly satisfactory for an assessment instrument. The internal consistency estimates for the remaining subscales are highly satisfactory. Measures selected to assess concurrent validity of the
CAEMQ showed that the subscale of *support* was significantly correlated with the STAI-state anxiety measure and the *personal* subscale was significantly correlated with the STAI-trait, HADS-A and the HADS-D anxiety and depression measures. These correlations are indicative of a previously unidentified area of presurgical stress for epilepsy patients. It appears as though external resources are areas of concern and anxiety for these patients. Specifically, they are anxious about support from significant others and health professionals as well as fiscal worries and concern for family at home while they are in hospital. The reliability of the CAEMQ as measured by repeated testing four days apart was found to be satisfactory. Test-retest reliabilities in the high .70’s are regarded as fully adequate for assessment instruments (Bolton and Brookings, 1993) In summary, the CAEMQ sub-scales of *copalone* and *denial* scales endorse Lazarus and Folkman’s (1984) Ways of Coping Questionnaire which identifies problem focused, emotion focused and denial coping strategies. The *copalone* scale consists of five items which are problem focused coping strategies such as facing the problem, planning a course of action and following it, devising solutions to the problem, looking on the bright side and thinking of what can be done next to address the problem; the *denial* scale has four items which is a strategy employed by patients to cope with the present anxiety by ignoring the problem, pretending everything is okay and not thinking about the problem.

The practical significance of the development of the CAEMQ is evident when patients comments are taken into consideration. In the surgery, *copalone* and *monitoring* subscales a significant proportion of these patients indicated a need for information to be disseminated prior to hospital attendance for their epilepsy. Table 7.2 shows that the
means for these subscales are somewhat greater than those for the ‘personal’, ‘denial’ and support’ subscales indicating that patients are seeking more information about surgery procedure and outcomes, the monitoring process and treatments for epilepsy. There is also a perception that more information would reduce their concerns and that they are likely to use a problem-focused coping style to cope at this time.

The most appropriate use envisaged for the CAEMQ is during the monitoring and presurgical procedure in order to assess patient’s specific needs, concerns and anxieties when presenting for monitoring and /or possible surgery in hospital. Alternatively, it could also be used as a research instrument as a means of specifying whether identified concerns and anxieties can be ameliorated through various interventions such as information in the form of visual aids (e.g. videos, photos) about surgery and monitoring, counselling or other techniques.

**CHAPTER 8**

**Experiment 2. The effect of an intervention package on anxiety and concerns in patients undergoing presurgical monitoring for epilepsy**

An increasing number of studies, which were reviewed in Chapter 5, have reported the efficacy of a variety of interventions (relaxational, sensory, cognitive-behavioural and procedural) designed to reduce pre-operative anxiety and fears of individuals exposed to
stressful medical and surgical procedures (Egbert, Battit, Welch, and Bartlett, 1964; Wells, Howard, Nowlin and Vargas, 1986; Luck, Pearson, Maddern and Hewitt, 1997, Beddows, 1997). Amongst these studies there is general agreement that pre-operative information reduces anxiety by increasing understanding of the procedure and reducing uncertainty. These studies acknowledged that, to ignore psychological factors in preparing adults for surgical and invasive medical procedures causes unnecessary suffering and adds to the economic costs of surgery and hospitalisation. As was posited by (Hartfield, Cason and Cason 1982) accurate pre-operative information builds accurate expectations of surgery which then reduces emotional arousal. Buck, Jacoby, Baker, Graham-Jones, and Chadwick, (1996) found that epilepsy patients want information and to “want all there is available about epilepsy” (and) “lack of information provision was a source of concern to a significant proportion of patients.” (p. 847). It is likely that an information package about both monitoring and surgery would be of benefit for epilepsy patients presenting for monitoring and possible surgery. This would not only assist them in the overall process from monitoring to surgery and but is also likely to reduce premature termination of the procedure by the patient.

8.1 Procedural information - a caution

However, researchers (Miller, 1980; Miller and Mangan, 1983; Miller, Shoda and, Hurley, 1996) suggest that not all patients benefit from information regarding the sequence of pre-surgical events. They found differences in individual preferences for information. This view argues that the coping disposition (a trait) mediates the way a patient will utilize coping style (a specific coping strategy). Hence a person who is
identified as a monitor will employ a problem-focused strategy whereas a blunter is more likely to use distancing and/or avoidance type strategies. Miller (1980; 1988) has argued that anxiety will be precipitated or increased in blunters who are given information about surgery, whereas anxiety in monitors will decrease with such intervention. Further, she has argued that monitors report more anxiety than blunters when faced with an aversive event. From this and similar evidence there has been a growing tendency to match the most effective interventions with the coping dispositions of patients (Andrew, 1970; Cohen and Lazarus, 1973; Shipley, Butt, Horowitz and Farley, 1978). The present study will investigate whether there is evidence for caution in presenting information about invasive procedures to patients identified as blunters.

8.2.0 Method

8.2.1 Subjects

One hundred and twenty-one epilepsy patients who presented for monitoring at two acute general hospitals were voluntary participants in the study. Subjects were not chosen if their medical records indicated an age lower than 17 or above 60. This age limit was set to exclude patients older than 60 as they were not normally considered eligible for temporal lobe surgery. Patients with a history of hospitalization for psychiatric disorders
were also excluded on the grounds that this minority might obscure effects. Only one patient with a history of schizophrenia was excluded on these grounds.

The responses of twenty patients were also rejected because they did not complete the process. This left a pool of one hundred patients. Figure 8.1 shows the profile of the patients in the study and the contributing reasons for loss of twenty patients who were initially available for the study.
Figure 8.1 Trial profile of patients

<table>
<thead>
<tr>
<th>120 randomised</th>
</tr>
</thead>
<tbody>
<tr>
<td>59 assigned to intervention package</td>
</tr>
<tr>
<td>1 left due to sudden death of sister (too distressed to continue)</td>
</tr>
<tr>
<td>1 cited family concerns (missed her young children)</td>
</tr>
<tr>
<td>3 discharged themselves</td>
</tr>
<tr>
<td>5 discharged by hospital because seizure foci identified</td>
</tr>
</tbody>
</table>

50 completed monitoring process 50 completed monitoring process

One-way ANOVAs verified that there were no pre-treatment differences between the two information groups on age, age at onset and an estimate of their intellectual level, the National Adult Reading Scores (NART) scores. Descriptive characteristics and analyses of baseline differences of the total group are shown in Table 8.1.

Table 8.1. Means and (standard deviations) on age, age at onset and the NART.

<table>
<thead>
<tr>
<th></th>
<th>Low information Group</th>
<th>High Information Group</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>number</td>
<td>50</td>
<td>50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>35.2 (10.6)</td>
<td>34.2 (11.7)</td>
<td>0.0007</td>
<td>NS</td>
</tr>
<tr>
<td>Onset</td>
<td>13.6 (10.0)</td>
<td>18.8 (15.0)</td>
<td>1.9</td>
<td>NS</td>
</tr>
<tr>
<td>NART</td>
<td>91.5 (15.0)</td>
<td>94.4 (11.2)</td>
<td>0.75</td>
<td>NS</td>
</tr>
</tbody>
</table>
8.2.2 Materials

8.2.3 Pre intervention assessment

Subjects were assessed in the initial assessment on competency of comprehension, coping disposition, personality and anxiety/depression assessments using the following measurements; The National Adult Reading Test (NART), The Miller Behavioural Style Scale (MBSS), The Hospital Anxiety and Depression Scale (HADS), The State Trait Anxiety Inventory (STAI), and the newly devised Concerns About Epilepsy Monitoring Questionnaire (CAEMQ). (see Appendix 4 for a copy of all the tests in the order in which they were administered, including instructions to subjects)

The National Adult Reading Test (NART) (O’Carroll, 1987) was used to test adequate reading and intelligence levels. The NART consists of 50 words listed in order of increasing difficulty. The subject reads the list aloud and the number of errors made is recorded. The manual reports a split-half reliability (Cronbach Alpha) for the NART of .93.

The Hospital and Depression Scale (HADS) (Zigmond and Snaith, 1983) consists of 14-items, 7 each relating to anxiety and depression. It is a self-assessment scale specifically designed for use in hospital inpatients and outpatients. Patients rate their feelings of anxiety and depression on a 4-point Likert scale. Cronbach’s Alpha for the Anxiety-scale is 0.93 and for the Depression-scale it is 0.90. Concurrent validity coefficients range
between 0.54 and 0.79; internal consistency estimates range between .90 and .93 and test-re-test reliability was established as 0.92 for the A-scale and 0.89 for the D-scale.

The State Trait Anxiety Inventory (STAI) (Speilberger, Gorusch and Lushene, 1983) was used to assess patients’ current level of transitory anxiety. The STAI is a 20-item self-report questionnaire utilising a Likert Scale which differentiates between generalised (trait) and situational (state) anxiety. Concurrent validity coefficients range between .59 and .73 and internal consistency estimates range between .77 and .93.

The Miller Behavioral Style Scale (MBSS) (Miller, 1987)) measures the tendency to seek out or avoid threat-relevant information in the context of four hypothetical stress scenarios. The MBSS was used to distinguish between information seekers (monitors) and information avoiders (blunters) The MBSS measures subjects’ self reported preferences for information and a total monitoring and total blunting score is derived by subtracting blunting sum scores from monitoring sum scores. Subjects who score above the mean are classified as monitors and those below the mean as blunters. Predictive and discriminative validity data are described by Miller (1980;1987). Test-retest reliability for the scale is reportedly in the .80 range. Test-retest reliability with a sample of 110 subjects show the MBSS subscales to be highly stable over a four month period; for the monitoring subscale, r (78) = 0.72, p< .01: for the blunting subscale, r(98) = 0.75, p<.01.

The Concerns About Epilepsy Monitoring Questionnaire (CAEMQ) (Andrewes, Camp, Cook and Kilpatrick, 2000) is a questionnaire designed by the author specifically for
epilepsy patients which contains 58-items. It assesses the concerns and anxieties of patients undergoing the epilepsy monitoring program. A factor analysis of the CAEMQ used principal components analysis with Varimax Rotation which generated six subscales with inter-item consistencies (i.e. concerns about surgery, pecuniary and family concerns, concerns about the monitoring procedure, coping alone, denial, and support from family and others). The subscales were then used to compare pre and post test responses on the various scales to investigate whether concerns and anxieties had been affected by the treatment package as well as identifying specific concerns that need to be addressed when epilepsy patients present for monitoring and surgery. Test-retest reliability with a sample of 120 subjects show the CAEMQ subscales to be highly stable; surgery (.86, p< .05), personal (.84, p<.05), monitoring, (.83, p<.05), coping alone (.77, p<.05), and support (.73, p<.05). Concurrent validity coefficients range between .28 and .41 and internal consistency estimates range between .74 and .86 (Andrewes, Camp, Cook and Kilpatrick, 2000). (see previous for a validation of the questionnaire)

8.2.4 Intervention

On the day of presentation at hospital, patients were administered the battery of tests. They were then randomly assigned to one of two groups. One group (the high information group) received the intervention package while the other group (the low information group) received the standard information that all patients are given on arrival in hospital. The treatment package consisted of an information pamphlet which contained procedural and sensory information and a video.
The pamphlet included information regarding the various procedures that the patient may encounter while being monitored (i.e. video monitoring, neuropsychological testing, neuropsychiatric interview and MRI and SPECT scans). The video recording showed two epilepsy patients, (one male, one female) who had undergone temporal lobe surgery being interviewed where they are asked to share their experiences prior to and post surgical treatment for epilepsy. The content of their delivery was generally positive (coping) and attempted to allay the fears and anxieties of prospective monitoring and surgical patients.

8.2.5 Post- Intervention assessment

At post-intervention assessment all subjects were re-administered three of the tests they had responded to in the first phase of the study procedure- the HADS, STAI and the CAEMQ.

8.2.6 Procedure

Participants were recruited to the study on the day that they presented for monitoring at the hospital, at which time subjects provided informed consent and were provided with a plain language statement of the research prior to any assessments being conducted (see Appendix 5 for a copy of the plain language statement and the consent form). Upon obtaining consent, the baseline questionnaires were administered (NART, MBSS, STAI, HADS and the CAEMQ). Subjects were then randomly assigned to the one of two information conditions (low or high). Subjects in the high information group, together
with the researcher, watched the video and then read the pamphlet. The researcher discussed the subject’s reaction to the video as well as ensuring the information package was understood. In the low information condition, the subjects received routine standard information that all patients were given by the respective hospitals at the time of admission which described basic hospital policy and facilities for the patients in the epilepsy monitoring program. The final phase of the procedure occurred three to four days after admission so that there would be an interaction between the hospital environment and the information package in the high information group. In this phase, all subjects were again administered the STAI, HADS and the CAEMQ. The NART was not re-administered as it had been used as a screening test to ascertain competency of comprehension.

The time span between the initial and final assessments was deemed optimum as this enabled the researchers to monitor the effect of the intervention on the interaction with the hospital environment and before any decision had been made as to the prognosis of the patient. No patient was informed of the outcome of the monitoring procedure or when they would be discharged from hospital at the final assessment. This controlled for confounding variables between subjects. All subjects were initially told by the respective hospitals that their stay would be from between seven to fourteen days and none of our subjects knew when they were going home at the time of the second assessment.
8.3 Results

High and low information condition groups

Multivariate testing (MANCOVA) used the four anxiety measures’ (HADSA, HADSD, STAIS, STAIT) pre-intervention scores as covariates and the post intervention scores as the dependent variables. Results of evaluation of assumptions of normality, homogeneity of variance-covariance matrices, linearity, and multicollinearity were satisfactory. Covariates were judged to be adequately reliable for covariance analysis. With the use of Wilks’ criterion, a main effect showed those in the high information group were less anxious, $F(4,90) = 6.37, p < .05$. Univariate ANCOVAs yielded group differences between pre and post-treatment for HADS- anxiety $F(1,93) = 19.17, p < .05$; HADS-depression $F(1,93) = 8.82, p < .05$ and STAI-state (transitory) anxiety $F(1,93) = 6.52, p < .05$. Therefore the patients in the high information group condition showed a significant decrease in anxiety and depression compared to those in the low information group condition on all measures except the STAI-trait $F(1,93) = 1.9, p > .05$. Table 8.2 shows the pre and post-test means of the low and high information groups on the four anxiety and depression measures.
Table 8.2  Means and standard deviations of pre and post tests of Low and High Information patients on the Hospital Anxiety and Depression Scale and the State Trait Anxiety Inventory

<table>
<thead>
<tr>
<th></th>
<th>Pre-testing</th>
<th>Post-testing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>low (M SD)</td>
<td>high (M SD)</td>
</tr>
<tr>
<td></td>
<td>low (M SD)</td>
<td>high (M SD)</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>HADSA</td>
<td>8.9 (4.4)</td>
<td>8.0 (3.3)</td>
</tr>
<tr>
<td>HADSD</td>
<td>5.05 (3.2)</td>
<td>4.0 (3.5)</td>
</tr>
<tr>
<td>STAI-state</td>
<td>48.2 (12.9)</td>
<td>51.9 (12.7)</td>
</tr>
<tr>
<td>STAI-trait</td>
<td>50.7 (12.8)</td>
<td>54.0 (13.2)</td>
</tr>
</tbody>
</table>

At pre-intervention assessment there were no significant differences between the groups on the CAEMQ subscales or the three visual analog scales. At post-test assessment, of the six subscales of the CAEMQ, a one-way analysis of variance revealed that there was a significant difference $F(1,98) = 5.82$, $p < .05$ between the two information groups on the ‘personal’ subscale, specifically that those in the low information group were more anxious about how family were coping at home while they were in hospital as well as concerns about finances at present and in the future.

No significant effects were found for the remaining five subscales or the three visual analog scales. An inspection of the means of the pre and post intervention subscale shows that there is little difference between the responses at the two times on all measures except the ‘personal’ subscale for the two information groups (see Figures 9.1 and 9.2). The ‘copalone’ subscale shows that epilepsy patients tend to use more problem-focused coping strategies at the time of monitoring.
Figure 8.1 The six CAEMQ subscales on low and high information groups at pre-intervention: pre-surgery (presurg), pre-monitoring (premonit), pre-coping alone (precopal), pre-denial (predeni), personal (prepers), and pre-support (presuprt)
Figure 8.2 The six CAEMQ subscales on the two information groups at post intervention: post-surgery (posurg), post-monitoring (pomonit), post-coping alone(pocopal ), post-denial (podeni), post-personal (popers) and post-support(posuprt)
Dispositional Measures

When the recommended (Miller 1987) split-mean was calculated for the present study on the dispositional MBSS measure, the mean score was 4.91 (SD=3.62) and the mean split of scores assigned the subjects who scored above the mean score as monitors and those who scored below the mean score as bluters. This resulted in seventy-four monitors and twenty-six bluters with fifteen bluters in the low information group and eleven bluters in the high information group (see Table 8.3 below)

Table 8.3 Numbers of monitors and bluters in the two information groups when the recommended split-mean was used.

<table>
<thead>
<tr>
<th></th>
<th>Low information group</th>
<th>High information group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitors</td>
<td>35</td>
<td>39</td>
</tr>
<tr>
<td>Bluters</td>
<td>15</td>
<td>11</td>
</tr>
</tbody>
</table>

No significant differences were found on any of the pre or post tests across the four groups (high-information monitors, low-information monitors, high-information bluters, low-information bluters).

A further analysis was conducted on bluters (subjects who scored less than zero) and monitors (subjects who scored above zero). This resulted in eighty-eight monitors and twelve bluters with seven in the low information group and five in the high information group (see Table 8.4 below).

Table 8.4. Showing numbers of monitors and bluters in the two information groups
when the cutoff score was less than zero

<table>
<thead>
<tr>
<th></th>
<th>Low information group</th>
<th>High information group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitors</td>
<td>43</td>
<td>45</td>
</tr>
<tr>
<td>Blunters</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

When this cutoff criterion was used, one way ANOVAs reported significant differences between the two groups on five of the pre-tests.

It was found that on arrival in hospital, blunters reported less anxiety than monitors, as reported by the STAI-state anxiety measure, $F(1,98) = .0009, p < .05$; that monitors were more in need of support than blunters at this time, as shown by the CAEMQ ‘support’ subscale, $F(1,98) = 5.24, p < .05$; monitors reported that they used more problem focussed coping strategies than blunters, as reported by the CAEMQ ‘coping alone’ subscale, $F(1,98) = 3.29, p < .05$; that monitors were more anxious about surgery and wanted more information about the surgery procedure than blunters as reported by the CAEMQ ‘surgery’ subscale, $F(1, 98) = 7.39, p < .05$ and that blunters used significantly more avoidant/denial coping strategies than monitors, as reported by the CAEMQ ‘denial’ subscale $F(1,98) = 4.29, p < .05$.

Due to the small numbers in the cells, no meaningful statistical analyses could be conducted comparing post-intervention anxiety levels across the four groups (high -
information monitors, low-information monitors, high-information bluters, low-information bluters).
8.4 Discussion

The results in this study support the prediction that pre-surgical patients may gain benefit from exposure to an intervention package which includes visual information about epilepsy surgery outcomes and the monitoring procedure. Epilepsy patients who were exposed to the intervention package showed a significant decrease in anxiety compared to those who did not receive the intervention. This supports other studies using procedural and/or sensory interventions with other patient populations (Johnston and Vogele, 1993; Egbert, Battit, Welch and Bartlett, 1964; Wells, Howard, Nowlin and Vargas, 1986; Luck, Pearson, Maddern and Hewitt, 1997, Beddows, 1997) that acknowledge the efficacy of such interventions.

Patients who received the intervention package showed a significant decrease on three of the four anxiety and depression measures, specifically on the HADSA, HADSD and the STAI-state anxiety measures. There was no change on the STAI-trait anxiety measure which perhaps would not be expected given this is a trait measure and designed to measure enduring characteristics of personality. A further positive outcome was the difference in the number of patients who terminated the procedure prior to completion in the two groups. Specifically, four removed themselves from the process in the information group whereas seven left prematurely from the control group.

The CAEMQ scales indicated that epilepsy patients continued to use more problem-focused coping strategies at post-test during the monitoring stage. There was also the
finding that patients in the high information package group were less concerned about their family situation at post-intervention assessment than those in the low information group which may have been an outcome of their reduced anxiety. Further, the CAEMQ was successful in identifying areas which indicated concerns other than those identified by validated psychometric measures.

Previous studies have identified the two coping dispositions; monitors who seek out information to reduce uncertainty and anxiety and blunters who prefer to avoid such information. Blunters report an avoidant coping style, preferring to ignore the present aversive situation, pretending that everything is all right and not thinking about the situation very much (Miller, 1980; Cohen and Lazarus, 1973; Auerbach, 1989). As hypothesised, it was found that epilepsy patients who were identified as “monitors” reported that, on arrival in hospital, they were more anxious and required more support at this time from significant others and staff. They also needed more information about surgery and possible after-effects of surgery when compared to blunters. This is consistent with past research (Miller and Mangan, 1983; Miller and Brody, 1988) where it was reported that information seekers are more anxious and required more information on arrival in hospital for invasive surgery.

The third hypothesis that predictions concerning the influence of individual differences in the ways in which monitors and blunters responded to pre-surgical monitoring were found, but only after the use of a more strict cutoff criterion was used. While the more lenient cut-off of a split-mean is often used in other studies (Miller, 1980; Miller and
Mangan, 1983; Miller, Shoda and Hurley, 1996; Miller, 1987; Miller, Brody and Somerton, 1988) it is not obvious why the use of this cut-off can be rationalized, given that this would include persons within the blunter’s category who could be construed as still requiring information to reduce anxiety. It is likely that because real blusters are relatively rare compared to information seekers, that the more lenient cut-off was used in these studies because of sample size considerations.

Hence an interaction between personality trait and information load was evident in this study. All subjects who scored less than zero were classified as blusters as a minus score reflects ‘true’ blusters and significant effects were found between the two groups on five of the pre-tests. In contrast, the use of a split-mean resulted in no significant differences on any of the tests between monitors and blusters in the two information groups and it is proposed that this was because the use of a split-mean captured monitors who were classified as blusters. Although coping disposition may be seen as a continuous variable, the MBSS questionnaire itself measures a dichotomous variable. Hence respondents are either monitors or blusters and even a score of one would indicate the requirement of information to reduce anxiety whereas a split-mean would capture many such patients. The classification in the present study had appropriate face validity in that a negative score identified those who were ‘strict’ blusters and significant effects were found.

The main findings of this study provide encouraging results, given the advantages of reduced anxiety and reduced concerns in the high information group. These results promote a strong recommendation that epilepsy patients presenting for pre-surgical
monitoring would benefit from this type of intervention as a routine component of their monitoring assessment. The findings support past research in that coping styles mediate the amount of information pre-surgical patients require.

A more extensive study may be required to assess whether there are patients who are categorized as blun ters whose condition actually deteriorates upon being given more information. This eventuality is unlikely, but may be pre-empted by first briefly assessing the patient as to their coping style. Given this precaution, the intervention used here could be a standard treatment for all patients being monitored for epilepsy, assuming they have the resources to take advantage of this multi-modal therapy. It can be argued that it is difficult to state conclusively which part of the intervention was responsible for the resultant positive effects. However, with a multi-modal approach to therapy, such as the one in the present study, benefits of a combination of procedural and sensory information and the interaction with the researcher were achieved.
Chapter 9

9.0 General Discussion

The first study in this thesis was a validation of a newly devised questionnaire, the Concerns About Monitoring Questionnaire the CAEMQ (refer to Chapter 6). The study was concerned with developing a measure which could identify the specific concerns of epilepsy patients presenting for monitoring and possible surgery. The findings from the validation reported six subscales in the CAEMQ, each of which tapped into different areas of concern, identified coping strategies used by patients during monitoring, and investigated whether they felt the need for more information. Specifically, the six scales were:

1. ‘the concerns and information about surgery’, reflecting the need for more information about surgery;

2. ‘personal concerns,’ worries about hospital accounts, how the family is coping without them;

3. ‘information about treatment and monitoring,’ reflecting the need for information about the monitoring process prior to admission at hospital;

4. ‘coping alone,’ reflecting whether the patient is utilising positive, problem-focused, coping skills;
5. ‘denial,’ revealing that the patient copes by distancing and avoiding confronting the unpleasant event, and
6. ‘support from significant others,’ identified the people/ significant others such as health professionals and family from whom the patient would like support during the monitoring process.

The findings indicated that patients needed information about the monitoring procedure and surgery outcomes and treatment. There was also the finding that more information would be likely to reduce their concerns. Attrition numbers differed between the two groups. Specifically, fewer patients terminated the procedure in the intervention group than in the control group. Further, coping strategies, as identified by Lazarus and Folkman, (1984), which were incorporated in the ‘cope alone’ (problem-focused strategies) and ‘denial’ (distancing strategies) scales of the CAEMQ, were likely to be used by these patients during the monitoring procedure. Lazarus and Folkman (1984) maintained that those who used problem-focused coping were less anxious, and that those using a ‘denial’ coping style, while initially less anxious, reported more anxiety as the aversive event continued. The present study supported their suggestion. The ‘copealone’ scale, based on problem-focused ways of coping, successfully identified patients using this style of coping. They were found to be less anxious than those using distancing strategies as identified by the ‘denial’ scale of the CAEMQ. In the second study of the thesis, these two scales on the CAEMQ successfully identified two personality coping styles, namely monitors and blunters, (as posited by Miller, 1986), amongst epilepsy patients.
The major finding from the second study in this thesis was that an information package was successful in reducing anxiety amongst epilepsy patients presenting for monitoring and possible surgery. The efficacy and cost-effectiveness of the information package, utilising a multi-faceted approach, was established in the current study, producing a reduction in anxiety in these patients. Temporal epilepsy patients are faced with many challenges which may undermine an already vulnerable personality (Mattson, Tibblin, Kihlgren and Kumlien, 2005; Ruber, Anderson, Elger and Helmstaedter, 2004; de Toffel, 2004; Wrench, Wilson and Bladin, 2004), therefore any intervention which reduces apprehension and anxiety must be welcomed if it could be incorporated into a program. This has been easily achieved by the Victorian Epilepsy Foundation.

The package, incorporating a video and a pamphlet, were viewed and discussed with the experimenter. The ensuing conversational interaction with patients provided an insight into the level of distress they were experiencing. This interaction resulted in qualitative information important to a complete overall picture of the epilepsy patient’s thoughts and feelings in a pre-surgical situation. For instance, many patients were clearly able to identify with the two people in the video, exclaiming, “That’s how I feel at the moment,” or “I’ve said that, too!” as they watched the post surgical patients describing their monitoring experiences, fears, thoughts and feelings. During interaction with the researcher, patients conveyed their apprehensions regarding possible surgery, but they were also hopeful that their surgery would be as successful as it was for the patients depicted in the video. Further information offered by epilepsy patients about possible impending surgery ranged from patients eager for surgery so that their life with seizure
episodes would be markedly reduced or eliminated, to patients who were staunchly opposed to any brain surgery. In the words of one patient, “It’s the only part of me that’s me- and no-one is touching it!” Thus, to have successfully reduced anxiety in TLE patients presenting for monitoring and possible surgery through an information package is encouraging, indicating that these patients, presenting for monitoring with a plethora of problems, can be assisted during the monitoring process with such an economical and simple intervention.

9.1 Future directions

Due to the success of the information intervention package in reducing pre-surgical anxiety in TLE patients, future research could investigate the efficacy of such a package on different personality coping styles. As it is uncertain which particular aspect of the package was most successful, future research could set out to determine this. Further, an investigation into the usefulness of the package in reducing anxiety and concerns amongst those patients with a ‘blunting’ disposition compared to those with a ‘monitoring’ disposition. This would determine whether the package is effective in all cases, or, as Miller (1986; 1987) has suggested, that caution needs to be taken in administering information as those with a ‘blunting’ disposition may become more distressed.

The success of the CAEMQ in identifying areas of concern in patients arriving for monitoring, as well as its ability to indicate the types of coping strategies used by these
patients, suggests that the measure can be useful in future research investigating epilepsy patients at pre-surgery.

In conclusion, patients with temporal lobe epilepsy, reporting for long-term video-EEG monitoring in hospital, responded to an intervention package based on information about monitoring and surgery. Their anxiety and depression levels were significantly reduced by the package, and it is suggested that such patients be exposed to this type of intervention so as to reduce their anxieties about surgery and monitoring, anxieties which are already compromised by the nature of living with their disorder.
References


Briellmann, R.S., Kalnins, R., Hopwood, M.J., Ward, c., Berkovic, S.F., Jackson, G.D.(2000).Postictal psychosis in TLE: microdysplasia and anterior Hippocampal preservation. (Brain imaging research institute Dep’t of
Neurology, A&RMC, Heidelberg and University of Melbourne.) In Press


Folkman, S. and Lazarus, R.S. (1985). If it changes, it must be a process; a study of emotion and coping during three stages of a college exam. Journal of


*Archives of Neurology, 41*, 766-770.


APPENDIX 1

EPILEPSY MONITORING QUESTIONNAIRE

(Confidential Question for Research only) Thank you very much for helping out. Your results will not be shared with people in the hospital, will be anonymous and be used for research in order to improve conditions for patients. Do not put your name on this questionnaire. When you have completed it place it in the envelope provided and give it to the nurse to place in the internal mail. Thank you for your participation.

Date: ______________________

Married/Partner/Single (please circle) Do you have any children? Yes No If yes, how many?

How many days have you been in hospital?

How many days do you think you have to go? Don’t Know:

Age: Age at onset:

SEX: Male/Female

Educational Level reached e.g. years at school and or qualifications:

Brief Reason for stay in hospital: ________________________________

How are you feeling right now?

1. Do you find your stay in hospital boring?

   Not at all  A little  Moderately  Quite a lot  Very much so

   I          I          I          I           I

2. Do you find the tests and the observations uncomfortable?

   Not at all  A little  Moderately  Quite a lot  Very much so

   I          I          I          I           I

3. How strongly do you feel you could leave the hospital before your assessment and monitoring is complete?
4. Do you feel frustrated because your treatment is getting nowhere?

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What other things do you dislike about your stay in hospital?

______________________________________________________________________________________________________
______________________________________________________________________________________________________
______________________________________________________________________________________________________

-----

**Information**

5. Do you feel you need more information about possible treatments?

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6. Would you like more information about your epilepsy?

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7. If you were going to have surgery would you like more information about how you would feel just after surgery?

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8. Would you like more information about how you would feel after the operation?

Not at all          A little               Moderately                Quite a lot          Very much so
I                             I                             I                             I                               I

9. Would you like information about the effect of an operation on your physical health?

Not at all          A little              Moderately               Quite a lot           Very much so
I                            I                             I                             I                               I

10. Would you like information about the effect an operation would have on you mentally?

Not at all          A little             Moderately     Quite a lot    Very Much so
I                            I                             I                             I                               I

11. Would you have liked more information about what was going to happen to you when you first came onto the ward for monitoring? (e.g., more information about staff and tests)

Not at all        A little               Moderately              Quite a lot           Very much so
I                            I                             I                             I                               I

12. Would you like more information on other, additional areas, which are not mentioned above? (e.g. more information on medication, length of stay in hospital, recovery time, etc.)

Not at all        A little               Moderately              Quite a lot             Very much so
I                            I                             I                             I                               I

Please name the additional areas
..........................................................................................................

13. Do you think that having more information would reduce your anxiety?

Not at all        A little               Moderately              Quite a lot             Very much so
I                            I                             I                             I                               I
14. Would it distress you or make you feel uncomfortable if you were given more information

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15. If you were presented with information, how would you prefer it to be presented?
   Please rank answers if you choose more than one.
   A) Personally _______   B) Booklet _______
   B) Video_________   D) Combination_________

If you would prefer having information presented by other means, please indicate your preference(s) -----------------------------------------------

16. If you were to be given information who would you like to receive this from?
   Please rank your preferences from 1 to 7 in the spaces provided
   A) Nurse (   )
   B) Neurologist (   )
   C) Neuropsychologist (   )
   D) Doctor on the ward (   )
   E) Family (   )
   F) Someone who has already had your operation (   )
   G) Other (   ) please indicate who

17. Do you find this questionnaire difficult to understand so far?

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18. Do you have difficulty in concentrating while you are answering these questions?

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Other comments: What have we left out in this information section?
_________________________________________________________________
_________________________________________________________________
Emotional Support

19. Do you feel that you are in need of more support during the time you are being monitored?

Not at all  | A little  | Moderately | Quite a lot | Very Much so
---|---|---|---|---
I | I | I | I | I

20. Would you like further support from your family?

Not at all  | A little  | Moderately | Quite a lot | Very Much so
---|---|---|---|---
I | I | I | I | I

. Which members of your family? Please say who.  
--------------------------------------------------------------------------------------------------------------------------
--------------------------------------------------------------------------------------------------------------------------

21. Would you like support from other patients on the ward?

Not at all  | A little  | Moderately | Quite a lot | Very Much so
---|---|---|---|---
I | I | I | I | I

22. Would you like further support from the staff?

Not at all  | A little  | Moderately | Quite a lot | Very Much so
---|---|---|---|---
I | I | I | I | I

Which staff would you like further support from?  

23. Would you like emotional support from someone who has had a similar experience to yourself?

Not at all  | A little  | Moderately | Quite a lot | Very Much so
---|---|---|---|---
I | I | I | I | I
24. What kinds of emotional support would you prefer?
Please rank in space: 1-5.

A) Encouragement. (  )
B) Just someone being there. (  )
C) Reassurance. (  )
D) Being Kind. (  )
E) Other, please tell us the kind of support required. (  )

At the present time who do you gain most emotional support from?

Other comments about the types of support you would like……………
………………………………………………………………………….

Concerns

25. Are you concerned about whether you will have enough money when you leave hospital?

Not at all A little Moderately Quite a lot Very Much so
I I I I I

26. Are you concerned about whether you will have enough money later on in life?

Not at all A little Moderately Quite a lot Very Much so
I I I I I

27. Are you concerned about your hospital expenses?

Not at all A little Moderately Quite a lot Very Much so
I I I I I

28. Are you concerned about how people are coping at home while you are away?

Not at all A little Moderately Quite a lot Very Much so
I I I I I
29. Do you have concerns about your future after you leave hospital?

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30. Do you have concerns about the safety of surgery, if you were being assessed for this?

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31. Do you have concerns about your physical well-being following an operation if you had one?

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32. Do you have concerns about your mental well-being after an operation if you had one?

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33. Do you have concerns about your illness/disorder after you leave hospital?

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Do you have other concerns? Please state.

What issues or things worry you most?

What issues or things make you most angry?

What things make you most uncomfortable?
**Coping**

34. Do you have difficulty in coping at this time?

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35. Do you cope better by asking others?

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36. Do you cope better at the present time by organising, planning and keeping track of what is happening?

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37. Do you cope better by talking to someone who knows more about the situation?

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38. Do you cope better by just ignoring everything?

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39. Do you cope better by facing your problems?

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40. Do you cope better by asking someone you respect for advice?

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41. Do you cope better by pretending everything is okay?

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42. Do you cope better by forming a plan of action and following it?

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43. Do you cope better by talking to someone who can do something to help you with the situation?

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44. Do you cope better by trying not to think of the problem too much?

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45. Do you cope better by devising different solutions to a problem?

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46. Do you cope better by sharing your feelings with others?

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47. Do you cope better by looking on the bright side of things?

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48. Do you cope better at the present time by pretending that you are not in hospital by somewhere more enjoyable?

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49. Does sympathy and understanding from others help you to cope better?

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50. Do you cope better by focusing on what should be done next to help the situation?

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51. Do you cope better by changing something about the situation in the hope that things will work out better?

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52. Do you cope better by not taking things too seriously?

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Are there other ways that you cope? _______________________________________
____________________________________________________________________

**Ways of Coping**

53. Would you like to reduce any concerns by using strategies which make your thoughts more positive?

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54. Would you like to reduce concerns by using certain techniques such as relaxation exercises?

Not at all  A little  Moderately  Quite a lot  Very much so
I _______ I _______ I _______ I _______ I _______

55. Would you like to reduce your concerns by having more information?

Not at all  A little  Moderately  Quite a lot  Very much so
I _______ I _______ I _______ I _______ I _______

56. Would you like to reduce your concerns by just ignoring your problems?

Not at all  A little  Moderately  Quite a lot  Very much so
I _______ I _______ I _______ I _______ I _______

57. Do you like being in control of your problems?

Not at all  A little  Moderately  Quite a lot  Very much so
I _______ I _______ I _______ I _______ I _______

58. Do you prefer to let the treatment take its course without your having to do anything?

Not at all  A little  Moderately  Quite a lot  Very much so
I _______ I _______ I _______ I _______ I _______

What other styles of coping do you have? Please state ______
________________________________________________________________________
61. Although you may not want to leave the hospital before your assessment and monitoring is finished we are interested to know how you are feeling about staying in hospital.

Please indicate the degree to which you feel that you would like to leave the hospital before your assessment and monitoring are finished by marking the scale with a cross anywhere along the line between the two end points.

A) I feel happy to stay in hospital
   and want to leave hospital

B) I don’t feel anxious about staying in hospital
   and want to leave hospital

C) I don’t feel upset about staying in hospital
   and want to leave hospital

Thank you very much for helping out. Your results will not be shared with people in the hospital, Your results will be anonymous and will be used for research in order to improve conditions for patients.
APPENDIX 2

Factor 1: Surgery (Alpha .86)

1. If you were going to have surgery would you like more information about how you would feel after surgery? (.82)
2. Would you like more information about how you would feel after the operation? (.76)
3. Would you like information about the effect of an operation on your physical health? (.75)
4. Would you like information about the effect of an operation on your mental health? (.82)
5. Do you have concerns about your physical well being following an operation if you had one? (.48)
6. Do you have concerns about the safety of surgery if you were being assessed for this? (.58)
7. Do you have concerns about your mental well being after an operation if you had one? (.56)

Factor 2: Personal (Alpha .85)

1. Are you concerned about whether you will have enough money when you leave hospital? (.79)
2. Are you concerned about whether you will have enough money later on in life? (.81)
3. Are you concerned about your hospital expenses? (.62)
4. Are you concerned about how people are coping while you are away? (.68)
5. Do you have concerns about your future after you leave hospital? (.73)

Factor 3: Monitoring (Alpha .80)

1. Do you feel you need more information about possible treatments? (.69)
2. Would you like more information about your epilepsy? (.70)
3. Would you have liked more information about what was going to happen to you when you came in for monitoring? (.75)
4. Would you have liked more information on other, additional areas which are not mentioned above? (.75)
5. Do you think that more information would reduce your anxiety? (.68)
6. Would you like to reduce your concerns by having more information? (.53)
Factor 4: Coping Alone (Alpha .77)

1. Do you cope better by facing your problems? (.66)
2. Do you cope better by forming a plan of action and following it? (.61)
3. Do you cope better by devising different solutions to a problem? (.72)
4. Do you cope better by looking on the bright side of things? (.71)
5. Do you cope better by focusing on what should be done next to help the situation? (.49)

Factor 5: Denial (Alpha .76)

Do you cope better by just ignoring everything? (.62)
Do you cope better by pretending everything is okay? (.71)
3. Do you cope better by trying not to think of the problem too much? (.76)
4. Would you like to reduce your concerns by just ignoring your problem? (.76)

Factor 6: Support (Alpha .74)

1. Do you feel that you are in need of more support during the time you are being monitored? (.63)
2. Would you like further support from your family? (.58)
3. Would you like support from other patients on the ward? (.82)
4. Would you like further support from the staff? (.73)
5. Would you like emotional support from someone who has had a similar experience to yourself? (.65)
APPENDIX 3 (Pamphlet)

NO TEXT INCLUDED
APPENDIX 4

Tests in order of presentation and instructions given to patients prior to administration of each test

National Adult Reading Test (NART)

I’d like you to read the words aloud to me, reading them down each column. If you see a word which is too difficult and you have no idea how to say it, just say ‘pass’. Don’t rush—read it at a normal pace. I’ll give you a minute to familiarise yourself with the list. Let me know when you are ready.

NO TEXT INCLUDED HERE
Short scale Eysenck Personality Questionnaire-Revised (EPQ-R)

*Please circle either ‘Yes’ or ‘No’ to the following statements.*

NO TEXT INCLUDED HERE
The Hospital Anxiety and Depression Scales (HADS)

In this questionnaire, please read the instructions on the sheet and tick one box only for each question.

NO QUESTIONNAIRE INCLUDED HERE
The State Trait Anxiety Inventory (STAI)

*In this questionnaire, read the directions and circle one number only in each question.*

*NO QUESTIONNAIRE INCLUDED HERE*
Monitor - Blunter Style Scale (MBSS)

_In this questionnaire I’d like you to put a tick beside all the things you would be likely to do in each situation given. There are four situations - put as many ticks beside the statements that indicate how you would respond._

Vividly imagine that you are _afraid_ of the dentist and have to get some dental work done. Which of the following would you do? Tick _all_ of the statements that might apply to you.

___ I would ask the dentist exactly what s/he was going to do.
___ I would take a tranquillizer or have a drink before going.
___ I would try to think about pleasant memories.
___ I would want the dentist to tell me when I would feel pain.
___ I would try to sleep.
___ I would watch all the dentist’s movements and listen for the sound of the drill.
___ I would watch the flow of water from my mouth to see if it contained blood.
___ I would do mental puzzles in my mind.

Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick _all_ of the statements that might apply to you.

___ I would sit by myself and have as many daydreams and fantasies as I could.
___ I would stay alert and try to keep myself from falling asleep.
___ I would exchange life stories with the other hostages.
___ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
___ I would watch every movement of my captors and keep an eye on their weapons.
___ I would try to sleep as much as possible.
___ I would think about how nice it’s going to be when I get home.
___ I would make sure I knew where every possible exit was.

Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Check all of the statements that might apply to you.
___ I would talk to my fellow workers to see if they knew anything about what the supervisor’s evaluation of me said.
___ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
___ I would go to the movies to take my mind off things.
___ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.
___ I would push all thoughts of being laid off out of my mind.
___ I would tell my spouse that I’d rather not discuss my chances of being laid off.
___ I would try to think which employees in my department the supervisor might have thought had done the worst job.

___ I would continue doing my work as if nothing special was happening.

Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

___ I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

___ I would make small talk with the passenger beside me.

___ I would watch the end of the movie, even though I had seen it before.

___ I would call for the stewardess and ask her exactly what the problem was.

___ I would order a drink or tranquiliser from the stewardess.

___ I would listed carefully to the engines for unusual noises and watch the crew to see if their behaviour was out of the ordinary.

___ I would talk to the passenger beside me about what might be wrong.

___ I would settle down and read a book or magazine or write a letter.
Concerns About Epilepsy Monitoring Questionnaire (CAEMQ)

(This questionnaire can be found in APPENDIX 1.)

Instructions: Please answer the following questionnaire—there is provision throughout the questionnaire for your comments—please make use of these spaces as your input is valuable to us.
APPENDIX 5

Plain language statement and consent form

NO TEXT INCLUDED HERE
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Author/s: Pniewski, Krystyne

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