PATIENT-RATED SEIZURE SEVERITY AND ADJUSTMENT TO EPILEPSY

by

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Studies have indicated that many, although by no means all, people with epilepsy have difficulty in adjusting to the disorder, manifest by higher rates of psychological and social problems than amongst the general population. A variety of neurological and environmental factors have been hypothesized to contribute to these consequences. It has been suggested that the severity of seizures may be an important factor in determining psychological and social well-being, but very little research has investigated this empirically.

This study was therefore undertaken to investigate the relationship between patient-rated seizure severity and adjustment to epilepsy. If greater seizure severity was associated with poorer adjustment, measurement of seizure severity might provide a suitable means of identifying those patients who could benefit from a psychoeducational intervention programme, and may also serve as a useful measure of treatment efficacy.

In addition, the research considered the value of Wright's (1990) comprehensive conceptual model for the definition and assessment of adjustment, as much research in the area of adjustment to chronic illness has suffered from insufficient definition and difficulties with measurement.

The results indicated that seizure severity was only weakly associated with psychological and illness-related measures of adjustment. These associations would not be sufficiently strong to allow the proposed use of seizure severity as an indicator of poor adjustment, although there may be some value in using this variable as a measure of treatment efficacy in addition to seizure frequency.

The conceptual model of adjustment was found to be of value as a framework for guiding operationalisation and measurement of adjustment. Results tentatively confirmed the associations currently suggested within the model and further additions were proposed.

Suggestions for future research are made.
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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region based in Southmead Health Services NHS Trust and the research was conducted in collaboration with Southmead Health Services NHS Trust and Frenchay Healthcare Trust.

Signed

Date 1st October 1992
1.0 INTRODUCTION

The awareness of epilepsy is ancient, certainly being a well-known disorder by 2000 B.C. It is also a disorder with an ancient associated stigma. One of the oldest theories of aetiology attributes it to possession by the devil. The dominance of the satanic theory meant that for centuries 'epileptics' were considered untouchables in many cultures, and treated, if at all, with such things as ground skull bone, human blood and religious incantations. It was not until the 17th century that the cerebral origin of seizures was recognised, although this belief was not fully confirmed until the first electroencephalogram (EEG) in 1929; and people with the disorder had to wait until 1938 before blood, rattlesnake and mistletoe were replaced with the first anti-convulsant drug, phenytoin.

The historical residues of such a deviant status remain and it seems that epilepsy is a disorder which is able to evoke an emotional response that differs significantly from other chronic illnesses.
1.1 The medical conception of epilepsy

1.1.1 Definition

An epileptic seizure is the product of an abnormal, paroxysmal discharge of cerebral neurones, and epilepsy is usually defined as a continuing tendency to epileptic seizures. The use of the word 'continuing' is designed to exclude, for example, the case of an individual who experienced one seizure, aged 20 and none thereafter. What constitutes 'continuing tendency' may vary however between doctors. In general, a neurologist will make a diagnosis of epilepsy if they hear of more than one non-febrile seizure of any type. This would appear straightforward if the time period is relatively short, but would the diagnosis be given to a man who has one seizure at the age of 19 and another at 75? Definition can then be more problematic than one might imagine and the label 'epilepsy' obviously has to be applied with common sense.

1.1.2 Epidemiological aspects

Problems with diagnostic criteria and case ascertainment constitute major problems for the collection of meaningful epidemiological statistics. However, most studies give annual incidence rates of 20-25 per 100,000. The rates are highest in the pre-school years, then fall rapidly, staying low until the age of 60. A study in Minnesota shows a considerable increase in the rates for people aged 60 and
Estimates of the prevalence of active epilepsy - that is, those who have had two or more non-febrile seizures and have had a seizure within the previous two years or are on anticonvulsant medication - usually range from 3-6 per 1000. Most studies show a slight excess in males and higher rates in the lower socio-economic groups.

Studies of the prognosis of people with epilepsy have tended to focus on the issues of remission of symptoms and survival (Schoenberg, 1985). Hauser (1978) has estimated that the average duration of symptoms amongst people with epilepsy is about 12 years. Goodridge and Shorvon (1983) emphasise the 'temporal aspects of prognosis', finding that most people enter remission early, that the longer the epilepsy remains active the less likely was eventual remission, and that relapse after remission was relatively rare.

1.1.3 Types

Epileptic seizures may take a number of different forms, depending on the site and pattern of the abnormal neuronal discharge in the brain. If the discharge is confined to one part of the brain, the resultant seizure is described as a partial seizure. If discharge occurs in one part of the brain and subsequently spreads, through the involvement of the mesodiencephalic system (central, lower part of the brain) to all parts, the seizure is known as a partial
seizure with secondary generalization. Sometimes paroxysmal discharges originate in the mesodiencephalic system and spread to all parts of the brain almost simultaneously. This seizure is known as a primary, generalized seizure.

Within each seizure type, clinical manifestations vary.

1.1.3.1 Generalized seizures

Common generalized seizures include the generalized tonic-clonic (grand mal) seizure and the absence (petit mal) seizure. There are a number of other generalized types of seizures which are less common: myoclonic jerks, clonic, tonic, atonic. These will not be discussed.

Tonic-clonic (grand mal) seizures

Whether the discharge is primary, or secondarily generalized, consciousness is lost. The first phase is the tonic (contraction) phase. Because of widespread contraction, the body becomes rigid and incapable of maintaining a normal coordinated posture so the person falls to the ground. The respiratory muscles contract, forcing air through the larynx so there may be involuntary noise; the jaw muscles contract so the tongue may be bitten; no respiratory movements occur so the person rapidly becomes cyanosed (a blue appearance of the skin due to insufficient oxygen in the blood). After 1 to 2 minutes of the tonic phase, the seizure passes into the clonic or
convulsive phase, with violent movement of the limbs and trunk muscles. These gradually cease after a few minutes, followed by complete relaxation of the muscles, with normal ventilation returning. Consciousness gradually lightens and the person is likely to feel confused for minutes or even hours and to complain of headaches, nausea and drowsiness.

Absence seizures (petit mal)

These are another form of generalized seizure, largely confined to childhood, so will not be discussed here.

1.1.3.2 Partial (focal) seizures

Partial seizures begin and usually remain confined to neurones in proximity of an area of local cerebral damage. Clinical symptomology depends on the site of damage. A common site is the temporal lobe where discharges may result in hallucinations of sight, sound, taste, smell, touch and memory (auras). The gustatory and olfactory sensations tend to be unpleasant and may be accompanied by lip smacking or chewing movements. Deja vu and jamais vu are common transient disturbances of memory. The person does not lose consciousness, but remains in a dreamy state. Coordinated behaviour may continue throughout or there may be stereotyped movements often involving the jaw and facial muscles. Emotional experiences are very frequent in temporal lobe seizures; they may be described as a 'horrible' feeling although sometimes the sensation of fear is overpowering. Short-lived partial seizures arising in
the temporal lobe may be very similar clinically to absences, but the distinction is worth making because of differences in the cause, treatment and outcome.

As far as is known, all partial seizures arise from some focal area of structural abnormality, so that all partial seizures and secondarily generalized seizures can be said to be symptomatic of an underlying problem, or symptomatic epilepsy. Primary generalized seizures are never symptomatic of structural brain damage, and can be described as idiopathic epilepsy (that is, of unknown cause).

There are many other forms of seizure which have been recorded (see Commission of Classification and Terminology of the International League Against Epilepsy, 1981). The above describes the most common forms and gives an indication of the range of severity of seizures, in terms of their predictability and ictal and post-ictal phenomena. Table 1. summarizes the different types of seizures.
<table>
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<th>Partial</th>
<th>Generalized</th>
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<tr>
<td>Simple</td>
<td>Absence (petit mal)</td>
</tr>
<tr>
<td>Complex (consciousness is impaired)</td>
<td>Myoclonic</td>
</tr>
<tr>
<td>Partial becoming secondarily generalized</td>
<td>Tonic</td>
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<td></td>
<td>Clonic</td>
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<td>Tonic-clonic (grand mal)</td>
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<td>Atonic</td>
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Table 1. Classification of seizures

1.1.4 Aetiology

The causes of epilepsy vary widely. Freeman (1979) categorizes causality in relation to prenatal, perinatal and postnatal factors. Prenatal factors include infectious diseases, hormonal disturbances, premature birth and genetic influences (on metabolism or convulsive threshold). Anoxia, severe birth trauma, and abnormalities of foetal positioning are examples of perinatal factors. Finally, postnatal factors include brain tumours, head injuries, parasitic infections involving the central nervous system and vascular diseases affecting the brain's blood vessels. In many cases however, aetiology is difficult to determine.
1.1.5 *Precipitants of seizures*

Although the cause may be difficult to determine, there are a number of short-term stimuli which may precipitate seizures in susceptible people. These include sleep deprivation which alters cerebral electrical activity; excess alcohol, or more exactly the 'hang over' when blood alcohol is falling; menstruation; stress/worry; and photosensitivity, although this latter precipitant is fairly rare.

1.1.6 *Treatment*

The main form of treatment for epilepsy is drugs. The majority of people can be rendered seizure free by pharmacological means, although chronic, intractable epilepsy develops in approximately 20% of cases. Occasionally surgery may be appropriate for those who have a single, discrete focal abnormality. People can learn to prevent seizures by avoiding particular known precipitants.

A study of the literature regarding epilepsy and its consequences leads one to ask the question, not whether and how clinical psychology might play a role in management of the disorder, but why there is not more clinical psychology input into neurology outpatient clinics or GP surgeries where people with epilepsy receive their medical care.
1.2 Consequences of epilepsy

The diagnosis of epilepsy can pose a serious threat to the physical, psychological, and social well-being of an individual. A body of research has developed over the years that indicates that epilepsy is indeed often associated with a variety of psychological and social difficulties, which some suggest may be more handicapping than the seizures themselves (Livingstone, 1981).

Although a plethora of studies deal with the importance of psychosocial factors to people with epilepsy, comparisons across studies are difficult to make due to various methodological issues. There is no standard definition of a psychosocial problem, nor complete agreement on which psychosocial problems exist (Dodrill, 1983). Further methodological limitations of the studies which prohibit firm conclusions being drawn include problems with the diagnosis of epilepsy, inadequate sampling procedures, small sample sizes and lack of adequate or non-existent control groups. Invalid or inadequate measures of psychological, behavioural and social factors are frequently found.

To facilitate presentation of the literature in this area, the framework developed by Dodrill, et al. (1980) to 'permit a comprehensive, systematic, and objective assessment of psychosocial problems' will be used to order the information. Using this framework as a basis, Dodrill et al. (1980) designed the Washington Psychosocial Seizure
Inventory (WPSI) for adults with seizure disorders, identifying general areas of psychosocial concern to people with epilepsy. These provide an appropriate basis within which to discuss the literature.

1.2.1 Family background and adjustment

Studies in this area relate to patterns of relationships which develop within the family as a result of a family member developing epilepsy and the effects these interrelations have on the individual with epilepsy. Reactions can range from overprotection to scapegoating and rejection (Arangio, 1980; Shaw, 1983). Other responses have included disbelief, anxiety, embarrassment, depression and avoidance, (Heisler, & Friedman, 1981; Ziegler, 1982; Ford, et al., 1983) which may lead to behaviours such as poor compliance, overindulgence and decreased parental expectations (Dodrill, 1983; Ford, et al., 1983; Potter & Roberts, 1984). The effects of such reactions on the individual with epilepsy, and their own reaction to the diagnosis can be guilt and concealment (Lechtenberg, 1984) withdrawal and denial, (Laakonsen, 1983), dependency, (Lechtenberg, 1985) and low self-esteem (Fenton, 1983).
1.2.2 Emotional adjustment

Much of the literature concentrates on epilepsy and its association with emotional and behavioural difficulties, psychiatric disorders and personality problems. Generally, there seems to be a consensus that people with seizure disorders do have an increased tendency toward psychopathology and emotional maladjustment (Kogeorgos, 1983; Dodrill, 1986; Dodrill & Batzel, 1986).

In the area of psychiatric symptomology, Kogeorgos, et al (1982) reported that 45% of their sample had psychiatric symptoms as assessed by the GHQ and Crown Crisp, compared to 22% of the community control group without epilepsy. Betts (1981), Dikmen, et al., (1983), Trimble & Perez (1980) and Robertson (1986) all report a high incidence of depression amongst people with epilepsy. Mulder & Daly (1952), Currie, et al., (1971) and Dowds, et al (1983) reveal a prevalence of anxiety problems. It should be noted however, that many studies draw their samples from specialist clinics or hospital settings where patients tend to have chronic, intractable epilepsy and may therefore demonstrate more psychiatric difficulties than people who are treated only by their GPs, whose seizures are easier to manage.
1.2.3 Interpersonal adjustment

This refers to a person's ability to relate to other people. Relationships with significant others are considered to be of vital importance in psychosocial adjustment (Dodrill, et al. 1980). Most studies have focussed on marriage and sexual adjustment, and it is generally agreed that people with epilepsy have a lower rate of marriage than people without epilepsy (Batzel & Dodrill, 1984; Fraser & Clemmons, 1981). Lechtenberg (1984) estimated that 56% of men with epilepsy and 69% of women are unmarried. Social isolation and withdrawal are also commonly reported in the literature on psychological adjustment (Heisler & Friedman, 1981; Fraser & Smith, 1982), to which fear, anxiety and the attitudes of others are hypothesized to contribute (Laaksonen, 1983). Low rates of self-esteem in people with epilepsy have also been reported in several studies (Woodward, 1982; Britten, et al., 1986; Collings, 1990).

1.2.4 Vocational adjustment

There is agreement in the literature that unemployment and underemployment of people with epilepsy is much more frequent than in the general population (Scambler & Hopkins, 1980; Dodrill, 1983; Masland, 1983), although there is little agreement on the specific rates. In Dodrill's (1983) study, about 60% of adults with epilepsy reported concerns in the vocational area. Scambler &
Hopkins (1980) reported career inhibition due to epilepsy in 42% of their sample. Employer discrimination is thought likely to have a significant negative impact on vocational adjustment, although neuropsychological functioning and psychosocial adjustment are also relevant to employment status (Batzel, et al, 1980; Dikmen & Morgan, 1980). There is fairly good evidence that seizure frequency and seizure type are essentially unrelated to employment status (Batzel, et al, 1980; Dennerll, et al, 1966).

Higher rates of under- and unemployment inevitably has an impact on financial status, and many reports have maintained that people with epilepsy have lower than average incomes (Batzel, et al, 1980; Laaksonen, 1983; Dodrill, et al, 1984).

1.2.5 Adjustment to seizures

This construct concerns the person's acceptance of their seizure disorder and feelings of not being accepted because of epilepsy. Although there have been reports of patterns of adjustment, little statistical research has been undertaken. A multicentre study by Dodrill, et al (1984) indicates that between 8 and 16% of cases have severe problems with adjusting to their seizures, with further subjects having definite problems. A study by Hermann, et al (1990) indicates that poor adjustment to seizures was predictive of increased psychopathology, as measured by the GHQ.
1.2.6 Medicine and medical management

A person's view of treatment received or medical management can also affect psychosocial adjustment (Dodrill, et al, 1980; Shope, 1980). Reactions to the doctors who are responsible for their care, medication and degree of compliance are all thought to be significant factors.

A study of physicians attitudes showed that they held negative attitudes toward people with epilepsy (Beran, et al, 1981), and Beran & Read (1983) reported that physicians accepted the idea of an 'epileptic personality'.

The patient-physician relationship plays a role in compliance with treatment regimens, as does acceptance of the disorder (Masland, 1985; Stanaway, et al, 1985). Stanaway, et al (1985) reported that 37% of patients with epilepsy were not taking medication as prescribed and 31% of seizures were estimated to occur as a result of failure to comply.

The literature therefore indicates that a diagnosis of epilepsy can have a significant impact on an individual's life in a variety of areas, although contradictory evidence abounds as to exactly what will result, to what extent and to whom.
1.3 Reasons for psychosocial consequences - Why should there be problems?

Several hypotheses exist to explain why people with epilepsy should experience greater emotional and psychosocial difficulties than would be found in the general population. These fall into two main areas: neurological and environmental.

1.3.1 Neurological hypotheses

The neurological hypotheses reflect the belief that disorder in people with epilepsy is largely a function of central nervous system dysfunction. At the time of a seizure the brain is clearly not functioning as it should and between seizures most people with epilepsy continue to demonstrate brain dysfunction as evaluated by interictal EEG. Therefore if brain functioning is compromised one might expect to find evidence of this in patient behaviour.

Rodin, et al (1977) completed comprehensive evaluations of 369 patients with epilepsy and found only 23% with no evidence of other significant intellectual, behavioural or neurological problems.

Considerable interest has centred on the relationship between psychopathology and specific seizure type (ie complex partial or temporal lobe), although many other seizure-related variables have been implicated as among precursors for psychopathology. In general, the hypothesis
that temporal lobe epilepsy predisposes individuals to higher rates of psychopathology compared to people with other types of seizures has not been demonstrated unequivocally, and variables other than seizure type are considered to be more important determinants of psychopathology. Of relevance to this study are seizure control and seizure severity.

1.3.1.1 Seizure severity

Although clinical observations have tended to support the expectation that poor control and increased severity of seizures are associated with poorer behavioural and psychosocial adjustment (Betts, 1982; Fenton, 1981a,b; Arnston, et al, 1986), there has been relatively little direct empirical research devoted to this relationship, particularly in comparison with the quantity of research on other seizure-related variables. This paucity of empirical information and the potential importance of severity as a measure of treatment outcome and indicator of level of adjustment warrants further research, both for theoretical and clinical interest.

Research which has been undertaken on seizure severity in particular suffers from the common problem in this area of differences in definition, as well as differences in variables used to assess psychological and social status. Seizure control has tended to be defined by seizure frequency.
One study by Kogeorgos, et al (1982) which assessed psychiatric morbidity in 66 neurological outpatients with epilepsy quantified seizure severity in 2 ways. The first assigned each patient a numerical score based on the total of 9 negative prognostic indicators, which included variables such as duration of disorder, age of onset and EEG abnormality. The second method assessed severity based on current frequency and type of seizures. Their results indicated that both measures of seizure severity correlated well with the degree of psychiatric impairment (GHQ), with greater severity being associated with a greater degree of psychiatric difficulty.

However, in terms of the definition of severity, their composite measure included variables where considerable conflicting evidence exists regarding the association with various indices of psychopathology, for example, age of onset and duration of illness, which leads one to question the predictive value of each of the variables, and therefore the overall validity of the severity measures.

A study by Smith, et al (1991) assessed severity using a novel, patient-based seizure severity scale based on the patient's perception of control of their seizures (considered to be mainly influenced by their predictability) and the severity of ictal and post-ictal phenomena. Their results showed that seizure severity was related to self-esteem, locus of control and anxiety. Seizure frequency was not found to be related to any of the
psychological factors measured, although Collings (1990) found that high seizure frequency was significantly associated with low well-being (a composite measure which included similar scales to those used by Smith, et al).

Smith, et al’s operationalisation of severity has the advantage of measuring only a limited number of factors directly related to the seizures, and does not presume the importance of other illness-related factors (eg duration) to a rating of severity.

Naturally, the ‘severity of a disease’ is a relative term, and its definition will differ depending on whether one is describing its medical status as defined by physicians, its consequences for the patient’s social situation, or the patient’s subjective experience of the disease.

It is of particular importance when discussing severity of seizures and the consequences of epilepsy to make explicit what is being discussed. It would seem most useful and sensible to define the severity of a seizure in terms of its actual ictal (the attack or seizure) and post-ictal phenomena, and its predictability (eg does the person experience a warning or aura?), as these clearly form a continuum. Although this might be equated with particular types of epilepsy, and a measure of severity should be able to distinguish between types, it also goes beyond that, as two people who both have primary generalised tonic-clonic seizures will not necessarily experience seizures of equal length, or incur equal levels of injury or equal duration.
of confusion. Defining severity in terms of its impact on the individual’s life confuses it with psychosocial consequences, resulting in a concept which has little use in furthering an understanding of epilepsy and its consequences as it becomes simply tautological.

Defining severity in terms of seizure phenomena also has the advantage of providing an additional outcome measure for treatment regimens, as clinical observation indicates that anti-epileptic drugs can prevent more minor seizures (such as simple partial seizures) developing into major generalized seizures (Glaser, 1980). Using only seizure frequency as a measure of drug efficacy may therefore be misleading, as the seizures may remain as frequent, although the drug has had an impact on severity through altering the type of seizure.

A further decision must also be made when assessing severity of seizures, and that is who should make such an assessment. A physician may base a rating of severity on the diagnosis of a particular type, relying on medical knowledge of what symptoms tend to occur with such seizures, and the limited information they have from the patient. This may well not relate to how the patient perceives their experiences. The patient is in a far better position to describe the details of an event, and will tend to classify their own seizures depending on their subjective experience. As it is the patient’s psychological well-being and physical status which is hopefully of
central importance, it is logical that one assesses the patient’s perception of their seizures rather than a physician or observer.

Recent research also suggests that there is little agreement between doctors and patients regarding the severity of their illness (Slevin, et al, 1988).

Although it has been recognized that seizure severity may influence adjustment to epilepsy, and that it may be useful as an outcome measure for treatment efficacy, very little empirical research has been undertaken to investigate this.

1.3.1.2 Other seizure-related variables

Other seizure-related variables such as age of onset, duration, and aetiology have also been the focus of much research into the determinants of psychopathology in epilepsy but once again the findings are confusing and frequently contradictory. There is likely to be considerable intercorrelation among several of the neuroepilepsy variables which contributes to the difficulty in disentangling their individual impact on psychological and social factors.
1.3.2 Environmental hypotheses

The second general type of hypothesis to account for psychosocial and emotional difficulties in epilepsy is mainly environmental. Epilepsy exposes those who have it to many unique social and psychological stresses. Specific risk factors for psychosocial difficulties include stigma, discrimination, social isolation, fear of seizures, acceptance of seizures and feelings of helplessness, hopelessness and loss of control (Betts, 1981, 1982; Hermann, et al, 1990).

1.3.2.1 Stigma

Much of the literature on the consequences of epilepsy states that the disorder bears a substantial stigma, and it has long been thought to be a variable which could predispose the individual to various forms of psychopathology.

The perceptions of people with epilepsy of the disorder as stigmatizing are rooted in what they understand the common perspective of epilepsy within the lay community to be. Eighty-four percent of subjects in a study by Scambler (1984) indicated that they regarded lay people as typically ignorant, intolerant and predisposed to discriminatory practices. A study by Caveness and Gallup (1980) suggests however that public attitude has improved substantially (at least in the US) over the last 30 years, although negative attitudes do still exist; 3% still thought epilepsy a form
of insanity.

Scambler (1984) draws a distinction between 'enacted' and 'felt' stigma. Enacted stigma refers to episodes of discrimination against people with epilepsy solely on the grounds of their social and cultural unacceptability. Felt stigma has two factors. The first is shame associated with having epilepsy, which Scambler and Hopkins (1986) suggests derives from the feeling that epilepsy is evidence of imperfection. The second is the fear of encountering enacted stigma.

It is suggested that felt stigma in particular can lead to psychosocial problems, although there is very little empirical evidence to support this. One study by Arnston, et al (1986) of 357 people with epilepsy found their measure of perceived stigma to be positively and significantly related to perceived helplessness, anxiety, depression and somatic symptoms. There were also negative and significant associations with self-esteem and life satisfaction. Ryan (1980) however, has provided evidence that people with epilepsy do not feel universally stigmatized by it. Around 70% of his sample reported that they felt neither unreasonably limited, nor differently treated because of their epilepsy.

A study by Jacoby (1992) of 607 people involved in multicentre drug withdrawal study also reported small numbers of people who felt stigmatised, although their
answers to a number of questions indicate that many people felt epilepsy to be stigmatising even though few gave specific instance of discrimination or disadvantage.

1.3.2.2 Fear of seizures

Fear of seizures has also been hypothesized to be a potential contributor to psychological problems. Mittan and his colleagues (Mittan, 1983; Mittan & Locke, 1982a, b) found widespread fears of seizures and their consequences in their sample of 378 patients. Approximately 70% reported that they were afraid they might die during their next seizure and 45% lived in continual dread of seizures. Two-thirds of the sample were depressed, and Mittan postulated a causal link between fear of seizures and their consequences and anxiety, depression and other psychopathologies, and has reported that people with a relatively high level of fear of death and/or brain damage do have substantially increased levels of psychopathology (Mittan, 1986).

1.3.2.3 Acceptance of seizures

It has frequently been noted that people with epilepsy resent their seizures, have difficulty coming to terms with the disorder, are embarrassed when seizures occur and feel they are less worthy because of their epilepsy (Dodrill, et al, 1980) and it has been suggested that the degree of acceptance of the disorder is linked to various behavioural
problems, depression and hostility (Betts, 1982; Williams, 1981). Again there seems to be little empirical research on this association, although there is some circumstantial evidence from the development of the WPSI (Dodrill, et al, 1980). The intercorrelation matrix they presented shows a high correlation between 'Adjustment to Seizures' subscale, which is a measure of acceptance, and 'Emotional adjustment', suggesting an association between acceptance of seizures and psychological problems.

1.3.2.4 Control

Several researchers have postulated that individuals with epilepsy, by virtue of their lack of control over their seizures, and possibly other areas of their lives might be prone to develop learned helplessness or external locus of control (Matthews, et al, 1982). It has been shown in one study that patients with epilepsy do have significantly greater external locus of control and associated depression relative to healthy people (DeVellis, et al, 1980) and diabetic patients (Matthews, et al, 1982). Studies by Matthew and Barabas (1986), Arnston et al (1986) and Smith, et al (1991) have also found significant associations between an external locus of control and psychopathology.

An additional factor which may have an impact on several areas of adjustment is the implications for driving. A
person who is diagnosed with epilepsy must inform the driving licence authorities and relinquish their licence, until they have been free of daytime seizures for two years or nocturnal seizures for one year. This forced change in behaviour has the potential to significantly effect social and vocational adjustment.

There can therefore be pervasive psychosocial consequences of seizures including stigma, discrimination, social isolation, transportation and employment difficulties. Additional stressors include the consequences of coping with repeated episodes of loss of consciousness, often associated with embarrassment and loss of dignity, uncertainty of never knowing when a seizure will occur and the effects of all the above on psychological well-being.

Having said that, it should be noted that between 50 and 80% of seizures can be well- or completely controlled. The tendency in research on the consequences of epilepsy has been to use samples of patients with intractable epilepsy, and it has been suggested that such bias may mean that the prevalence of psychosocial problems is over-estimated (Hauser & Hesdorffer, 1990).

A study reported by Jacoby (1990) using a large sample (N=607) of people in whom epilepsy was well-controlled, the majority having been seizure-free for more than 2 years, found that levels of distress over epilepsy were low. In general the respondent emerged as being well-adjusted and
For the majority it had ceased to be a salient feature of their lives. That epilepsy did not profoundly effect the quality of life in a majority of people may be attributable to being seizure free.

A community-based study of 112 patients, assessed using the WPSI, showed a low level of psychological and social impairment, in contrast to other studies using the same measure. This was partly explained by a high proportion of the sample not having had recent seizures. Although the majority of the sample reported few problems with coping with the illness, the authors do not conclude that epilepsy poses no adjustment problems, as 19% did have an overall psychosocial functioning score indicating major problems (Trostle, et al, 1989).

Another study of 192 recently diagnosed patients receiving GP care, found that although there were fairly widespread psychosocial problems these were mild, contrasting with findings from research using participants with chronic, intractable seizures (Chaplin, et al, 1992).

Although the literature on this area is fraught with methodological shortcomings, and awash with contradictory and often inconclusive results, the overriding consensus of opinion would seem to suggest that epilepsy can have a significant impact on psychological and social well-being, and that there are a number of reasons for this. However, psychosocial difficulties are not an inevitable consequence
of such a diagnosis and it tends to be those people who continue to experience seizures who are most at risk of problems. As approximately 20% of patients do continue to experience seizures however, it is important that continued efforts are made to alleviate problems, whether this be through medical, psychological or social means.

The following section will discuss in some detail the concept of adjustment to chronic illness as there is a need within research in this area for this term to be more specifically defined and related to a theoretical framework.
1.4 The concept of adjustment

Much of the research on adjustment to chronic illness suffers from the common complaint of methodological problems, not least of which is lack of definition and appropriate operationalization of adjustment.

Frequently the terms 'adjustment' and 'adaptation' are used interchangeably as summary concepts of coping outcome, and there appears to be a lack of substantive theoretical definition, the reader being left to deduce what is meant by 'adjustment' from the outcome measures used.

In this discussion, the term 'adjustment' will be defined as the outcome of coping efforts (behavioural, cognitive and affective) aimed at reducing the potential negative impact of chronic illness.

Although the focus is on adjustment and not coping as such, it is worth mentioning Folkman's (1984) comments that 'coping refers to efforts to manage demands, regardless of the success of those efforts... The theoretical separation of coping efforts from outcomes is necessary if the coping construct is to be used to predict outcome, because when coping is confounded with outcome, any use of coping as a predictor is tautological and meaningless'. This refers to the issue of whether the concepts of coping and adjustment are seen in transactional or end-state terms. Theoretical discussions emphasise that coping and adjustment are best
viewed in process terms with bidirectional effects, and two longitudinal studies have provided evidence of the influence of adjustment on coping, indicating the likelihood of feedback cycles developing (Felton & Revenson, 1984; Filipp, et al, 1990).

However, this poses further difficulties for measurement. How are coping and adjustment to be distinguished, and how should such dynamic processes be assessed? It is necessary to consider a certain amount of stability in the two constructs for the purposes of measurement, but to recognise that they are input to and outcome from a transactional process.

Returning to the issue of definition, Wright (1990) suggests that conceptualisations of adjustment may be derived from theoretical summaries of desired end-states of the process of coping with chronic illness.

Wright suggests 4 possibilities including his own model.

1.4.1 Models of adjustment

Moos & Tsu (1977) distinguish 7 major adaptive tasks involved in coping with chronic illness; coping with physical results of illness, medical technology, communication with medical staff, preserving emotional balance, preserving satisfactory self-image, preserving relationships within the social network and preparing for an uncertain future. Although this provides a comprehensive
overview of the possible tasks an individual may be faced with, its generality poses problems for precise measurement.

Cohen (1987) proposes 3 areas in which adjustment may be assessed. Psychological, which includes anxiety, depression and well-being; social, including changes in interpersonal relationships and ability to fulfil social roles, and physiological, both short-term (eg immunological) and long-term (eg development of coronary heart disease). Wright suggests that although the scheme is useful in distinguishing these levels, consistent with the 'biopsychosocial' model of health and illness, until there is greater evidence regarding the inter-relationships between variables at these levels, the implications of the scheme for measurement are unclear.

Taylor (1983) discusses 3 themes around which the adjustment process centres: a search for meaning in the experience, an attempt to regain mastery over the event in particular and over one's life in general and an effort to restore self-esteem through self-enhancing evaluations.

Although it would seem useful to consider such cognitive adaptations when considering the concept of adjustment, chronic illness would also seem to require behavioural adaptation which this model does not address directly. It also poses some problems for measurement.

Wright (1990) attempts to provide a comprehensive overview,
and distinguishes between two levels of coping outcome.

Primary (illness-related) outcome is concerned specifically with acceptance of illness, adherence to medication and behavioural adaptation (i.e., the extent to which behavioural methods are employed to counteract the potentially disabling aspects of illness). In this scheme, adaptation and acceptance are defined specifically as first-order behavioural and cognitive/affective outcomes respectively of responses to illness and treatment.

Higher-order outcomes (subjective well-being and self-perceived health status) are those which might be expected to be influenced by the illness, but which are not specifically related to illness, and are likely to reflect the contribution of a variety of factors unrelated to illness.

Figure 1. presents the model in diagrammatic form.
Higher-order outcomes

Self-perceived health status

Subjective well-being

(Illness status)

Adherence Adaptation Acceptance

Coping

Primary outcomes

Figure 1. A process-oriented conceptual model of coping and its outcomes in chronic physical illness

The model at present suggests some links between the various outcome elements. Wright proposes that adherence and adaptation will influence perceived health status (via illness status) presumably as poor adherence and adaptation are likely to result in a deterioration or exacerbation of the condition, and therefore to have an impact on the current health status of the individual.

Adaptation and acceptance are thought likely to be reflected in subjective well-being. As previous research had indicated that poor acceptance of seizures is associated with poorer psychological well-being (Hermann,
et al, 1990) such a link would seem appropriate. It is not clear whether adaptation might be associated with subjective well-being because changes in valued behaviours or activities are made necessary by illness and this results in poorer psychological state, or because despite behavioural changes being necessary or desirable, these are not made and consequently this poorer adaptation has an impact on psychological state, particularly perhaps on anxiety.

Illness status is included in this model and it is suggested that it would be assessed at the level of the person rather than of the organ or body systems, using measures of symptom indices such as the Sickness Impact Profile (Bergner, et al, 1981). This is mainly for pragmatic reasons as there are few measures of disease severity. Presumably however, a measure of illness-specific severity if available could be included here. Inclusion of this physical measure highlights the process nature of chronic illness, coping and adjustment.

The conceptualisation of adjustment is thought of as a summary of primary outcomes, equivalent to a composite of acceptance, adaptation and adherence, although it is not clear whether these will be, or are meant to be considered as statistically related. At this stage in its development, the model does not make explicit links between the primary outcome variables. Empirical research is needed to allow comment on the model and to contribute to its development.
This theoretical scheme requires that several constructs relevant to coping outcomes are assessed within each level. The definition of each outcome allows for the use, almost entirely, of existing measurement tools, thereby overcoming one of the difficulties faced by other schemes in finding appropriate measurement tools for their constructs.

Variables which might be measured in the higher-order level outcome of subjective well-being include happiness (positive/negative affect), self-esteem, anxiety, depression and life-fulfilment.

The maintenance of a balance of positive feeling towards one's life and self whilst in the process of contending with stress is considered an important consequence of effective coping (White, 1974). A person's position along such a dimension of avowed happiness or feeling of psychological well-being can be seen as resulting from their position on two independent dimensions, one of positive affect and the other of negative affect (Bradburn, 1969). This model suggests that an individual will be high in psychological well-being/happiness if he or she has an excess of positive over negative affect. The factors which contribute to positive affect have been shown to differ from those which create feelings of dissatisfaction (see Costa & McCrae, 1980), therefore it is necessary to measure both positive and negative components of well-being.

Feelings of self-worth and acceptance are considered to be important to an individual's positive well-being and
adjustment. Diagnosis of a chronic and stigmatizing illness can have a significant impact on a person's self-image and self-esteem. Low self-esteem and a feeling of loss of control over their lives can be features of people with epilepsy (Arnston, et al., 1986). As discussed by Taylor (1983), when faced with the threat of a chronic illness/disorder, part of the process of adjustment will include efforts to enhance one's self-esteem. The results of these efforts are therefore important indicators of adjustment.

Anxiety and depression can be common consequences of chronic illness, and are frequently cited as correlates of epilepsy, warranting inclusion in an overall assessment of adjustment.

Life-fulfilment/satisfaction can be thought of as a component of the 'quality of life' construct, which has been of increasing interest to researchers and clinicians over the recent years. An individual's subjective feeling about the quality of the life they live while coping with chronic illness is becoming an important factor to consider when planning and evaluating treatment strategies in particular, and as a consequence of chronic illness in general (Burckhardt, et al., 1989). However, the concept has immense problems with definition and research has yet to agree on a common instrument that can be used across client groups. However, some common dimensions have been identified, which people feel are important to their
quality of life. These include physical and material well-being, relations with other people, participation in social, community, and civic activities, recreation and personal development and psychological well-being.

Life-fulfilment can then be seen as an aspect of quality of life, but can not be equated with quality of life, as this would also need to include physical and psychological status. Life-fulfilment should be viewed as a higher-order outcome measure, which is likely to reflect factors both related and unrelated to illness. For the purposes of this study it is defined as a measure of satisfaction with a variety of aspects of life including, relationships, housing, participation in social activities, personal self-worth, job and financial status.

Subjective well-being will therefore consist of a variety of variables considered to be important in psychological adjustment to chronic illness.

Self-perceived health status is a higher-order outcome measure which might reasonably be expected to be influenced by the chronic illness in question, but is also likely to reflect the contribution of other factors unrelated to the illness, particularly in the case of epilepsy, due to its episodic nature.

A further advantage of Wright's scheme, in addition to that of measurement, is that it provides a comprehensive framework, recognising that behavioural, cognitive and
affective factors specific to the illness are important as indicators of adjustment, as well as measures of psychological well-being. Many studies focus only on psychological factors (which in this scheme would be considered higher-order outcomes), and do not consider the behavioural, illness-related factors as additional measures of adjustment (eg Arpin, et al, 1990).

Occasionally acceptance of illness (eg Felton, et al, 1984) has been included as a measure of adjustment, along with one or two psychological variables, but there does not seem to be research which measures a variety of adjustment factors based on a comprehensive framework.

Although Wright considers subjective well-being to be a composite of the various psychological variables mentioned, he does not explicitly state that this should be considered as part of a definition of adjustment. The researcher suggests an extension to the conceptualisation of adjustment that includes a second composite measure of psychological adjustment (the subjective well-being outcome measure of the model), seen as a summary of levels of anxiety, depression, happiness, life-fulfilment and self-esteem.

Adjustment is therefore operationalized as consisting of primary, illness-related adaptation, adherence and acceptance, higher-order psychological well-being and self-perceived health status.
When undertaking research on adjustment, whether it be to a chronic illness or other life stresses, it is important to bear in mind the myriad of influences there will be on the outcome measures other than the independent variable(s) under consideration. Although background factors can be measured and their potential effects controlled statistically, it is not possible or necessarily desirable or appropriate to include all possible variables which may contribute to the outcome.
**Summary of definitions**

Adjustment - the outcome of coping efforts (behavioural, cognitive and affective), aimed at reducing the potentially negative impact of chronic illness.

Adaptation - the extent to which behavioural changes have been made to avoid risk associated with the illness or to avoid exacerbation of the illness.

Adherence - compliance with medical advice or treatment regimens.

Acceptance - a cognitive/affective outcome of coping which refers to the extent to which the person has come to terms with the illness and its consequences on their life.

Primary outcomes - outcomes which are specific to illness (adaptation, adherence & acceptance).

Higher-order - outcomes which are likely to be influenced by the illness, but which are not specifically related to illness; likely to reflect the contribution of a number of factors unrelated to illness (subjective well-being & self-rated health status).
1.5 Rationale

A wide variety of factors, both neurological and environmental, have been considered to influence a person’s adjustment to epilepsy, and to contribute to the secondary problems which have been documented.

Although severity of seizures has been recognized as a factor which may influence adjustment to epilepsy and which therefore may be an important variable to consider in assessing treatment efficacy, and for identifying patients who may benefit from psychoeducational interventions, little research has been undertaken to investigate this relationship.

The study by Smith, et al (1990) which utilizes an appropriate, patient-rated measure of severity, whilst giving an indication of the relationship between severity and some psychosocial factors, does not investigate the contribution to overall adjustment to the disorder.

Much of the research on adjustment to chronic illnesses in general, as well as on epilepsy in particular, has methodological difficulties with definition, operationalisation, and measurement of the term adjustment.

A study of adjustment to chronic illness which is based on a comprehensive conceptual framework would be of value in furthering understanding of the influence of particular variables on the wide range of factors which are considered important indicators of the success or otherwise of efforts
aimed at coping with a chronic illness. The use of such a model of adjustment would in addition allow assessment of the value of such a comprehensive framework in research of this nature.

A study which considers the relationship of seizure severity to overall adjustment, using such a comprehensive framework would contribute to the body of knowledge regarding epilepsy and its consequences, and in addition may provide information relevant to the identification of patients who could benefit from psychoeducational treatment programmes.
1.6 **AIMS OF PRESENT STUDY**

This study attempted to investigate the relationship between seizure severity as rated by the patient and adjustment to epilepsy.

The aims of the study were:

1) to investigate whether there is an association between seizure severity and adjustment to epilepsy, as measured by a comprehensive set of variables considered of relevance in adjustment to a chronic illness.

2) to determine whether these adjustment variables are related

3) to determine the feasibility of combining the individual adjustment variables into composite measures of illness-related adjustment and psychological adjustment, which would allow a summary statement to be made of an individual's overall level of adjustment.

4) to consider the value of using this particular comprehensive conceptual framework to operationalize and measure adjustment.
1.7 Hypotheses

1) Greater seizure severity will be associated with poorer adjustment, as measured by individual illness-related and psychosocial measures of adjustment. Greater seizure severity will therefore be associated with higher levels of anxiety and depression, lower levels of self-esteem, happiness and life-fulfilment, lower levels of behavioural adaptation, adherence to medication and acceptance of seizures and poorer compliance.

2) There will be a significant association between the individual components of adjustment.

3) Exploratory data analysis will reveal that the individual components of adjustment can be described and calculated as composite measures of illness-related adjustment and psychological adjustment.

4) The comprehensive model of adjustment will be found to be of value in the operationalization and measurement of adjustment.
2.0 **METHOD**

2.1 **Design**

The study used a within-subjects correlational design to test for an association between seizure severity and individual measures of adjustment (anxiety, depression, self-esteem, happiness, life-fulfilment, acceptance, adaptation, adherence and self-rated health status); seizure severity and composite measures of adjustment and for associations between individual adjustment variables.

Exploratory data analysis was used to consider the statistical validity of combining individual adjustment variables into composite measures of adjustment.

2.2 **Participants**

The sample consisted of patients with a diagnosis of epilepsy, who attended either a general hospital neurology outpatient clinic or the outpatient clinic of a neurological hospital. Patients were included if they had had diagnosed epilepsy of any type for more than 1 year and if they had experienced at least 1 seizure within the previous 6 months. Patients were excluded if they were under 16 years, had significant learning difficulties, such that completion of the questionnaire was not possible or if they were experiencing psychiatric difficulties for which they were receiving psychiatric help. The latter information was obtained from the medical notes or from the
medical physician.

Fifty-five people with epilepsy participated in this study. Of these, 23 (42%) were men and 32 (58%) were women. The sample had a mean age of 38 years (SD = 13.8) with a range of 19 to 72 years. Fifty-eight per cent of the sample were married, 25 percent single and the rest were either divorced/separated or widowed. Twenty-four people (43%) were either in part-time or full-time employment, twelve were housewives and the rest were either on permanent sick, unemployed or retired.

Checks were made on the comparability of these groups across measures of adjustment.

2.3 Measures

Each participant in the study completed a questionnaire battery consisting of a measure of seizure severity, three illness-specific adjustment scales, five measures of psychological well-being, and other questions relating to their epilepsy and background (Appendix II).

2.3.1 Seizure severity

Seizure severity was measured using a patient-rated scale which has been developed recently as a potential outcome measure in the evaluation of treatment of intractable epilepsy (Baker, et al., 1991).
The scale consists of 19 items, divided into 2 sub-scales: perception of control (9 questions) and ictal and post-ictal effects (10 questions). The first scale (percept) includes questions about timing of seizures (nocturnal, any time of day, at random or in clusters), the presence of an aura and whether the patient could predict the seizure and hence minimize the consequences. The second (ictal) scale included questions about loss of consciousness, confusion, incontinence, injury, and prevention of normal activity. Each question is rated on a 4-point Likert scale where 1 is the least severe score and 4 the most severe.

A score is obtained for each sub-scale. The range of possible scores for the percept sub-scale is from 9 to 36 and from 10 to 40 for the ictal sub-scale.

The test-retest reliability coefficient for the scale is 0.79 for the percept sub-scale and 0.8 for the ictal scale confirming consistency over time. Cronbach's alpha was 0.69 for the percept scale and 0.85 for the ictal sub-scale confirming internal consistency.

Preliminary findings suggest that the scale is valid, in that is able to distinguish between seizure types.
2.3.2 **Primary (illness-related) outcome measures of adjustment**

2.3.2.1 **Adherence**

A self-report measure of adherence to the medication regimen was used, which asked participants to indicate how frequently they forgot to take their medications from 'Never' to 'Miss tablets more often than once a week'. Patient report is the most commonly used measure of compliance (adherence). A review of investigations conducted over a 6 year period (Caron, 1985) found that patient report was used as either the sole criteria or one of the criteria of compliance with medication in 68%.

2.3.2.2 **Acceptance**

This illness-specific cognitive/affective outcome variable was assessed using the 'Adjustment to Seizures' subscale of the Washington Psychosocial Seizure Inventory (WPSI). The WPSI consists of 8 subscales designed to measure the effect of epilepsy on a variety of psychosocial factors. Each subscale is considered reliable and valid independent of the other scales. The 'Adjustment to Seizures' subscale has a test-retest reliability coefficient of 0.70, and split-half reliability of 0.88, indicating that it is reliable across time and has internal consistency. The validity coefficient derived from professional ratings is 0.66, (p=.01).
In addition, the WPSI has been widely used since its construction in 1980. In the last 10 years, there have been 40 published studies which have used the WPSI or its subscales, contributing to the reports of reliability and validity.

The scale consists of questions which can be considered to reflect the patient’s cognitive and emotional response to epilepsy, such as 'Do you feel resentful that you have seizures?' and 'Are you concerned people won't like you or want you around after a seizure?'. They are answered simply 'Yes' or 'No', with a range of scores from 0-10, with a higher score indicating lower acceptance of their epilepsy.

2.3.2.3 Adaptation

Adaptation refers to behavioural changes which may be necessary to counteract or avoid potentially dysfunctional aspects of illness. In the case of epilepsy, this might refer to changes in behaviours known to trigger seizures or behaviours which are potentially dangerous considering the nature of the disorder. As no scale was found which specifically measures this aspect of adjustment, it was necessary for the researcher to develop one.
Development of the adaptation questionnaire

Items were selected initially after discussion with a neurologist and a study of the literature regarding trigger factors and potentially risky behaviours. These were then listed in a 2-part questionnaire. As not all behaviour changes would apply to all patients with epilepsy, it was not appropriate to simply ask whether each change in behaviour/lifestyle had occurred or how often such behaviours were avoided, as a negative response may simply mean that the particular item is not applicable to that patient, rather than reflecting poorer adaptation. Instead, patients were asked how important they felt it was for them to avoid each particular activity/behaviour because of their epilepsy and in the second section, how often they were able to avoid these, recognising that people can not always avoid certain activities even if they do consider them important to the state of their disorder.

Each item was answered on a 4-point scale and a score obtained by subtracting the ‘actual’ behaviour score from the ‘important’ score. This yielded discrepancy scores which could then be summed to give a total adaptation score.

The questionnaire was then piloted on 6 patients with epilepsy who were asked to complete the scale and to add any further changes which they felt had been important for them to make because of their epilepsy. No further items were added following the pilot, and no comments were made
on the style or presentation of the questionnaire or instructions. The questionnaire was also given to 7 trainee Clinical Psychologists for comment on format and ease of comprehension.

The questionnaire was subsequently checked for reliability using a test-retest method. Twelve patients completed this procedure over a 2 week period and the reliability coefficient was 0.7.

The questionnaire was considered to have face validity, as it appeared to contain items which are pertinent when adapting behaviourally to a diagnosis of epilepsy. Content validity might be assumed from the method of construction, taking into account information from the literature, a neurologist and people with epilepsy, although there may still be other items which could be included. It was not possible to assess criterion-related validity as no other measure was found against which this could be measured.

2.3.3 Higher-order (subjective well-being and self-perceived health status) outcome measures

2.3.3.1 Happiness

The Affect Balance Scale (Bradburn, 1969) was chosen to measure happiness or well-being as it is designed to measure both positive and negative affect.
The Affect Balance Scale (ABS) has been widely used in studies on psychological adjustment and illness. Felton & Revenson (1984) used it as a measure of well-being in their sample of patients with various chronic illnesses and it has been used in studies looking specifically at epilepsy and its psychosocial consequences (Collings, 1990; Smith, et al, 1991).

The scale consists of 10 items divided into two 5-item subscales measuring positive and negative affect. A Yes/No choice is used for scoring. Several methods have been used to obtain an overall score, and the method used by Smith, et al (1991) was adopted in this study to allow comparison if necessary. Each item is scored either +1 or -1 depending on whether it occurred or not and whether the item is positive or negative. Once summed, this leads to a range of scores from -10 to +10, reflecting the balance of positive or negative items. Higher scores indicate greater well-being or happiness.

2.3.3.2 Self-esteem

Rosenberg's self-esteem scale (Rosenberg, 1965) was used to evaluate the individual's overall sense of being capable, worthwhile and competent. This 10-item scale was initially designed for use with adolescents, but has been widely used with adult samples and found to have high construct validity (Robinson & Shaver, 1973). It has also been shown to have a reproducibility coefficient of .92 (Rosenberg,
1965) and a test-retest coefficient of .85 (Silber and Tippett, 1965). This shows high reliability for a short scale.

In their study of adults with one of four chronic illnessess, Felton & Revenson (1984) found that the scale produced a coefficient alpha of .81.

Each item is answered using a 4-point agree-disagree format. The possible range of scores is between 10 and 40, with higher scores indicating higher self-esteem.

2.3.3.3 Anxiety and depression

The Hospital Anxiety and Depression scale (HAD) (Zigmond & Snaith, 1983) is a brief assessment of both anxiety and depression for use with an outpatient population. It was considered an appropriate measure as it specifically excludes somatic items and concentrates instead upon cognition and affect which increases its validity amongst a medical population. The scale has been found to be widely acceptable with non-psychiatric medical patients (Wallace & Lees, 1987; Maguire & Selby, 1989). Test-retest reliability and internal consistency have been demonstrated (Zigmond & Snaith, 1983) and 'cut-off' points are available for the establishment of psychiatric 'caseness'.

The test consists of two 7-item subscales for anxiety and depression, scored on a 4-point scale. The range of scores is 0-21 for each subscale and the authors suggest a cutoff
point of 9 for establishment of caseness. Higher scores indicate higher levels of anxiety and depression.

2.3.3.4 Life-fulfilment

A new life-fulfilment scale devised by Baker (1992) was used as it has advantages in its construction over other measures of life satisfaction and has been used specifically with people with epilepsy. Preliminary findings suggest it is a valid and reliable scale. The results from this study show that it has a Cronbach's alpha of .8 which indicates a good level of internal consistency.

Life-fulfilment is measured in a variety of areas including family life, relationships, housing, finance, health and employment. Participants first rate the importance of 13 aspects of life on a 4-point scale and then indicate how satisfied they are with each aspect on a 4-point scale. An 'ideal' score for each aspect is calculated by multiplying the 'importance' score by the highest possible satisfaction score (ie 4). An 'actual' score is then calculated by multiplying the 'importance' score for each aspect by the 'satisfaction' score for the corresponding aspect. The 'actual' score is then subtracted from the 'ideal' score to obtain a discrepancy score. These are then summed to obtain and overall life-fulfilment score. Fulfilment is then operationalised as the discrepancy between the actual and the ideal circumstances.

This method is similar to that developed by Krupinski
(1980) and acknowledges that not all areas of a life are equally important to people. Most life satisfaction measures do not account for this and simply ask respondents to rate their satisfaction with a particular aspect whether it is important to them or not.

The scores range from 0 to 156, with higher scores indicating lower life fulfilment.

2.3.3.5 Self-perceived health status

This was measured using a visual analogue scale of the participant's current health from poor to perfect. The participants also rated how satisfied they were with their current health status and what they considered the average health status of someone of their age and sex. This was to provide a context against which to evaluate their current self-ratings.

2.3.3.6 Overall self-rated adjustment

Participants were asked to rate how well they felt they had adjusted to having epilepsy on a visual analogue scale. This was included to see whether simply asking a patient how well they had adjusted was correlated with the other measures of adjustment.
2.3.4 Measures of epilepsy

These included seizure type (major, minor or both), seizure frequency, age of onset and duration. A diagnosis of epilepsy type was obtained where possible from the patient’s notes.

2.3.5 Additional information

Information was gathered on age, sex, marital status and employment status.

2.4 Procedure

The consultant neurologist at a large district general hospital was initially approached and the aims of the study discussed with him. He gave permission for his patients to be interviewed and suggested that if there were problems obtaining sufficient participants, a further source might be the Neurological Hospital in a neighbouring health district. Consequently, the proposal was discussed with 2 consultant neuropsychiatrists at this hospital who both agreed to participate in the study.

The proposal was submitted to both Health Authority Ethics Committees and approval obtained from both.

The procedure differed slightly between the two locations of the general hospital or the neurological hospital. Data collection took place between April 1992 and October 1992.
At the general hospital the researcher attended one general neurology outpatient clinic each week during the period of data collection. At each clinic, suitable participants were identified from the medical notes and brought to the attention of the consultant neurologist or his junior staff. The medical staff briefly explained what the study was about and asked each patient whether they would be willing to talk to the researcher about it further.

The patient was then given a full explanation of the research and asked if they would be willing to participate. An interview room was available in the outpatient department for the participants to complete the questionnaire immediately if they had sufficient time. The researcher remained with them whilst they completed the information so any questions could be dealt with immediately.

At the neurological hospital, suitable patients were identified from the medical notes prior to clinic, as it was not possible for the researcher to attend a second weekly outpatient clinic. Letters were then sent to patients outlining the research and noting the support of the consultants at the hospital (Appendix I). They were told that the researcher would be available at their outpatient appointment for further information. These patients were then approached at the clinic and the aims and practicalities reiterated. If patients agreed to participate, they were asked to complete the questionnaire.
at that time, again in an interview room with the researcher present.

In both settings, a small number of participants were unable to remain after their appointments to complete the questionnaire, but were willing to return it by post. In each case all the items within the questionnaire were explained by the researcher before they left and a stamped addressed envelope provided.

2.5 Analyses

The initial descriptive analyses computed the mean responses of the sample for each of the variables considered. This was followed by a correlational analysis which considered the interrelationships between all the variables which had interval data, using Pearson's product-moment correlation. Eta was used to test for associations between variables with less than interval data.

Exploratory principal components analysis was used to consider the factorial validity of constructing composite scales of adjustment.

Factor analysis techniques can assess the degree to which a set of variables (eg individual questions, scores on psychological tests) are tapping the same concept. Factor analysis is concerned with the description and interpretation of interdependencies within a set of

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variables, and achieves this by reducing the original set of variables to a smaller number called factors, which may be viewed as source variables which account for the intercorrelations observed in the data (Ferguson & Takane, 1989). The procedures are all strictly statistical; the factors that emerge from an analysis still have to be subjectively examined to determine whether they represent salient psychological dimensions.
3.0 RESULTS

3.1 Data screening and manipulation

Data were screened to check they did not violate assumptions of normality and for outliers. Small deviations in the distribution of data were not considered for transformation. The measure of adherence showed insufficient dispersion to be included in the analysis.

The outlier on the measure of life-fulfilment was changed so it was close to the next, non-extreme score (Tabachnic, & Fiddell, 1989).

In order to maximise the numbers of participants in the analysis, the sample was not divided into sub-groups according to seizure type. One-way analysis of variance indicated that there were no significant differences between types (major/minor/both) on measures of adjustment, so it was considered acceptable to ignore this classification.

For those who had both major and minor seizures, the severity score for major seizures was used (the severity measure allows for severity of both seizure types to be rated). This followed from the study by Smith, et al (1991) where patients who had more than one seizure type were asked to complete the severity scale with respect to the type that they felt to be more severe, unless this type occurred very rarely. As would be expected, for the group who had both types, 'major' seizures were rated as...
significantly more severe than 'minor' seizures and therefore were selected for inclusion in the analyses.

T-tests and Mann-Whitney U tests indicated that the groups 'major' only and 'major-both' did not differ significantly in seizure severity (percept: \( t=0.88; \ p=0.386 \); ictal: \( t=0.26; \ p=0.793 \)) or frequency (\( U=93.0; \ p=0.483 \)). It was therefore felt acceptable to collapse the type variable into 'major' and 'minor' groups which allowed continuous severity scores across the entire sample.

### 3.2 Demographic variables: adjustment and seizure-related information

One-way ANOVA and t-tests indicated that life-fulfilment was the only adjustment variable which demonstrated differences within demographic groups (sex, marital status, employment status and age). For the ANOVAs, the Scheffe procedure was used to identify whether there were significant differences in means within the groups and where these lay.

Males were identified as being less fulfilled than females, \( (t=2.28; \ p=0.015) \), as were people who were divorced compared to the group who were married \( (t = 3.94; \ p = .0001) \). The unemployed group were less fulfilled than either those who were employed or housewives \( (F = 4.81; \ p=0.0012) \). There were no significant differences between
the groups on duration of seizures, age of onset, seizure severity (percept or ictal scales), or seizure frequency.

3.3 Descriptive statistics: Seizure-related variables

Table 2. provides information relating to seizures. Seizure type refers to patient-rated classification. Insufficient information was available in medical notes to obtain specific diagnoses.

<table>
<thead>
<tr>
<th>Type</th>
<th>Major</th>
<th>Minor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>30 (55%) *</td>
<td>25 (45%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Major</th>
<th>Minor</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 1 per year,</td>
<td>16 (53%)</td>
<td>6 (26%)</td>
</tr>
<tr>
<td>&lt; 1 per month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 1 per month</td>
<td>9 (30%)</td>
<td>7 (38%)</td>
</tr>
<tr>
<td>&lt; 1 per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 1 per week,</td>
<td>5 (17%)</td>
<td>6 (17%)</td>
</tr>
<tr>
<td>&lt; 1 per day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On average,</td>
<td>0</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>&gt;1 per day</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2. Frequency, means, standard deviations and ranges of seizure-related information.
Table 2. continued

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percept</td>
<td>27.15</td>
<td>4.39</td>
<td>18 - 34</td>
</tr>
<tr>
<td>Ictal</td>
<td>23.18</td>
<td>8.66</td>
<td>10 - 37</td>
</tr>
<tr>
<td><strong>Duration (years)</strong></td>
<td>17.78</td>
<td>14.52</td>
<td>1 - 55</td>
</tr>
<tr>
<td><strong>Age at onset (years)</strong></td>
<td>20.24</td>
<td>15.53</td>
<td>0 - 63</td>
</tr>
</tbody>
</table>

* This figure includes 13 participants with major seizures only and 17 who also experience minor seizures.

Investigation of the associations between these seizure-related variables and the measures of adjustment indicate that duration is significantly but weakly positively correlated with happiness, .24 (p<.05), and life-fulfilment -.29 (p<.05), and negatively correlated with depression -.24 (p<.05). The direction of scoring on the life-fulfilment measure (ie higher scores equal poorer life fulfilment) means that the actual correlation coefficients are negative, but are interpreted in the opposite direction.

Analysis of seizure type (major or minor), now there are two rather than three categories, shows that there is a significant difference between major and minor seizures in
levels of anxiety ($t = 2.25; p < .05$). The mean scores and standard deviations for major and minor seizures are 10.2 (4.69) and 7.6 (3.85) respectively. There is also a significant difference in ratings of health status ($t = -2.28; p < .05$). The mean score on this variable for major seizures is 4.8 (2.85) and for minor seizures, 6.5 (2.21). Age of onset and seizure frequency are not associated with any of the adjustment variables.

In addition, there is a significant difference between major and minor seizures on scores of percept severity ($t = 2.64; p < .01$) and ictal severity ($t = 9.79; p < .0001$) as would be expected. Mean scores for major and minor seizures for percept severity are 28.5 (4.48) and 25.5 (3.73) respectively and for ictal severity are 29.5 (5.39) and 15.6 (4.00) respectively. Ictal severity is also associated with duration $-0.22$ ($p < .05$).
3.4 Descriptive statistics: Adjustment variables

Table 3. gives the mean scores for each of the variables considered.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happiness</td>
<td>1.42</td>
<td>5.06</td>
<td>-10 - 10</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>28.09</td>
<td>5.28</td>
<td>18 - 40</td>
</tr>
<tr>
<td>Anxiety</td>
<td>9.00</td>
<td>4.49</td>
<td>0 - 20</td>
</tr>
<tr>
<td>Depression</td>
<td>4.67</td>
<td>4.20</td>
<td>0 - 16</td>
</tr>
<tr>
<td>Life-fulfilment</td>
<td>51.89</td>
<td>22.99</td>
<td>10 - 99</td>
</tr>
<tr>
<td>Acceptance</td>
<td>3.98</td>
<td>2.68</td>
<td>0 - 10</td>
</tr>
<tr>
<td>Adaptation</td>
<td>2.16</td>
<td>2.29</td>
<td>0 - 9</td>
</tr>
<tr>
<td>Self-rated health status</td>
<td>5.58</td>
<td>2.68</td>
<td>0 - 10</td>
</tr>
<tr>
<td>(Av. health status of person of same age and sex)</td>
<td>7.03</td>
<td>2.54</td>
<td>0 - 10</td>
</tr>
</tbody>
</table>

Table 3. Means, standard deviations and ranges of adjustment variables and severity measures

The results from the psychological adjustment variables indicate that 42% of the sample were experiencing significant anxiety (scoring 9 or above, the cutoff for caseness), and 16% were significantly depressed. A division of self-esteem into low (scores between 10-20), medium (between 20 and 30) and high (30 to 40) levels, indicates
that only 3 people in the sample scored below 20, and fifty percent show a balance of positive over negative affect. The recent construction of the life-fulfilment scale does not allow categorisation as of yet.

The primary, illness-related outcome measures indicate that approximately half (49%) of the sample have definite problems with acceptance of their seizures (scoring 4 or above) but that the majority of people are very well behaviourally adapted to epilepsy (94% scoring below 8/24). The self-report measure of adherence indicates that only 12 people (22%) admitted to missing their tablets at any time, and only one of these people missed tablets more frequently than once a week. Comparison of the group who never miss with those who miss at some time indicates that there are no significant differences on any of the measures considered.

The measure of current health status shows that 37 per cent of the sample rated their health as 5 or below indicating a below average perceived level of health. Forty-two per cent indicated dissatisfaction with their current health status (rating of 5 or below). There was a significant difference between the mean scores on ratings of current health and perceived health status of people of the same age and sex ($t = -4.84; p < .0001$).
3.5 Hypothesis 1 - Greater patient-rated seizure severity will be associated with poorer adjustment, as measured by a variety of illness-related and psychological adjustment variables.

Table 4. shows the results of the correlations between the two measures of severity and the individual adjustment variables. As a reminder, the scales of depression, anxiety, and life-fulfilment are scored so that higher scores indicate poorer well-being.

<table>
<thead>
<tr>
<th>Happy</th>
<th>Sesteem</th>
<th>Anxiety</th>
<th>Depress</th>
<th>Fulfil</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percept</td>
<td>-.07</td>
<td>-.09</td>
<td>-.04</td>
<td>.36**</td>
</tr>
<tr>
<td>Ictal</td>
<td>-.26*</td>
<td>-.17</td>
<td>.18</td>
<td>.25*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adapt</th>
<th>Accept</th>
<th>Health</th>
<th>Adjust (self-rated)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percept</td>
<td>.04</td>
<td>.24*</td>
<td>-.24*</td>
</tr>
<tr>
<td>Ictal</td>
<td>.11</td>
<td>.40**</td>
<td>-.32*</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01

Table 4. Correlations of seizure severity scores and measures of adjustment.

The severity percept scale (perception of predictability and control) correlated with two psychological adjustment measures, depression .36 (p<.01), and life-fulfilment .26
(p<.05), one of the illness-related adjustment measures, acceptance of seizures .24 (p<.05) and self-rated health status -.24 (p<.05).

The severity ictal scale (ictal and post-ictal phenomena) correlated with happiness -.2647 (p<.05), depression .2460 (p<.05) and life-fulfilment .2666 (p<.05). In addition to acceptance .4005 (p<.01), the ictal scores also correlated with self-rated health status -.3158 (p<.05).

All correlations were in the expected direction.

3.6 Hypothesis 2. There will be an association between the individual components of adjustment.

It can be seen from Table 5. that all the psychological adjustment measures are highly intercorrelated. The two illness-related adjustment variables are only weakly associated .22 (p<.06). In addition, acceptance of seizures is correlated with all the psychological adjustment measures and self-rated health status. The latter measures is correlated with all the adjustment measures. The overall self-rated adjustment VAS score is correlated with all the five psychological measures, but is most strongly correlated with acceptance of seizures -.51 (p<.001).
<table>
<thead>
<tr>
<th></th>
<th>Adapt</th>
<th>Accept</th>
<th>Happy</th>
<th>Sesteem</th>
<th>Anxiety</th>
<th>Depress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapt</td>
<td></td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accept</td>
<td></td>
<td></td>
<td>-.17</td>
<td>-.51***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Happy</td>
<td>-.25*</td>
<td></td>
<td>-.51***</td>
<td>0.71***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sesteem</td>
<td>0.28*</td>
<td></td>
<td>0.53***</td>
<td>-.69***</td>
<td>-.63***</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td>0.56***</td>
<td>-.60***</td>
<td>-.61***</td>
<td>0.57***</td>
<td></td>
</tr>
<tr>
<td>Depress</td>
<td>0.32*</td>
<td></td>
<td>0.66***</td>
<td>-.55***</td>
<td>-.59***</td>
<td>0.46***</td>
</tr>
<tr>
<td>Fulfil</td>
<td>0.25*</td>
<td></td>
<td>-.48***</td>
<td>0.29*</td>
<td>-.38**</td>
<td>-.54***</td>
</tr>
<tr>
<td>Health</td>
<td>0.34*</td>
<td></td>
<td>0.33**</td>
<td>.46***</td>
<td>-.24*</td>
<td>-.23*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Fulfil</th>
<th>Health</th>
<th>Adjust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fulfil</td>
<td>-.43***</td>
<td>-.34**</td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td>0.30*</td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; ** p < .01; p < .001 (1-tailed significance)

**Table 5. Correlations of psychological and illness-related adjustment variables.**
3.7 **Hypothesis 3. Exploratory factor analysis will reveal that the individual components of adjustment can be described and calculated as composite measures of illness-related and psychological adjustment.**

The adjustment variables were factor analysed using principal components analysis. The initial factors produced suggested that the variance accounted for by the first factor is 4.416 or 55.2 per cent of the total variance, with a further 12.4 per cent being contributed by the second factor. Which factors to retain is usually decided by Kaiser's criterion which selects those factors which have an eigenvalue of greater than one. As the total variance that any one variable can have is standardized as one, this means that a factor which explains less variance than a single variable is excluded. In this analysis only the first factor had an eigenvalue greater than one. However, the eigenvalue of the second factor was .98875 and it was therefore decided to retain this factor.

These factors were then rotated using the oblimin procedure which produces oblique or related factors. This procedure was selected as it is likely that these factors will be related and orthogonal rotation may result in a more artificial solution. The results of this procedure are presented in Table 6. and show that the psychological variables and the acceptance of seizures variable load most strongly on the first factor and adaptation and health
status on the second.

<table>
<thead>
<tr>
<th></th>
<th>FACTOR 1</th>
<th>FACTOR 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy</td>
<td>-.93273</td>
<td>.23317</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>-.86479</td>
<td>.07158</td>
</tr>
<tr>
<td>Depression</td>
<td>.77209</td>
<td>.10596</td>
</tr>
<tr>
<td>Fulfilment</td>
<td>.76220</td>
<td>.10086</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.75924</td>
<td>.11254</td>
</tr>
<tr>
<td>Accept</td>
<td>.71191</td>
<td>.13140</td>
</tr>
<tr>
<td>Adaptation</td>
<td>-.06572</td>
<td>.89654</td>
</tr>
<tr>
<td>Health</td>
<td>-.31474</td>
<td>-.60610</td>
</tr>
</tbody>
</table>

Table 6. Item loadings on obliquely rotated factors

The results from this analysis suggest that the psychological variables relate to the same concept which might be thought of as 'subjective well-being'. However, in addition, the analysis suggests that acceptance of seizures also relates to the same concept. Although this variable is related to the psychological variables, in terms of the aim of constructing a composite psychological adjustment or well-being scale, inclusion of this illness-related variable would not be useful in clarifying or simplifying the operationalization of adjustment. It was therefore excluded from the composite measure.

The second factor on which adaptation and health status
load does not represent a salient dimension.

The results therefore suggest that only a composite scale of psychological adjustment may be constructed, and not a composite scale of illness-related adjustment.

The scale was constructed by converting the individual adjustment scores into T-scores \((z \text{-scores} \times 10) + 50\). This means that all the measures have standardized scores which are whole numbers and without negative values. The psychological variables were then summed to produce a composite psychological adjustment score, with a mean of 250 (15.8) and a range between 222 and 291.

Tests of association between the composite measure of adjustment and seizure related and background variables indicated that psychological adjustment is associated with percept severity \((r = .25; p < .05)\), but none of the other seizure-related or demographic variables. It is also associated with acceptance of seizures \((r = .46; p = .0001)\), health status \((r = -.44; p = .001)\) and more weakly with adaptation \((r = .27; p = .03)\). Self-rated adjustment had a near zero correlation with psychological adjustment.
4.0 **DISCUSSION**

4.1 **Seizure severity and adjustment**

The hypothesis that greater severity would be associated with poorer adjustment as measured by a variety of illness-related and psychological variables was only partially borne out.

Greater seizure severity on both the percept and ictal severity scales was related to increased levels of depression, poorer life-fulfilment, poorer acceptance of seizures and lower levels of self-rated health status. In addition, greater ictal seizure severity was associated with less happiness/well-being.

Greater severity, on either scale was not associated with higher levels of anxiety or poorer self-esteem, nor with poorer behavioural adaptation.

Percept severity is more highly correlated with depression than is ictal severity which suggests that predictability and control of seizures (which the percept subscale measures) is a greater influence on depression than are the actual seizure phenomena. This is consonant with the theory of learned helplessness which has been posited to explain the prevalence of depression in people with epilepsy.

Ictal severity is however more highly associated than percept severity with acceptance of seizures suggesting in this case that the ictal and post-ictal phenomena are more
important than the predictability of the seizures in coming to terms with epilepsy. The measure of acceptance covers items such as whether the person continually dreads the possibility of a seizure or whether they are concerned people will not want them around after a seizure, which one might expect to be affected by the nature of the attacks themselves more than whether the person can predict when they might occur. A seizure in which the person falls to the ground, injures themselves and results in a considerable period of confusion is perhaps more likely to be dreaded and may result in greater awkwardness in observers than a less severe attack.

In addition, percept severity was associated with the composite measure of psychological adjustment. This suggests that the predictability of seizures may be of relevance to overall psychological well-being, although this may just be a reflection of the stronger association of percept severity with depression.

However, all the correlation coefficients for these associations, although significant, are small, accounting for only a small proportion of the variance in each particular adjustment variable, so their importance should not be overemphasized.

The results from this study indicate therefore that although greater seizure severity is associated with poorer outcome on some psychological and illness-related
adjustment variables, it is not a strong predictor of adjustment overall. Seizure severity might then be of some use as an additional measure of treatment efficacy in that it would give some indication of psychological state, but it would be insufficient as a simple measure of identifying those who are having particular problems in adjusting to the disorder and who might benefit from psychoeducational intervention.

Comparison with the results from the Smith, et al (1991) study which, in using the same measure of severity and some of the same psychological measurement tools is the only comparable study, shows a different pattern.

The Smith, et al study used multiple regression to assess the relevance of seizure severity to psychological factors and found that after the psychological variables were removed from the analysis, seizure severity was the most significant predictor of self-esteem, anxiety and locus of control. The former two variables were assessed using the same scales as were used in this study, but in this case neither were significantly correlated with severity. In addition, Smith, et al found that severity was not significantly predictive of depression, again using the same scale, whereas in this study depression was associated with both measures of severity. Happiness was the other scale which was measured by the same instrument in both studies, and was shown to be more highly associated with severity in this study. Illness-related adjustment scales
were not used in the Smith, et al's research.

It is possible that these contradictory findings are to do with differences in samples. Smith, et al used a larger sample (N=100) of people with refractory partial seizures, recruited either from a drug trial, a surgery waiting list or a neurology outpatient department. Forty patients experienced complex partial seizures and secondary generalised seizures. A comparison of seizure severity scores is not possible as these results are not reported in the paper, although the seizure types which are represented in their sample are likely to result in a similar range of severity scores to this study.

It is difficult to find reasons why these differences have been found between the studies. Sample size might account for non-significant results in the smaller study but does not explain why other measures are significant.

4.2 Other seizure-related variables and adjustment

Results from analysis of other seizure-related variables and measures of adjustment, indicate that a longer duration of the disorder is associated with greater happiness, less depression and greater life-fulfilment, although again the correlation coefficients are small and not too great a weight should be put on these results. They do however suggest a trend.

When the data on seizure type were combined into major
seizures and minor seizures, differences were found on two adjustment variables which had not been apparent when three categories of seizure type had been analysed in the initial data screening. Analysis indicated that the group who experienced major seizures were significantly more anxious than those people with minor seizures and that they also rate their health status as poorer. As there is an obvious relationship between seizure type and seizure severity, it is interesting that neither percept nor ictal severity were shown to be significantly associated with anxiety. This suggests that the significance of seizure type for adjustment goes beyond the seizure phenomena experienced, although this study can not provide results which might account for this.

In the case of health status, the difference between types may be a reflection of severity as ictal severity is associated with health status.

The other seizure-related variables of age of onset and frequency of seizures were not associated with any of the adjustment variables.
4.3 Individual measures of adjustment

The second hypothesis that the individual components of adjustment would be associated was for the most part borne out.

As would be expected amongst measures of psychological state, the higher-order outcome scales of subjective well-being were all inter-correlated (p < .001). Acceptance of seizures (a primary, illness-related outcome measure) was also associated at this level of significance with all the psychological measures. Behavioural adaptation, another illness-related measure was not associated significantly with acceptance of seizures or happiness, but was significantly correlated with the remaining adjustment variables (p < .05), although the correlation coefficients were fairly small. In addition, the self-rated VAS adjustment to epilepsy measure was correlated significantly with all measures bar adaptation.

Although one might expect an association between acceptance of seizures and behavioural adaptation, it may be that adaptation is a factor which is independent of other seizure-specific variables, as there was also no association between adaptation and seizure severity, frequency, duration or age of onset. It is possible that an individual will alter their behaviour so that they avoid potentially dangerous activities (eg driving, operating heavy machinery) or known trigger factors (eg overtiredness or excess alcohol) for reasons of self-preservation or for
the sake of complying with the doctor's orders, without necessarily having come to terms with the disorder. There must certainly be factors which influence adaptation other than the cognitive or affective response to the seizures themselves.

Making the changes in behaviour which are required to help ensure fewer seizures or fewer injuries is an important indicator of adjustment to epilepsy. It may be that some individual's are well adapted, but have yet to adjust psychologically.

From a physician's point of view, adaptation is likely to be a more important target than psychological well-being, as poor adaptation is likely to lead to increased seizures, possibly dangerous or illegal behaviour and therefore greater need for ongoing medical services. From a psychologists point of view, reducing seizures must also be a priority, as although frequency was not associated with psychological adjustment either in this study or in Smith, et al's study, length of time since the last seizure or being seizure free has been shown to be associated with fewer psychological or social problems. A psychologist's role if working with people with epilepsy will not only be to facilitate greater psychological adjustment per se, but should also involve facilitating adherence to treatment regimens and behavioural adaptation, as these can both lead to a greater control of seizures and consequently a better psychological state.
An alternative explanation for the lack of association between adaptation and the other adjustment variables may of course be related to methodological factors. The range of scores on the adaptation scale was not wide, with the majority of people appearing to be well-adapted. This may be a reflection of the questionnaire design and will be discussed further in the section on methodological considerations.

4.4 Composite adjustment variables

The third hypothesis that factor analysis would suggest that individual components of adjustment could be combined to form composite scales of psychological and illness-related adjustment was only partially borne out.

The results did show that the psychological variables all loaded on the same factor, but that in addition acceptance of seizures was also related to the same factor, and not a separate 'illness-related' adjustment factor. As discussed in the results, it was decided not to include this in a composite scale as it made better sense to retain a scale made up purely of psychological or higher-order measures. Inclusion of a scale specific to the illness may result in the composite psychological measure being confounded by other illness-related variables, which otherwise might not be of such relevance.

The second factor showed higher loadings for adaptation and
health status. These scales however measure very different areas and can not be considered to reflect a common factor.

It was not possible therefore to construct a composite scale of illness-related adjustment which could be used as a summary of an individual's adjustment to the illness in particular. Adherence of course was not included and a more sensitive assessment method might provide results which could be considered if there were to be an association between adherence and acceptance.

The psychological adjustment scale was associated with the other adjustment variables of acceptance, adaptation and health status and also with percept severity, as one would expect from the individual correlations. This supports the links made in the model and in addition suggests, although weakly, that the predictability and perceived control of seizures are associated with overall psychological well-being.

Once the psychological measures had been combined the self-rated adjustment scale was no longer correlated. This scale had been introduced in order to see whether simply asking participants how well they had adjusted to epilepsy could give an indication of their psychological or illness-related adjustment, and therefore provide a very simple method of identifying those people who might benefit from intervention. The complete lack of association with the psychological adjustment scale suggests that
participants do not perceive the question to relate to their psychological state, but more as a question regarding how well they have come to terms with or accepted the diagnosis and illness phenomena. The significant correlation with the acceptance of seizures scale also suggests this. However, the correlation of .51 only accounts for 25% of the variance of self-rated adjustment indicating that other factors must contribute to an assessment of this sort. A simple, global question regarding level of adjustment is therefore not a particularly useful measure, as it does not reflect the range of psychological and illness-related factors which can be considered as coping outcomes.

A composite scale of psychological adjustment allows analysis and interpretation of variables in relation to adjustment as a more general term but without loss of information, or reference to only one or two psychological variables. Such a scale allows individual psychological factors to be studied but also a more general statement to be made regarding overall well-being. Such a composite scale also facilitates comparison between individuals or groups. Instead of having to specify how two people differ on individual measures, a composite score will allow an overall comparison taking into account all the individual scales. This may be of particular use as an outcome measure when considering treatment (physical or psychological) efficacy.
4.5 Concept of adjustment

The results appear to provide preliminary validation of Wright’s comprehensive model of adjustment. It has allowed considerable information regarding the outcome of coping efforts to be gathered, and the investigation of the influence of seizure-related factors on these. By using such a framework, it is possible to see that one particular variable is related to different outcome factors, and is not necessarily an influence on all areas of adjustment. This highlights the importance of viewing adjustment as a multifactorial construct, and not using it simply as a vague, poorly defined, global term which is considered to relate in some way to coping with chronic illness. This model is useful in that it encourages investigation into various aspects of adjustment, which could be useful clinically in directing any intervention to the most appropriate area.

The inclusion of multiple variables and their intercorrelations highlights the influences of the adjustment variables on each other, and therefore the interactional nature of adjustment. Although the term adjustment is defined here as ‘the outcome of coping efforts’ in order to facilitate measurement, the model recognises the dynamic, bidirectional influences of the individual variables related to coping and adjustment, which is likely to be of particular relevance to epilepsy. The episodic nature of the disorder is likely to mean that
people are required to a certain extent to re-adjust after each attack, so that adjustment can never be seen as a purely static end-state. It would be necessary to undertake a longitudinal study to investigate the dynamic nature of adjustment.

The links which are currently posited in the model have been validated to some extent by the results from this study. Apart from those between illness status (seizure severity) and adaptation and adherence (which is unknown, although clinically very likely to be associated with severity), significant correlations have been found between the remaining links which are drawn in. In addition, further lines may tentatively be included between illness status and subjective well-being and illness status and acceptance. Obviously correlations suggest only associations and can not say anything about direction. It is likely from a theoretical viewpoint that many of these links will be bidirectional.

It has proved relatively simple to assess each construct within the two levels of coping outcome, which had been a criticism of other theoretical frameworks relating to adjustment, although adherence may always be a factor for which it is difficult to find a simple and reliable method of assessment.

In practical terms, the questionnaire resulting from the model, which, although lengthy, did not prove overly burdensome to complete. No participant failed to complete
the questionnaire, despite being asked to remain after their appointment with the consultant, when one might expect people to be reluctant to spend extra time in such a setting. This suggests that the model provides an acceptable and practical method of assessment, in addition to its theoretical advantages.

The results from the factor analysis raise the issue of statistical versus clinical validity. Although the level of correlations led the analysis to suggest that the acceptance of seizures variable and the psychological variables are related to the same concept, and that health status and adaptation are related to another, clinically, and in terms of the model, this is not a useful division. One of the purposes of factor analysis is to assess the degree to which items are tapping the same concept, but it remains up to the researcher to decide whether meaningful psychological dimensions are being described.

4.6 Additional influences on adjustment

As mentioned in the introduction, the influences on adjustment (and coping) will be myriad and it would be a Herculean task to consider all of these in one study. However, it is possible to think of a few perhaps more obvious factors which could be considered when undertaking research of this nature, and which might be added to the periphery of Wright’s model as factors which should perhaps
invariably be included in assessment.

It has been suggested in relation to epilepsy that the diagnosis itself has a powerful impact on well-being and that this is independent of the physical status of the disorder. Jacoby (1992) found that even among patients whose epilepsy is well-controlled, there remains the burden of the diagnosis of their epilepsy and the uncertainty about its future course. This is similar to the findings of Trostle, et al (1989) discussed in the introduction. Therefore the simple existence of epilepsy may be an important determinant of psychosocial well-being and should perhaps be considered in investigations of epilepsy and its consequences, although disentangling this from the measures of illness status would prove difficult. This variable is also likely to be of importance in other chronic illnesses, such as diabetes where for the most part the illness is invisible and well-controlled, but its existence and need for medication or particular diet may be sufficient cause for psychological or illness-related problems.

A further addition could be a measure of recent life events which are likely to have an impact on subjective well-being and may also be reflected in illness status. For example, a recent loss of some sort may result in depression and a coping strategy of drinking. This in turn may have an impact on the epilepsy by triggering a seizure. If a seizure has not occurred for some time, this might have an impact on subjective well-being or psychological
adjustment, and possibly acceptance of seizures. Not having knowledge of such factors may then result in misleading results and conclusions.

One further factor which should be considered is the influence of personality factors. Research suggests that personality has an influence on the coping strategies which are employed, such that a number of commonly identified coping strategies (e.g., self-blame, wishful thinking) may more accurately be seen as measures of personality (McCrae & Costa, 1986) and that neurotic coping strategies are negatively related to psychological well-being. In regard to the primary outcome level, Pollock, et al (1990) reports that the characteristic of hardiness is associated with better behavioural adaptation and subsequent physiological adaptation.

In addition to the influence on coping strategies, personality characteristics influence self-report of subjective well-being and physical state. As levels of anxiety and depression are used as defining characteristics of personality types, results which suggest, for example, that higher levels of anxiety and depression are associated with greater illness severity, might simply be a reflection of the numbers of participants who have high neuroticism scores. These individuals (high-N) also have a tendency to inflate the frequency or severity of physical complaints (Watson & Pennebaker, 1989), due to increased sensitivity to bodily sensations (Larsen, 1992). It may be therefore
that research of this nature should not be undertaken without a measure of personality being included, with the effects of personality type on physical and psychological well-being subsequently being statistically controlled, for example with partial correlations.

Figure 2. presents a diagram of the additional factors which might be considered in research on adjustment and coping, with additional links suggested by the results of this study. Personality might best be viewed as an 'umbrella' variable which is likely to influence several areas.
In regard to the research on psychosocial consequences of epilepsy presented in the introduction, it is not possible to say how the psychological profile of this sample compares with previous research, because of differences in measurement techniques. Lack of norms or a control group also mean that no comment can be made about the sample in relation to the general population. However, one result does suggest that people with epilepsy perceive their...
health status to be significantly worse than the average health status of people of the same age and sex, and analysis indicates that poorer perceived health status is associated with poorer psychological well-being.

4.7 Methodological considerations

Although for the most part the model of adjustment allowed the use of existing measurement tools, it was necessary to construct a measure of behavioural adaptation. Although the appropriate steps were taken to help ensure reliability and validity, this questionnaire construction was necessarily a subsidiary aspect of the study. The lack of or weak association between adaptation and other variables might be explained by problems resulting from the construction of the measure.

The design of the questionnaire, in allowing participants to nominate items which were of importance to them, resulted in scores which were in effect related to different totals. Not all participants indicated that it was important to make changes in all eight areas of behaviour or activity, which therefore reduced the possible discrepancy total. This, however, was not considered in scoring and resulted in the range of scores being smaller than expected, and the sample appearing well adapted. The average number of items which were considered even of slight importance was five, which would mean a total
possible discrepancy score of 15, and the mode was three (total possible, nine).

However, even with this reduced range, greater scores will be indicative of poorer adaptation, as even a score of 6 would mean that at least 3 activities or behaviours have been considered very important to change because of epilepsy, but in fact no action is taken to do so. It should perhaps then be the interpretation of scores as indicating levels of adaptation which should be ignored, rather than the results.

As it is important to allow participant selection of items which are relevant to them, an alternative method of scoring which would account for the different totals of individuals might overcome these difficulties. A percentage of the greatest possible discrepancy might be one method, which could also account for the three levels of importance given to items.

In addition, the reliability score of .7 is not particularly high, .8 and above being more usually considered as a suitable level of test-retest reliability. This may have been due to the fact that the questionnaire was initially completed in the presence of the researcher who was able to clarify the instructions when necessary, whereas the second score was obtained from questionnaires completed at home and returned by post. This reduced reliability may therefore reflect the clarity of the written instructions. Having said that, during the study...
nearly all of the questionnaires were completed in the presence of the researcher and were therefore fully explained, or were explained to an individual before they took them to be completed at home. Any difficulties with understanding should therefore have been overcome.

The other measure which resulted in a small range of scores was that of adherence. The potential difficulty with self-report as a measure of adherence is that many patients may simply overreport self-administration of medication (Gordis, et al, 1969) as there is a desire to be viewed positively.

Other possible methods include therapeutic outcome, physician estimate, pill/bottle counts, mechanical devices and blood/urine tests, although these all also have their problems. Results of correlations between patients' reports and other methods of assessing compliance summarized by Ley (1988) suggest however that patients' reports will give similar results to other methods. Although a more direct method such as drug blood levels would have proved a more reliable type of assessment, this would not have been appropriate for the nature and scope of this study, and self-report was considered sufficient.

The alternative explanation for the results of course is that people do very rarely miss their medication. A disorder such as epilepsy may result in greater adherence to medication, as slips in a regimen can quickly result in
a reappearance of seizures. However, with epilepsy which is proving difficult to control (all participants in this study having had at least one seizure within the previous month), people may feel that even if they do take the medication there is no obvious improvement, so the odd lapse is nothing to worry about. Poor adherence is however one of the major causes of continuing seizures, and the efficacy of a drug can not be fully assessed if there is not a stable blood drug level. It is difficult however to say whether the results from self-report are overreporting of adherence or not. As an indicator of adjustment, adherence would appear to be an obvious factor to investigate, and should remain in the model; whether an alternative method of assessment is selected would depend on the focus of future research.

As discussed above, other factors such as personality may have an influence on adjustment and might have accounted for any associations between severity and the adjustment variables. It would therefore have been advisable to include a measure of personality such as the EPQ in the study, so that this factor could be controlled for, both in reporting of illness status and psychological well-being. However it would also have been possible to include a whole variety of factors which might account for the results, but in a study of this nature and size this would not have been feasible.

The final point methodologically is to note the relatively
small number of participants. Although the numbers were not too small to allow multivariate statistics, a larger sample would have allowed greater weight to have been given to the results and greater comparability with other research.

4.8 Future research

In view of the somewhat contradictory findings regarding seizure severity, the research should be repeated using a larger sample, in an attempt to clarify the relevance of severity to adjustment. Although seizure severity is only one of the seizure-related factors which could have an impact on adjustment, it is of interest and importance clinically in that it is possible to alter the level of seizure severity through drug intervention.

Although research has been undertaken on many of the factors hypothesized to influence adjustment, a comprehensive large-scale study using this multidimensional model of adjustment to direct measurement would help to clarify the individual contribution of these factors. The use of this model would overcome some of the criticisms levelled at previous research relating to poor definition and operationalization of adjustment. The research might include assessment of perceived stigma, fear of seizures, life-events, type of medication, aetiology of seizures, and a measure of personality, in addition to seizure severity.

In order to develop the model and to further understanding
of the process of coping and adjustment, a longitudinal study would be of interest to consider the transactional nature of coping and adjustment.

4.9 Summary and conclusions

There was partial support for the hypotheses. Seizure severity was associated, if weakly, with some measures of adjustment. It would not be a powerful enough measure however to use as a means of identifying individuals who are less well adjusted and who might need psychoeducational intervention, although it might be included as an additional outcome measure for assessment of treatment efficacy. Acceptance of seizures was more strongly associated with psychological well-being which might make this variable a suitable measure for identification of those requiring help with psychological adjustment.

Most of the individual measures of adjustment were associated. Adaptation was not associated with acceptance or happiness, nor with the seizure-related variables. This might be because adaptation is independent of these factors, or for methodological reasons.

There was evidence to suggest that the psychological variables could be described as an overall factor of subjective well-being or as a summary of psychological adjustment. The illness-related variables could not however be combined into a summary variable of illness-related
adjustment, although this may be a possibility with a wider range of scores from the measures of adherence and adaptation.

The conceptual model of adjustment which was used as a framework for measurement was considered to be of value in research of this nature. Defining adjustment as the outcome of coping at two levels encourages a comprehensive range of psychological and illness-related variables to be included in assessment. This is in contrast to much of the previous research on adjustment to chronic illness which either considers adjustment as a vague, ill-defined, global factor, or which uses only a few outcome measures which are then equated with 'adjustment'.

This model allows the impact of 'independent' variables to be assessed in a variety of areas without information being lost behind a global definition of adjustment.

In addition, the specification of the constructs within each level allows the construction of a measurement battery which is acceptable to participants.

Results from the study have allowed preliminary validation of the links within the model and tentative additions have been suggested. Further research is needed to validate this model for use with other chronic illnesses.

Finally, by undertaking this research and through interviewing a large number of people with epilepsy, it is
clear that there is a great need for sufficient information to be given to people at the time of diagnosis, and for psychoeducational intervention to be made available to a good sized minority who require this at a later stage.
APPENDIX I
LETTER TO PARTICIPANTS

Dear

I am currently involved in research looking at how people cope with having epilepsy. There are a number of things which may affect coping, such as frequency, type and severity of seizures. The aim of this study is to look at whether these things do affect coping.

Coping with epilepsy can be a difficult task. We hope that increasing our knowledge about the sorts of things which affect how people cope will help us to develop services for people facing this in the future.

I am asking a number of people with epilepsy to help with this study by answering a few questions and your name was given to me by Dr . If you are willing to take part in the study, I will ask to see you for 20-30 minutes when you come for your appointment with Dr on . This could either be whilst you are waiting to see the doctor, or after the appointment if you have time. The answers you give will of course be strictly confidential and anonymous.

If you would like more information before you decide to take part, I will be happy to provide this.

Thank you for taking the time to read this and I look forward to meeting you.

Rosalind Walker
Psychologist

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APPENDIX II
RESEARCH QUESTIONNAIRE

No. __

Most of the questions can be answered by placing a tick in the box next to the answer which applies to you. Please write in any other comments or answers. If you are unable to answer a question for some reason, please write this on the questionnaire.

First some questions about your seizures, by which we mean your usual epileptic attacks.

1) How old were you when you had your first seizure? ________

2) Do you have:

   Major seizures only   []
   Minor seizures only   []
   Both                 []

If you have both major and minor seizures, please answer the following question for both types. If you have only one seizure type, please tick the box which is appropriate for the type of seizure you have.

3) How many seizures have you had in the last 5 years?

   Please tick appropriate box

   None                       [] [ ]
   On average less than one per year     [ ] [ ]
   More than one per year but on average less than one per month   [ ] [ ]
   More than one per month but on average less than one per week   [ ] [ ]
   More than one per week but on average less than one per day      [ ] [ ]
   On average more than one per day                        [ ] [ ]
4) How regularly do you take your tablets? Would you say you:

Never miss taking the tablets? □
Miss the tablets less often than once a month? □
Miss the tablets more often than once a month? □
Miss the tablets more often than once a week? □
5) Now some questions about the nature of the seizures you have. If you have more than one seizure type, that is, both MAJOR and MINOR seizures, please answer every question for both types, by ticking the appropriate box in each column. If you have only one type of seizure, please answer the questions according to how you feel your seizures are (ie major or minor) and tick the appropriate column.

Some of the questions will refer to your auras/warnings. An aura/warning is a feeling that you usually experience, eg tummy pain or fuzzy head, which can occur on its own but suggests that an attack is likely to follow.

PLEASE ANSWER THE FOLLOWING QUESTIONS WITH REFERENCE TO HOW YOU HAVE BEEN OVER THE LAST FOUR WEEKS.

Please tick appropriate box

<table>
<thead>
<tr>
<th></th>
<th>MAJOR</th>
<th>MINOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) My attacks are</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) always at a particular time of day or night</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b) mostly at one particular time of day or night</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>c) sometimes at one particular time of day or night</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>d) my attacks can occur at any time of day or night</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2) Over the last four weeks when my attacks have happened</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) I have always been able to tell when I will have attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b) I have usually been able to tell when I will have attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>c) I have occasionally been able to tell when I will have attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>d) I have not been able to tell when I will have attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>3) Over the past four weeks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) I have always been able to fight off my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b) I have usually been able to fight off my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>c) I have sometimes fought off my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>d) I have not been able to fight off my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4) Over the last four weeks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) I have had an aura or warning with all my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b) I have usually had an aura or warning with my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>c) I sometimes have had an aura or warning with my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>d) I have not had an aura or warning with my attacks</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>
5) How much control do you feel you have over your attacks
   a) Very good control
   b) Moderate control
   c) Little control
   d) No control at all

6) Over the past four weeks when I have had my attacks
   a) they have always occurred in clusters with quite long periods between each cluster
   b) they have mostly occurred in clusters with quite long periods between each cluster
   c) they have sometimes occurred in clusters
   d) they have not occurred in clusters

7) My attacks are
   a) always when I am asleep
   b) mostly when I am asleep
   c) sometimes when I am asleep
   d) never when I am asleep

8) My attacks
   a) stop me doing all of the things I want to do
   b) stop me doing a lot of the things I want to do
   c) stop me doing a few of the things I want to do
   d) don't stop me doing anything I want to do

9) Over the last four weeks my attacks have been mostly
   a) very severe
   b) moderately severe
   c) mild
   d) very mild
10) Most commonly when I have blanked out over the last four weeks
   a) I blank out for less than 1 minute
   b) I blank out for between 1-2 minutes
   c) I blank out for between 2-5 minutes
   d) I blank out for more than 5 minutes

11) Over the last four weeks when I have recovered from my attacks
   a) I felt very confused
   b) I felt moderately confused
   c) I felt slightly confused
   d) I haven't felt confused at all

12) In the last four weeks when I have recovered from my attacks my confusion lasts for
   a) less than 1 minute
   b) between 1-5 minutes
   c) between 6 minutes - 1 hour
   d) over 1 hour

13) Over the last four weeks when I have had my attacks
   a) I have always fallen to the ground
   b) I have usually fallen to the ground
   c) I have sometimes fallen to the ground
   d) I haven't fallen at all

14) When I have recovered from my attacks over the last four weeks
   a) I have always had a headache
   b) I have usually had a headache
   c) I have sometimes had a headache
   d) I have not had a headache
15) When I have recovered from my attacks over the last four weeks
   a) I have always felt sleepy
   b) I have usually felt sleepy
   c) I have sometimes felt sleepy
   d) I haven't felt sleepy

16) When I have recovered from my attacks over the last four weeks
   a) I have always found that I have wet myself
   b) I have usually found that I have wet myself
   c) I have sometimes found that I have wet myself
   d) I have not wet myself

17) When I have recovered from my attacks over the last four weeks
   a) I have always found that I have bitten my tongue
   b) I have usually found that I have bitten my tongue
   c) I have sometimes found that I have bitten my tongue
   d) I have not bitten my tongue

18) When I have recovered from my attacks over the last four weeks (other than biting my tongue)
   a) I have always found that I have injured myself
   b) I more often than not found that I have injured myself
   c) I have sometimes found that I have injured myself
   d) I have not injured myself

19) In the past four weeks when I have had my attacks I can usually return to what I was doing
   a) in less than 1 minute
   b) between 1-5 minutes
   c) between 6 minutes - 1 hour
   d) over 1 hour
Sometimes people with epilepsy find that they have to make changes to their lifestyle. People differ in how important or unimportant they feel these changes are for them. We would like to know how important you feel it is for you to avoid the activities or behaviours listed below.

<table>
<thead>
<tr>
<th></th>
<th>Very important</th>
<th>Fairly important</th>
<th>Slightly important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Driving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Swimming</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Using heavy machinery</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Using electrical equipment</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>e) Excess alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Overtiredness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Flashing/ flickering lights or scenes</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>h) Baths/showers at certain times</td>
<td></td>
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<td></td>
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</tbody>
</table>

Please list any other changes in your lifestyle which you feel have been important for you to make because of epilepsy.

1. 
2. 
3. 
4. 
5. 
We would also like to know how often you are able to avoid these activities.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Always</th>
<th>Usually</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Driving</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>b) Swimming</td>
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<tr>
<td>c) Using heavy machinery</td>
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<tr>
<td>d) Using electrical equipment</td>
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<tr>
<td>e) Excess alcohol</td>
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<tr>
<td>f) Overtiredness</td>
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<tr>
<td>g) Flashing/flickering lights or scenes</td>
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<td>[ ]</td>
</tr>
<tr>
<td>h) Baths/showers at particular times</td>
<td>[ ]</td>
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<td>[ ]</td>
</tr>
</tbody>
</table>
7) The following questions are about how you feel having epilepsy. Please answer YES or NO.

Please tick the appropriate box

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Do you feel resentful that you have seizures?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Are you free from embarrassment about your seizures?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Have seizures ruined your life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Do you have trouble accepting your seizure problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Are you afraid people will find out you have seizures?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Do you continually dread the possibility of a seizure?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Are you fearful you will have a seizure in an embarrassing circumstance?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) Are you comfortable going out despite possible seizures?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) Are you concerned people won't like you or want you around after a seizure?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>j) Do you feel different or strange due to your seizures?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8) Please mark on this line how well you feel you have adjusted to having epilepsy

Very badly ---------------------------------------- Very well
8) Thinking about how things have been for you in the past few weeks please answer YES or NO to the statements below.

During the past few weeks did you ever feel...

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Pleased about having accomplished something?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) So restless that you couldn't sit long in a chair?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) That things were going your way?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Bored?</td>
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<td></td>
</tr>
<tr>
<td>e) Proud because someone complimented you on something you had done?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Depressed or very unhappy?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Particularly excited or interested in something?</td>
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<tr>
<td>h) Very lonely or remote from other people?</td>
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<td></td>
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<tr>
<td>i) On top of the world?</td>
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<tr>
<td>j) Upset because someone criticized you?</td>
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</tbody>
</table>
The statements below describe how people sometimes feel about themselves. Thinking about yourself, do you strongly agree, agree, disagree or strongly disagree with the statements? For each statement, please tick the box which matches your answer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) On the whole, I am satisfied with myself</td>
<td></td>
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<tr>
<td>b) At times I think I am no good at all</td>
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<tr>
<td>c) I feel that I have a number of good qualities</td>
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<tr>
<td>d) I am able to do things as well as most other people</td>
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<tr>
<td>e) I feel I do not have much to be proud of</td>
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<tr>
<td>f) I certainly feel useless at times</td>
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<tr>
<td>g) I feel that I am a person of worth, at least on an equal plane with others</td>
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<tr>
<td>h) I wish I could have more respect for myself</td>
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<tr>
<td>i) All in all I am inclined to feel that I am a failure</td>
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<tr>
<td>j) I take a positive attitude toward myself</td>
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</tbody>
</table>
10) Now some questions about how you have been feeling in yourself. Please read each statement and place a tick in the box opposite the response which comes closest to how you have felt in the last few days. Don’t take too long over your replies, your immediate reaction will probably be more accurate than a long thought out response.

1) I feel tense or ‘wound up’
   a) most of the time
   b) a lot of the time
   c) from time to time, occasionally
   d) not at all

2) I still enjoy the things I used to enjoy
   a) definitely as much
   b) not quite so much
   c) only a little
   d) hardly at all

3) I get a sort of frightened feeling as if something awful is about to happen
   a) very definitely and quite badly
   b) yes, but not too badly
   c) a little, but it doesn’t worry me
   d) not at all

4) I can laugh and see the funny side of things
   a) as much as I always could
   b) not quite so much now
   c) definitely not so much now
   d) not at all

5) Worrying thoughts go through my mind
   a) a great deal of the time
   b) a lot of the time
   c) from time to time but not too often
   d) only occasionally
6) I feel cheerful
   a) not at all
   b) not often
   c) sometimes
   d) most of the time

7) I can sit at ease and feel relaxed
   a) definitely
   b) usually
   c) not often
   d) not at all

8) I feel as if I am slowed down
   a) nearly all the time
   b) very often
   c) sometimes
   d) not at all

9) I get a sort of frightened feeling like 'butterflies' in the stomach
   a) not at all
   b) occasionally
   c) quite often
   d) very often

10) I have lost interest in my appearance
    a) definitely
    b) I don't take so much care as I should
    c) I may not take as much care
    d) I take just as much care as ever

11) I feel restless as if I have to be on the move
    a) very much indeed
    b) quite a lot
    c) not very much
    d) not at all
12) I look forward with enjoyment to things
   a) as much as ever I did
   b) rather less than I used to
   c) definitely less than I used to
   d) hardly at all

13) I get sudden feelings of panic
   a) very often indeed
   b) quite often
   c) not very often
   d) not at all

14) I can enjoy a good book or radio or TV programme
   a) often
   b) sometimes
   c) not often
   d) very seldom
Below are listed various aspects of life. People disagree about how important or unimportant each aspect is. We want to know how important you feel each aspect to be. Please put a tick in one of the four columns alongside each item to indicate your feeling about the importance of that item. Do not place ticks according to whether or not each aspect is true of your life; it is simply your view about the importance of each aspect, irrespective of whether it actually applies to you.

<table>
<thead>
<tr>
<th>ASPECT OF LIFE</th>
<th>Very important</th>
<th>Fairly important</th>
<th>Slightly important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) A good family life</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>2) Having close friends you can confide in</td>
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<tr>
<td>3) A happy marriage (or similar relationship)</td>
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<tr>
<td>4) Being happy with the area where you live</td>
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<tr>
<td>5) Having housing which meets your needs</td>
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<tr>
<td>6) Being able to do the things you enjoy in your spare time</td>
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<tr>
<td>7) Enjoying a good social life</td>
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<tr>
<td>8) Being in good health</td>
<td></td>
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<tr>
<td>9) Being happy with yourself as a person</td>
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<tr>
<td>10) Having a job which you consider satisfying</td>
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<tr>
<td>11) Having a secure and stable job</td>
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<tr>
<td>12) Having an adequate standard of living</td>
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<tr>
<td>13) Having enough money to do most things you want to do</td>
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</tbody>
</table>
12) Now we would like to know how satisfied you are with your own life situation. For each question below, please tick the box which best represents how you feel.

1) How satisfied are you, in general, with your family life?
   [ ] Very satisfied [ ] Satisfied [ ] Dissatisfied [ ] Very dissatisfied

2) How many close friends do you have whom you feel you can confide in?
   [ ] A lot [ ] Some [ ] A few [ ] None

3) How satisfied are you, in general, with the relationship you have with your spouse/partner?
   [ ] Very satisfied [ ] Satisfied [ ] Dissatisfied [ ] Very dissatisfied

4) How satisfied are you, in general, with the area where you live?
   [ ] Very satisfied [ ] Satisfied [ ] Dissatisfied [ ] Very dissatisfied

5) How satisfied are you, in general, with your present housing conditions?
   [ ] Very satisfied [ ] Satisfied [ ] Dissatisfied [ ] Very dissatisfied

6) How much do you feel able to do the things you enjoy in your spare time?
   [ ] Often [ ] Sometimes [ ] Rarely [ ] Never

7) How satisfied are you, in general, with your social life?
   [ ] Very satisfied [ ] Satisfied [ ] Dissatisfied [ ] Very dissatisfied

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8) How would you describe your health now?

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

9) How happy are you with the way you feel about yourself?

<table>
<thead>
<tr>
<th>Very happy</th>
<th>Fairly happy</th>
<th>Not very happy</th>
<th>Not at all happy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

10) How satisfied are you, in general, with the work you do?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

11) How much do you worry about the security of your job?

<table>
<thead>
<tr>
<th>A lot</th>
<th>Some</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

12) How satisfied are you with your present standard of living?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

13) How satisfied are you with the amount of money you have coming in?

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
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</tbody>
</table>
The following items are designed to assess your views of your current health status and of the average for your age and sex. Please respond to each item by marking a cross (X) at the point on the scale which you feel best represents your current health status. There are no right answers.

1. How would you rate your health as it is right now?

Poor .................................................................................. Perfect

2. What do you think is the average state of health for someone of your age and sex?

Poor .................................................................................. Perfect

3. How satisfied are you with your current state of health?

Very Satisfied ................................................................. Very Dissatisfied
Finally, a few details about yourself.

Age: ___  Male: ___  Female: ___

Are you:  Single
         Married or living as married
         Divorced
         Separated
         Widowed

At present are you:  In full-time employment
                    In part-time employment
                    Permanent sick
                    Retired
                    Housewife
                    Unemployed

Thank you very much for your help. We are grateful for the time and trouble you have taken.
REFERENCES


