Quality of Life in Epilepsy: The Role of Psychological Resilience

Kenny Day

Submitted in Part-Fulfilment of the Doctorate in Clinical Psychology
The University of Edinburgh
2008

I hereby that declare that following academic work is entirely my own:

……. (Signature)

Acknowledgements

The completion of this piece of research was in no way a solo effort. I would like to thank my academic supervisor, Dr Paul Morris, for his patience and hard work. His input into the revisions of the chapters was invaluable and he was always available for advice and discussion. My clinical supervisor, Penelope Fraser, provided me with support in assisting with my relationship with the Neurology department and was enthusiastic regarding the study. My colleagues in the clinical psychology department were a source of support and entertainment. My thanks also to Dr Emily Newman who contributed valuable statistical advice, and Drs Lucy Paterson and Fiona MacLeod who assisted with the final draft.

I would also like to thank my fellow final year and flexible trainees. They allowed me to express my frustrations at the whole process and keep me motivated.

Finally, I would like to thank my friends and of course, Hala.

Abstract

Introduction

The quality of life of those with intractable epilepsy is significantly lower than that of the general population. Researchers have found that seizure frequency accounts for a statistically significant amount of the variance in levels of quality of life in those with epilepsy. However, not all studies have shown this effect. Psychosocial factors have recently received more attention and there is some evidence that they may provide a better account of the variance than seizure frequency. Psychological resilience, the ability to adapt to stressful events with good outcomes, is one area that has received little attention in the quality of life of adults with intractable epilepsy.

Aims and Hypotheses

The aim of the current study was to examine the role of resilience in quality of life in adults with intractable epilepsy. The first hypothesis predicted that the correlation between resilience and quality of life would be both significant and positive. Secondly, it was hypothesised that resilience would provide a better account of the observed variance in quality of life than seizure frequency. A further hypothesis predicted that resilience would show a significantly negative correlation with measures of anxiety and depression.

Methodology

Postal questionnaires were presented to 223 patients with a diagnosis of epilepsy at their regular neurology review appointment. Exclusion criteria were; outwith the age range of 16-65, a diagnosis of intellectual impairment and seizure freedom for a period of 6 months. Measures of resilience, quality of life, seizure frequency anxiety and depression and several demographic variables were included. Of the 223 individuals invited to take part in study, 60 returned the completed questionnaires.

Results and Discussion

Correlations indicted that levels of resilience and quality of life showed a significant and large, positive correlation. Multiple regression analysis indicated that a significant proportion of the variance in quality of life was accounted for by resilience. Seizure frequency did not account for a significant amount of the variance. Measures of anxiety and depression were also significantly negatively correlated with resilience. The results are discussed in terms of their impact on future treatment options for those with intractable epilepsy.

CHAPTER 1: INTRODUCTION

Chapter 1: Introduction

1.1 General Introduction to Epilepsy

Epilepsy is a condition often marked by distinct physical difficulties and severe psychosocial problems. From restrictions on driving, to the threat of sudden death and early mortality, the condition can be a major cause of psychological difficulties and increased levels of disability (Cockerell, Hart, Sander, Goodridge, Shorvon, & Johnson, 1994). Significant stigma is often associated with the condition, leaving some individuals isolated from society and unable to achieve valued goals (Jacoby, Gorry, Gamble & Baker, 2004).

Current treatment of epilepsy is primarily medical, reliant on pharmacological intervention, requiring an intensive treatment regime, or on surgical resection. Such treatment demands commitment from the person with epilepsy, not only in adhering to the drug regime, but also in tolerating the often severe and potentially damaging side effects. For those who undergo psychosurgery, the risks inherent in the procedure provide a threat to their mortality, although these are often outweighed by the threat of death from the seizures and their sequelae. Many of those with the condition report that it impacts negatively on their overall quality of life both directly through the organic pathology and indirectly through psychosocial problems and stigma and the side effects of their anti-epileptic medication (Jacoby & Baker, 2008).

Previous research suggests that the greatest determinant of quality of life was absence from seizures, and there is good evidence that gaining complete seizure freedom can result in a return of quality of life to levels similar to those of normal controls (Jacoby, 2000). However, a third of those with epilepsy will be unable to gain adequate control over their seizures. Studies have shown that of this group, a sizable minority report that their overall quality of life is relatively unaffected, in spite of continued seizure episodes. Initial investigations suggested that seizure frequency might be able to account for this finding; with higher frequency equating to lower quality of life (Baker & Jacoby, 2002). However, the link between seizure frequency and quality of life has been an inconsistent finding (Jacoby & Baker, 2008).

Therefore, new discussions regarding the factors that may contribute to overall quality of life in treatment refractory epilepsy are required, which examine issues beyond that of seizure control or type. Theories concerning the psychosocial variables have been discussed as a possible additional factor that may explain some of the variance (Jacoby & Baker, 2008). Several authors have now published data regarding the influence of psychosocial factors in the quality of life of those with epilepsy, with a number of findings suggesting that these factors may actually have a more direct influence on quality of life, thereby providing more of an explanation of the variance than medical explanations alone (Szaflarski, Meckler, Privitera, & Szaflarski 2006).

The psychological characteristic of resilience is one factor that may be able to provide a useful contribution to the discussion. However, little research has been conducted into resilience in epilepsy. This is largely because of the difficulty of formalising a definition of resilience. However, recent work within the field of trauma and pain, aligned with the emergence of the positive psychology movement, has allowed for greater and more robust investigation into the characteristics associated with high levels of psychological resilience.

The current study will examine the role that levels of psychological resilience play in the quality of life of those with intractable epilepsy. It will begin by providing an introduction into the field of epilepsy, discussing historical factors, incidence, diagnosis, mortality and associations. The literature regarding the treatment of epilepsy will be examined alongside the evidence regarding outcomes. The notion of quality of life will be highlighted at a general, theoretical level, before specific issues concerning quality of life in epilepsy are introduced. The historical perspective of psychological resilience will follow, specifically focusing on the definitions and experimental investigations. The possible influence of resilience on quality of life in epilepsy will be introduced. The main hypotheses of the research will then be presented, followed

1.2 Introduction to Epilepsy

Epilepsy is one of the most common neurological disorders, with approximately 50 million people around the world meeting diagnostic criteria (WHO, 2001). To understand the condition and the associated stigma and fear that is associated with it, it is important to have knowledge of the historical genesis and of the more contemporary controversies and advances.

1.2.1 History

The early history of epilepsy is grounded, not in the realms of science, but in the crucible of myth and superstition. Early writings and reports from the Ancient Egyptian and Greco-Roman eras described epilepsy as a curse, arising from an individual having angered the Gods. Other popular beliefs included viewing those with the condition as being gifted seers, with the seizures themselves being prophetic in nature. Cures varied, with some espousing the virtues of sacrificial acts or prayer, and others believed that herbal remedies, such as mistletoe, would be the elixir to cure the condition (Eadie & Bladin, 2001).

Hippocrates, and those writing in the Hippocratic style, were some of the first generation of writers to suggest that the epilepsies may not have a spiritual genesis,

but a physical one[1]. Writing in the 5th Century BC, the essay entitled "On The Sacred Disease" suggested that epilepsy was a disorder of the brain, with little recourse required to supernatural causes. Although the mechanisms of action were not accurate (Hippocrates believed that an imbalance of "phlegm" was responsible), the thinking on the subject was instrumental in providing future researchers with the template with which to begin their investigations.

With the demise of the ancient civilisations, the medical advances associated with that period also regressed. Although many individual medical researchers continued to investigate epilepsy with a physical cause in mind, the influence of the Roman Catholic Church and the relative lack of access to education for the masses, meant that The Dark Ages coincided with an increase in supernatural thinking; again epilepsy fell into the realms of the priests rather than the physicians (WHO, 2001). Seizures were linked to either a religious or demonic experience, with those afflicted viewed as outcasts, degenerates and in some cases labelled as witches and executed. Indeed, a text from the 15th Century, the *Malleus Maleficarum,* meaning "The Hammer of the Witches", listed epilepsy as an indicator of potential witchery and called for those with the condition to be cleansed through their execution (Eadie & Bladin, 2001).

It was not until the mid-to-late 19th Century that a medical formulation of epilepsy came back into vogue. The pioneer of this sea change was John Hughlings Jackson. Known as "The Father of English Neurology" (Critchley & Critchley, 1998),

[1] Although Hippocrates is recognised as the father of modern medicine, other individuals were also noted to have had similar theories regarding epilepsy. Notably from Indian medicine, Atreya, whose views preceded Hippocrates by 400 years.

Hughlings Jackson was a consulting physician at the National Hospital for the Paralyzed (sic) and Epileptic in London from 1862 until his death in 1911. It is reported that his inspiration for investigating the true nature of epilepsy was a result of his wife's struggles and eventual death from what became known as Jackson's Epilepsy (Critchley & Critchley, 1998).

Hughlings Jackson's work centred on the theory that the motor convulsions observed in patients experiencing seizures may be functionally linked to specific areas of the brain. Using this theory, Hughlings Jackson postulated that epileptic seizures were the result of sudden electrical discharges within the brain and that the site and character of the motor convulsions could lead to an understanding of where in the brain the discharges were occurring (Taylor, 1931). This was a key moment in the demystification of the disorder, with investigation using scientific methods now able to provide a more testable explanation for the mechanism behind the seizures.

The German psychiatrist Hans Berger's observation, in 1929, that the brain's electrical activity could be recorded without the need for invasive surgical investigation, led to the development of the electroencephalograph (EEG). For the first time, physicians were able to explore the electrical profile of patient's brain activity, leading to the development of diagnostic techniques, which are still in use today (Temkin, 1971). This also contributed to the integration of epilepsy into the main body of medicine, with neurology becoming a more widespread discipline (Eadie & Bladin, 2001).

In spite of this increased understanding of the causes of epilepsy, everyday stigma and fear remained a reality for those with the condition. In the early 20th Century those with regular seizures were often held under section in psychiatric hospitals and sanatoriums, usually in separate wards due to fears that other patients may "catch" epilepsy. Routine sterilisations of those with epilepsy, in line with the eugenic beliefs that were popular at the time, were also common practice in these hospitals and those with the condition found integration into normal society made difficult by restricted access to employment and social contact (Temkin 1971).

However, the discovery of a physical correlate for the seizures led researchers to begin to investigate ways of controlling the condition and out of this came the forbearers of many of the anticonvulsant drugs used today. The first successful anticonvulsant medications were bromine and phenobarbitone, which started being used in the early 20th Century. However, the side effects of these drugs meant that it was not until the discovery of the anticonvulsant effects of phenytoin that a genuine, viable method of adequate seizure control was available. Merritt and Puttnam pioneered the use of the drug in a series of studies in the 1930's and it was included on the list of acceptable anticonvulsants in the American Medical Association's Council New and Nonofficial Remedies publication in 1939 (Shorvon, Fish, Perucca & Dodson, 2004). As the century continued, the discovery and development of new anticonvulsants continued, with the discovery of carbamazepine in the 1950's and sodium valproate in the 1960's. The development of pharmacological controls for frequent seizures can be seen to be the turning point in the demystification of epilepsy. By finding a physiological cause and providing an efficacious and reliable

solution, researchers were able to reduce some of the confusion and fear surrounding the condition thereby laying the foundations for improvements in the response to people with the condition by society.

More recent developments in the history of epilepsy are notable by their focus on more direct treatment models. The approval of Vagus Nerve Stimulation (VNS) by the Federal Drug Administration in the United States provided an adjunct to pharmacological methods. VNS works by providing a stimulating pulse directly to the vagus nerve, thereby impacting directly on the areas of the brain where seizures may originate. The exact action of the therapeutic effect is not clear, although improvements in both seizure frequency and severity have been well documented (Shorvon, 2004).

Surgical procedures in epilepsy are also a relatively new addition to the evidence base, although more crude methods have been used throughout history. The introduction of magnetic resonance imaging (MRI) coupled with the relative advances in the field of neurosurgery has meant that surgery has become a more viable option for those whose seizures are not well controlled by anticonvulsant medication (NICE, 2004). Although the risks inherent to any type of surgery are well known, there does appear to be a significant reduction in seizures in a high percentage of those who undertake the procedure (Shorvon et al., 2004).

Psychological approaches to epilepsy have also developed in more recent times. Their focus has largely been based around a cognitive behavioural approach to

reduce seizure frequency by addressing the internal precipitants that may contribute to seizure onset (Ramaratnam, Baker & Goldstein, 2005). Psychological approaches have also been used to improve quality of life and to assist individuals in dealing with the emotional sequelae of living with a chronic health condition. However, evidence in support of the effectiveness of these approaches is limited at best, and further research with more quality trials is required (Ramaratnam, Baker & Goldstein, 2005).

Associated with this increased focus on the psychological factors in epilepsy, is a greater focus on the less clinical aspects of the condition. An increasing number of interventions have been developed to assist people with the condition to address areas of difficulty beyond the scope of their illness. The NICE guidelines advocate this approach through the greater use of the specialist epilepsy nurse and the provision of services other than neurology (NICE, 2004). General practitioners in the UK are also being encouraged to assist in the screening of those people with epilepsy who are maintained in primary care for psychological difficulties (NICE, 2004).

Given the prolonged history of the condition, it is interesting to note that epilepsy is still relatively misunderstood by the population at large (NICE, 2004). The historical beliefs, whilst largely erroneous, have been pervasive enough to continue to have some influence in our apparently enlightened age. This can mean that the individual with epilepsy is faced with the daunting prospect of facing up to a potentially chronic and fatal condition, with the added pressure of functioning in a society that can view them with suspicion.

1.2.2 Modern Medical Description/Definitions

Epilepsy is a condition characterised by recurrent (two or more) epileptic seizures, unprovoked by any immediate identified cause. Multiple seizures occurring in a 24-hour period are considered a single event. An episode of status epilepticus is considered a single event. Those who have had only febrile seizures (seizures in childhood as a result of a fever) or only neonatal seizures (seizures in the first 28 days following birth) are excluded from this category (Commission on Classification and Terminology of the International League Against Epilepsy, 1993).

The Scottish Intercollegiate Guidance Network (SIGN, 2003) provides guidance as to how epilepsy should be classified. In line with international systems of classification, SIGN suggest that epilepsy can be classified into three main categories; Partial Seizures, Generalised Seizures and Unclassified Epileptic Seizures. Table 1 lists the categories with further clarification.

1. Partial Seizures	2. Generalised Seizures Convulsive or non-convulsive with bi-lateral discharges involving sub-cortical structures	3. Unclassified Epileptic Seizures
A. Simple partial seizures (no loss of consciousness) B. Complex partial seizures i. with impairment of consciousness at onset ii. simple partial onset with impairment of consciousness C. Partial seizures evolving to generalised tonic-clonic (GTC) convulsions	A. absence B. myoclonic C. clonic D. tonic E. tonic-clonic F. atonic	Seizures recorded as epileptic in nature but not described by the other definitions

Table 1: Classification of Epilepsies (adapted from Diagnosis and Management of Epilepsy in Adults, SIGN, 2003)

In summary, epilepsy is best viewed as a condition that is symptomatic of another underlying condition, rather than as a disease entity in its own right. The diagnosis of epilepsy is a complicated process and is reliant on self-report, witness observation, EEG, close ward based observations, induction of the seizures through sleep prevention or functional MRI. SIGN (2003) suggests that the most important factors in the attainment of an accurate diagnosis are a clear patient history and eyewitness information.

The difficulties in diagnosing epilepsy definitively mean that the condition can often go undiagnosed. Differential diagnostic issues are abundant and Shorvon et al.

(2004) estimate that up to 30% of those with a diagnosis of epilepsy will have a further diagnosis. Conditions such as syncope, fatigue, non-epileptic seizures, anxiety and panic, can all present in similar ways to true epilepsy. As with the SIGN guidance, Shorvon et al. (2004) advocate an extensive investigation of all the factors surrounding the seizures before any diagnostic label is given. His reasoning behind this is not only to ensure that the patient receives the appropriate treatment, but also because the impact of a diagnosis of epilepsy can be detrimental to the person's overall life.

1.2.3 Epidemiology and Economics of Epilepsy

The reliance on observations and lack of a specific diagnostic marker can mean that accurate estimates of the incidence or prevalence of epilepsy are difficult to obtain. Sander and Shorvon (1996) consider that the current classifications are unsuitable for epidemiological purposes, due to the subjective nature of the diagnosis, the potential confounds of non-epileptic activity and confusion in the use of terminology.

The heterogeneity of the disorder means that it is difficult to understand the true epidemiology of the condition. The most common difficulties in estimating the prevalence and incidence of the condition lie in the areas of diagnostic accuracy and case ascertainment. Sander & Shorvon (1996) state that the difficulties in diagnosing epilepsy to the exclusion of other conditions mean that there are likely false positive and false negative effects in any epidemiological study of epilepsy.

However, given these noted difficulties, there are many studies that have attempted to understand the frequency of epilepsy within populations.

In Europe, Forsgren, Beghi, Oun & Sillanpaa (2005) conducted a systematic review of epidemiological studies from states within the European Union. In studies involving adults, they found a prevalence rate in the range of 5.3-6.3 per 1000 (median 5.5), with an overall all ages prevalence of 3.3-7.8 (median 5.2). The study also calculated incidence rates, with the three adult studies reviewed providing rates of 24, 56 & 35 per 100,000 person years. Overall the study suggested that given the difficulties observed with case ascertainment, an overall prevalence rate 6/1000 and an incidence of 50-55 per 100,000 person years could be estimated.

In Asia, Mac, Tran, Quert, Odermatt, Preux & Tan (2007) report a similar systematic review to Forsgren et al. (2005). They found a varied prevalence rate with a range between 1.5-14.0 per 1000 (median 6) and incidence rates of studies in China and India of 28.8-35 per 100,000 and 38-60 per 100,000 respectively. The authors noted a number of difficulties with the data, namely the use of differing diagnostic techniques across countries as well as the cultural attributions made towards people with a disability, possibly leading to a larger unknown number of people with the condition.

In the United States two studies by Hauser, Annegers & Kurland (1991 & 1993) provided estimates of the prevalence and incidence of epilepsy in America. Their studies found prevalence rates of 6.8 per 1000 of population and an incidence of

approximately 44 per 100,000 person years. Both studies were limited to one geographic area, meaning that there may be further geographic and cultural variations throughout the rest of the United States.

Studies from the African continent are less common, but Preux and Druet-Carbanac (2005) examined the prevalence and incidence of epilepsy in sub-Saharan Africa. The authors found prevalence rates discovered in door-to-door studies of a range of 11.8-20.4 per 1000 (median 15) and an incidence in the range of 63-158 per 100,000 person years. Again, methodological difficulties were noted in the areas of diagnosis, local knowledge and geo-cultural variation.

Within the UK, the prevalence and incidence is similar to that of Europe as a whole. MacDonald, Cockerell, Sander & Shorvon (2000) examined the incidence and prevalence of neurological disorders across a sample of English GP practices. They found a prevalence rate of 4 per 1000 and an incidence of 46 per 100,000 person years. In 1997, the Clinical Standards Advisory Group (CSAG, 2000) was instructed by the health minister to investigate the services for people with epilepsy. Their report also indicated that the reported prevalence within the UK of epilepsy was approximately 5-10 per 1000 and the incidence may be as high as 80 per 100,000 person years. Similarly, the NICE Guideline "The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care" published in 2004, indicated figures based on both the MacDonald et al (2000) and CSAG studies. There are no specific published results for the prevalence or incidence rates for Scotland rather than the UK, although it could be assumed that these would

be similar to those conducted in England given the geographical and cultural proximity.

Within the epidemiological data, there are a number of trends. Age differences are noted within the two main systematic reviews (Mac et al, 2007; Forsgren et al, 2005) with most studies reviewed suggesting that the peak ages for prevalence is childhood or young adulthood and the elderly. Gender differences (males > females) are also noted, but in most studies reviewed these differences are not significant. In terms of types of epilepsy, the systematic reviews suggest that the most common are partial seizures rather than generalised seizures, although Forsgren et al. (2005) do note that up to 20% of epilepsies are unclassifiable.

The overall prevalence and incidence of the epilepsies in a Western population can therefore be estimated to lie somewhere in the region of 5-15 per 1000 and 25-80 per 100,000 patient years.

The economic impact of the epilepsies has also been extensively investigated. Pugliatti, Beghi, Forsgren, Ekman & Sobocki (2007) examined the health economics of the epilepsies across the 25 European Union member states in addition to Iceland, Norway and Switzerland. They examined the reports from all the states regarding epidemiology and cost of illness and extrapolated these results to fit into a model of cost for the year 2004. They estimated that for a population of 3.4 million Europeans with epilepsy, the cost of treating the disease was 15.5 billion Euros per annum. Indirect costs made up the majority of this figure through working hours lost and

premature death. Direct healthcare costs approximated 2.8 billion Euros, and direct non-healthcare costs (such as social services or home adaptations) contributed 4.2 billion Euros per annum. The study unfortunately did not examine the cost of the psychological impact of epilepsy, though the authors expected this figure to be substantial.

Since epilepsy can be regarded as the most common neurological condition in the medical world, and its effects have an impact both on a societal and individual level, any interventions that could assist in the management of the condition and reducing the impact that the condition has on the individual should be investigated and encouraged.

1.2.4 Co-morbidity of Epilepsy

Epilepsy is often associated in the published literature with other health conditions. In theory, this is unsurprising given that the epileptic activity will often be secondary to the presence of conditions such as brain damage. However, there is good evidence that psychiatric difficulties can also occur at a higher rate in people with epilepsy than they would in the general population. Gaitatzis, Carroll, Majeed & Sander (2004) examined the rates of somatic and psychiatric diagnoses amongst a population of people with epilepsy and found that 41% received a psychiatric diagnosis during their three-year study period. Given this high prevalence rate, it is important to understand which conditions may be more likely in those with epilepsy and also to explain some of the reasons behind this apparent elevated risk.

Anxiety Disorders

The co-morbidity of anxiety disorders and epilepsy is well documented. Gaitatzis and colleagues (2004) found that 15% of their sample received a diagnosis of neurosis and 11% receiving a diagnosis of anxiety during a three year period.

Piazzini, Canevini, Marggiori & Canger (2001) examined 150 patients with partial epilepsy, 70 individuals with idiopathic generalised epilepsy and a control group (n=100). Levels of anxiety were assessed using the State-Trait Anxiety Inventory Scale (STAI-S, Speilberger, 1967). The results indicated that the epilepsy group displayed significantly higher levels of anxiety than the controls. The group with partial seizures were also significantly more anxious than those with idiopathic generalised seizures. Within the partial epilepsy experimental group, patients with Temporal Lobe Epilepsy displayed significantly higher levels of anxiety than those with frontal lobe epilepsy. No significant relationships were found between anxiety and either seizure frequency or the time since the onset of epilepsy. The authors concluded from the results that anxiety disorders are more likely to be a manifestation of specific changes in brain function, rather than as a reaction to the stigma of having or the difficulties in coping with epilepsy. Although the design of the study was robust, patients who were currently on medication other than anti-convulsants (such as anti-depressants or anti-anxiolytics) were excluded. This may have served to dilute the true level of anxiety amongst the population of people with epilepsy.

An important delineation when discussing the link between epilepsy and anxiety is to differentiate between what can be regarded as normative levels of fear or anticipatory anxiety, and what is an excessive or phobic reaction. This is highlighted by Baker (1997) who states,

> "..although many patients are fearful of their seizures, only a relatively small number develop a true phobic anxiety" Baker, 1997 p98.

Baker goes on to provide a description of how anxiety may come about as a result of epilepsy. He states that on one level there is the fear about the potential to have a seizure. This can be regarded as a general level of fear or anxiety, which will be affected by individual characteristics. This general anxiety can lead to appraisals concerning the possibility of death or injury as a result of the seizure. A further concern resulting from the fear of having a seizure is the possibility of stigmatisation resulting from being observed to have seizure. Both these direct and indirect fears, or threats to self, can feedback into the general fears, resulting in a degree of hypervigilance or hyperarousal. The hypervigilance can lead to negative appraisals and the hyperarousal could lead to a lowered threshold for a seizure. This explanation is displayed in Figure 1.

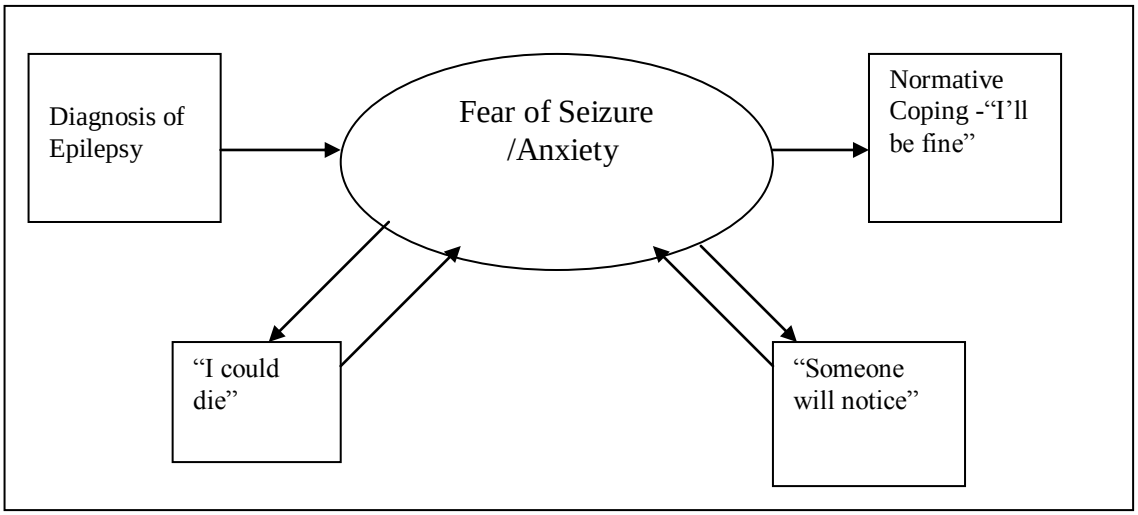


Figure 1: Anxiety model in epilepsy, based on Baker, 1997

Whatever the mechanism, the observation that those with epilepsy are at increased risk of experiencing anxiety disorders is one that requires consideration when professionals are working closely with those with the condition. This is important as although anxiety itself may or may not have an influence on the occurrence of seizures, it may have an impact on the person's overall level of wellbeing and functioning.

Depression and Suicidality

The prevalence of depression in those with epilepsy is much higher than that found in the general population. Harden (2002) estimates that depression is much more common in people with epilepsy than those in the general population, with a range of 9-22% in comparison with 1-8%.

The relationship between depression and the intractability of seizures has been investigated by Attarian and colleagues (Attarian, Vahle, Carter, Hykes & Gilliam, 2003). Using a cut-off on the Beck Depression Inventory-Second Edition (BDI-II, Beck, Steer & Brown, 1996) of 16 to indicate depression, the authors found that from 61 individuals with intractable epilepsy (defined as patients who had had seizures within a 6 month period and had already been on 2 or more anti-epileptic medications), 10 % displayed scores on the BDI-II associated with a diagnosis of depression. For those with well-controlled epilepsy (Defined as being seizure free for a period of 6 months or longer), 11% displayed symptomatic scores on the BDI-II. Analysis showed that there were no significant differences between the groups on measures of depression. Correlation analysis indicated that there was no relationship between seizure frequency and depression.

It should be noted that although this study produced useful data, they should be interpreted with caution. A low *n*, coupled with the use of a restricted range of measures, without a clinically based diagnosis, meant that factors such as patient perceived severity of the seizures and coping style were not included in the analysis. Also the use of the BDI-II may also have been a potential confound due to its emphasis on the physical indicators of depression, which may be attributable to the effects of epilepsy rather than true depression.

The results of Attarian et al. (2003) are useful in understanding the difficult nature of describing the mechanisms of depression in those with epilepsy. Intuitively, the effect of seizure frequency would appear to make sense; the higher level of intrusion

of the condition into one's world could lead to feelings of stigma, loss of control and ultimately depression. However, the relative lack of an effect indicates that perhaps alternative factors are implicated. Harden (2002), claims that it may be that the seizures themselves protect against depression through a crude form of electroconvulsive therapy, and provides evidence for this from a study by Robertson, Trimble & Townsend (1987) that reported a decrease in seizure frequency prior to the onset of depression. However, this study showed a number of methodological weaknesses, in particular a small sample size and inconsistent recording of seizure frequency.

One area where depression can be linked directly to the condition itself is peri-ictal depression. Occurring in less than 1% of patients with epilepsy, it presents as feelings of sadness and futility during the onset, duration or sequelae of the seizure itself (Aldenkamp & Hendriks, 2000). Patients often cite this change in mood as part of the aura that indicates the possibility of a seizure occurring (Kanner, 2003). Although the presence of peri-ictal depression has been linked to the changes in neurotransmitter functioning brought on by the occurrence of seizure activity, little is actually known about the mechanism of peri-ictal depression (Kanner, 2003)

Sleep disorders have been implicated as a possible factor in depression in epilepsy. Alanis-Guevara, Pen˜a,, Corona, Lo´pez-Ayala, Lo´pez-Meza. & Lo´pez-Go´mez, (2005) investigated the link between epilepsy and sleep disorder and found that in their sample, sleep disorders provided a significant proportion of the variance of

quality of life and depression in the final regression analysis. Part of this association may also be the impact that depression is known to have on sleep.

Genetic factors have received some attention in the aetiology of depression in epilepsy. Whilst a number of studies have indicated a higher rate of familial psychopathology in those with epilepsy and depression (Robertson et al. 1987), others have found levels similar to those within the general population (Robertson, Channon & Baker, 1994).

Suicidality in people with epilepsy has received a significant amount of attention within the literature. Whilst figures have fluctuated as treatments have improved (Blumer, Montouris, Davies, Wyler, Phillips & Hermann, 2002), there does seem to be an inflated risk of death through self-harm within this population. In a review of the literature, Matthews & Barbaras (1981) estimate that approximately 5% of people with epilepsy will die as a result of suicide compared to 1% of the general population.

Blumer et al. (2002) investigated the mechanisms that may contribute to the reported higher levels of suicidal behaviour and suicidality within the epilepsy population. They investigated a sample of 10739 patients in the United States over a 12-year period. During this period, 5 patients died as a result of suicide. Areas of commonality between the successful completers were, early age of onset, presence of complex partial seizures and high seizure frequency. Interestingly, the suicidal act occurred after a period of full seizure control through psychosurgery, vagus nerve

stimulation or medication. The authors felt that the psychosocial correlates were of little import in the overall contribution to the suicide, and that post/inter ictal psychopathology played a larger role. However, given the limited number of observed suicides in this study, it would be difficult to generalise these findings. The authors did note that the rate of suicide in their population was significantly lower than would normally be expected. They felt that the use of psychopharmacological measures in their sample was the main preventative factor in accounting for this lower rate.

Christensen, Vestergaard, Mortensen, Sidenius & Agerbo (2007) examined the risk of suicide in those with epilepsy. They investigated the association between epilepsy and suicide, with psychiatric diagnosis, socio-demographic factors and socioeconomic factors included in the analysis. Using a population sample, they found that the highest risk of suicide could be found amongst those who were newly diagnosed (defined as within 6 months of diagnosis) and who had a co-morbid psychiatric diagnosis. However, their analysis of this data also indicated that there is an increased risk of suicide in those with epilepsy even after psychiatric diagnosis was controlled for. The authors concluded that the pathology of epilepsy itself may increase the risk of suicide, independent of depression or anxiety.

The information presented above indicates that depression is more common in those with epilepsy than those in the general population. Although there is some disagreement regarding the mechanisms that lead to this increased risk, it is apparent

that this population is in need of greater psychological and practical support beyond that of controlling seizures.

Mortality, Illness and Sudden Unexpected Death in Epilepsy

People with epilepsy are at greater risk of early death than the general population (Yuen, Thompson, Flugel, Bell & Sander, 2007; Baker & Jacoby, 2007). Yuen et al (2007) report that the standardised mortality ratio for people with epilepsy usually lies between 2-3, although they do suggest that this figure can be as high as 4.1. Therefore, it would appear that individuals with epilepsy are 2-4 times more likely to experience premature death than an age/gender matched general population. This would mean that approximately 50-75% of the deaths in those with epilepsy arise from factors associated with the condition.

As well as the psychiatric co-morbidities noted within this chapter, other health conditions also occur at an increased level within the epilepsy population. One examination of the higher levels of physical co-morbidity indicated that people with epilepsy were at much greater risk of being diagnosed with dementias (such as Alzheimer's type), cancers, cardiovascular diseases and lung disease (Gaitatzis, et al., 2004). This in turn would increase the likelihood of premature death within this population.

A further area of discussion concerns sudden unexpected death in epilepsy (SUDEP). Annegers & Coan (1999) estimate that 20% of deaths in those with epilepsy could be as a result of SUDEP. Risk factors for SUDEP are acquired epilepsy arising from traumatic brain injury, intractability of the condition and possibly seizure severity (Annegers & Coan, 1999).

Psychosis

The reported link between the psychoses and epilepsy has troubled and intrigued researchers for many years (Toone, 2000). The belief within the field is that epilepsy acts as a risk factor for psychosis in the interictal stage, in particular a condition known as schizophrenia-like psychoses (SPLE). This presents, as the name would suggest, in a manner similar to the delusions associated with schizophrenia.

The published literature concerning the co-morbidity of epilepsy and psychosis is fraught with methodological difficulties. However, there does appear to be evidence that those with epilepsy have significantly higher levels of psychosis than chronically ill controls (Whitman, Hermann & Gordon, 1984). Toone (2000) suggests that there is a possibility that temporal lobe epilepsy may be associated with the development of psychosis, but there may also be a link with the age at which the individual's epilepsy first presented.

Toone presents two possible explanations as to the aetiology of psychosis in epilepsy (2000). A shared cerebral explanation for both the psychosis and the epilepsy, such as has been suggested in temporal lobe epilepsy is regarded as the most likely. In this theory, the cause of the epilepsy, either through a lesion or a tumour, also results in the development of psychotic symptoms. His second explanation suggests that seizure activity itself could result in the development of psychosis. However, he reports that neither of these theories has received substantial backing within the literature and concedes that, as with psychosis in the general population, the likely aetiology of psychosis in epilepsy will be multifactorial.

Cognitive Impairment

In the introduction to a special issue of *Epilepsy and Behavior* Albert Aldenkamp, Gus Baker and Kim Meador discuss the important multifactor causation of the cognitive impairments observed in those with epilepsy (2004). They argue that there are three important factors implicated in cognitive impairments associated with the condition. Firstly, the aetiology of the condition is important, as the structural difficulties that may be causing the seizures may also impact on an individual's cognitive functioning. Secondly, the seizures themselves can often lead to discreet or widespread damage to the brain. This specifically refers to the condition known as transitory cognitive impairment, a process by which a seizure may not noticed, but is marked by its symptoms of cognitive impairment (Baker & Jacoby, 2000) Finally, the side effects associated with treatment, be they pharmacological or surgical can also cause and contribute to the degree of cognitive impairment. To these three a

fourth could be added; the difficulties in managing the detrimental effects on employment and social opportunity associated with epilepsy. The relative lack of employment and the difficulties in maintaining or initiating positive social interaction may further contribute to cognitive impairment due to lack of opportunity to develop cognitive skills or through lack of stimulation.

Given the multiple co-morbidities apparent in those with epilepsy, it is important for both clinicians and researchers to be aware of the potential confounding and complicating factors that will be apparent in those with the condition. As will be discussed further within this chapter, people with epilepsy face many more challenges beyond the difficulties of experiencing seizures (Camfield, 2007).

1.2.5 Treatment of Epilepsy

Pharmacological Treatments

The historical discovery of the anti-convulsant medications used in regular clinical practice in western medicine is detailed above. Current practice in the United Kingdom advocates the use of anti-convulsant medications as a front line treatment in reducing seizure frequency following a diagnosis (NICE, 2004). Initial recommended treatment is for the older anti-convulsants (sodium valproate or carbamazepine) to be prescribed in the first instance, unless there are significant contraindications. Should this be the case, the guidance recommends the use of the newer classes of medication (i.e.gabapentin). Initially treatment should be continued

on a monotherapy basis, although polypharmacy can be deemed appropriate in individuals with intractable seizures.

The efficacy of pharmacological treatments of epilepsy is well established. In a descriptive study, Moran, Poole, Bell, Solomon, Kendall, McCarthy, McCormick, Mashef, Sander & Shorvon (2004), investigated the pattern of anti-convulsant drug use amongst a sample of 1652 people with a diagnosis of epilepsy. By means of a postal questionnaire, they found that the majority of their sample where on a monatherapeutic regime (68%). Carbamazepine, sodium valproate and phenytoin were the most commonly prescribed medications. Interestingly, 1.5% of the sample was not currently taking any anti-convulsant medication, which could be interpreted as a possible indication of non-adherence.

Adherence problems are common in chronic illnesses and epilepsy does not buck this trend (Jones, Butler, Thomas, Peveler, & Prevett, 2006; Buck, Jacoby, Baker & Chadwick, 1997). Leppik (1990) reports non-adherence rates of approximately 30-50% in a sample of patients with diagnosed epilepsy. The NICE guidelines for the management of epilepsy in children and adults (2004) present a number of factors associated with adherence rates (Table 2). Given that diminished life experiences appear to be linked to poorer adherence, it could be that improvements in quality of life may result in a higher adherence levels.

Good Adherence	Poorer Adherence
Aged over 60 years Aged over 19 years Once-daily dose Feeling that it is important to take medication as prescribed Finding the GP easy to talk to Concerned about health or health risks Absence of barriers, such as costs	Aged under 60 Teenager (aged under 19 years) Four-times daily dose Feeling stigmatized Experience of side effects Inability to obtain medication Diminished life experience

Table 2: Factors associated with adherence in epilepsy (Adapted from NICE, 2004)

Psychological Treatments

Psychological treatment of epilepsy has developed over many years and is now a common adjunct to treatment through medical techniques (Cull & Goldstein, 1997). The type of interventions reported are twofold; those which are aimed at the co-morbid disorders experienced by those with epilepsy and those aimed at disease specific areas such as seizure frequency.

Spector, Tranah, Cull & Goldstein (1999) investigated the effect of a group intervention using psychological approaches in reducing seizure frequency. Nine patients with intractable epilepsy were assessed regarding levels of anxiety and depression, social avoidance and distress, self-esteem and seizure frequency. Treatment consisted of eight, two hour sessions focussing on areas such as identifying triggers, dealing with stress and coping with negative emotions. The

results indicated that all of the participants who attended the group experienced a statistically significant reduction in seizure frequency, with an average reduction of 74%. The study was limited in terms of the number of participants, 2 of whom dropped out of treatment and were not included in the analysis. Furthermore, the lack of a control group makes it difficult to state that the noted improvements are directly attributable to the intervention.

In 2005, Ramaratnam, et al. (2005) conducted a systematic review of psychological treatments for epilepsy. They reported that the significant methodological deficiencies within the majority of the studies reviewed mean that the results of these studies cannot be considered valid. In those studies where the methodology was rigorous enough to be included in the review, the authors considered that relaxation therapy may provide a degree of benefit for seizure control. However, given the limitations of the studies reviewed, they were unable to make any conclusions regarding the efficacy of cognitive behavioural therapies in the treatment of seizures.

One area that has shown some promise in the psychological treatment of epilepsy is Acceptance and Commitment Therapy (ACT). ACT is based on the premise that individuals who avoid their experiences and cognitions in relation to their distress, are less likely to be able to cope with their difficulties. ACT concentrates on assisting individuals to begin to become more flexible regarding their symptoms and to choose solutions or behaviours that can provide them with the opportunity to successfully negotiate their experience (Hayes, Strosahl & Wilson, 1999). A recent study (Lundgren, Dahl, Melin & Kies, 2006) examined the effectiveness of ACT in a

population with intractable epilepsy. Using a randomised controlled design, participants were placed in either an ACT or supportive therapy group. The study aimed to examine outcomes including levels of quality of life and seizure frequency. The results indicated significant improvements for both quality of life and seizure frequency in the ACT group both at post-treatment and follow up. This suggests that ACT can have a positive effect on the incidence of seizures and also on quality of life.

Surgical Treatment

Surgery for epilepsy may appear to be a relatively new procedure, but the first procedures for relieving the symptoms were recorded in the middle ages, albeit with a view to allowing the 'humours and vapours' to leave the skull and relieve the patient from a demonic possession (Lüders & Comair, 2001). It was not until the late 19th Century that a more scientific approach was applied to the psychosurgery of epilepsy. Applied specifically to Jacksonian seizures (those with an identifiable lesion or injury site), these procedures involved the removal of a small circular piece of the skull in order to relieve pressure on the affected area of the cortex (known as trephination). Luders & Comair (2001) report that although these procedures produced reasonable success rates, the introduction of anti-convulsants meant that surgical options for the treatment of epilepsy were largely ignored for the first half of the 20th Century.

It was not until the 1940's that a resurgence in the surgical treatment of epilepsy occurred. However, limitations in brain imaging meant that it has only been in the last 20 years that surgery for epilepsy has become a more accessible procedure for those with the condition.

Surgery for epilepsy is often viewed as a radical and risky last resort (Wiebe, Blume, Girvin, Eliasziw, 2001). The NICE guidelines (2004) recommend that surgery should be provided as a tertiary care service following failure to gain adequate seizure control through the use of pharmacological methods for a period of two years and the use of at least two types of anti-convulsant medication. However, the guidelines state that epilepsy surgery is superior to long-term medical treatment in temporal lobe epilepsy. Although few robust studies exist, Weibe et al. (2001) report that 58% of their temporal lobe epilepsy sample were free from seizures impairing awareness compared to 8% in a matched medical sample. The authors reported that epilepsy surgery, where indicated, should not be viewed as a final intervention but as a primary treatment option.

A more recent addition to the treatment of epilepsy arose following the approval by the American Food and Drug Administration of a technique known as Vagus Nerve Stimulation (VNS). Although a full technical review of the procedure lies outwith the scope of this study, the technique appears to produce an effect through its impact on areas of the brain and central nervous. However, the exact mechanism of why it may have anti-epileptic utility is still not understood (Rutecki, 1990). The effectiveness of the treatment appears to be similar to that of the newer antiepileptic medications, although consistent results have not been found and further studies are

indicated (NICE, 2004). The NICE guidelines currently recommend that VNS be used as an adjunct to treatment in those who are not suitable for psychosurgery.

Current treatments for epilepsy are very much focussed on gaining either seizure reduction or seizure freedom. However, the limitations of the available interventions mean that for a number of patients, seizure freedom will not be a realistic aim.

1.2.6 Intractable Epilepsy

Although treatments for seizure activity have improved in both their effectiveness and tolerability, approximately 20-30% of individuals with a diagnosis of epilepsy will go on to have chronic or intractable seizures (Shorvon, 1991; Richens & Perucca, 1993; Chadwick, 1998). The likelihood of intractability is not universal, with those who experience partial seizures or seizures as a result of hippocampal sclerosis more likely to have ongoing seizures than those with generalised seizures (Semah, Picot, Adam, Broglin, Arzimanoglou, Bazin, Cavalcanti, & Baulac, 1998).

Surgery is often presented as the only option left for these individuals (Cull & Goldstein, 1997), although increasingly VNS is offered as an alternative. However, it is apparent that a significant number of those who are referred for tertiary level treatment continue to experience ongoing seizures. Therefore, it is vital that there is an understanding of how these individuals react to both their diagnosis and the consequences of living with a chronic health condition. As Cull and Goldstein (1997) suggest, it may be that psychological treatments and processes will be vital in the ongoing management of these patients.

One of the fears within the field is that those with intractable seizures are at greater risk of developing psychopathology. Attarian et al. (2003) examined the relationship between depression and the intractability of seizures. They found that intractability of seizures did not appear to have a relationship with levels of depression, suggesting that those whose seizures remain active are at no greater risk of depression than those who have achieved better control.

Although psychopathology does not appear to be increased in those with intractable epilepsy, quality of life for some does appear to be diminished for some. Baker, Smith, Dewey, Jacoby & Chadwick (1993) and Vickrey, Berg, Sperling, Shinnar, Langfitt, Bazil, Pacia, Kim & Spencer (2000) found that quality of life is significantly reduced in those with intractable epilepsy in comparison to those whose seizures were well controlled.

The attitudes of patients with intractable epilepsy towards treatment have also been explored. Swarztrauber, Dewar & Engel Jr (2003), used focus groups to ascertain how these individuals felt about living with intractable epilepsy. Most of the participants described difficulties in accessing employment and in maintaining positive social relationships. There was also evidence that the group felt significant frustration at the process of trying many different medications to control their seizures. This is an interesting finding as it implies that the aims of the medical interventions may be at a tangent with that of the patients.

It would seem that the intractability of seizures has a multifaceted effect on the lives of people with seizures. Although there is little evidence that this group is at a greater risk of psychopathology, it would appear that levels of quality of life can be diminished. It is important to try to examine how this may come to pass and then to find methods that can in any way redress this apparent difference.

1.3 Quality of Life

The advancement of medical science has resulted in an increasing ability for humanity to fight disease and prolong life. Whilst this has undoubtedly improved the overall wellbeing of the species in terms of increasing life expectancy and reducing preventable mortality, it has also produced a situation where the effects of disease management on longevity are promoted above the effects of the management strategy on the individual. This area is known as Quality of Life and suggests a focus beyond that of simple disease treatment with a more holistic approach to health outcomes.

When discussing quality of life in epilepsy, it is important to highlight the general theory behind quality of life research, before moving onto more specific epilepsy related discussion.

1.3.1 The History of Quality of Life in Healthcare

As a concept, quality of life has absorbed a great deal of interest both from the clinical and philosophical communities (Jacoby, 2000). Formal examination of quality of life began with earnest in the 1940's with Karnovsky's creation of a formal measure, the Karnovsky Performance Index (Karnovsky, Abelmann & Craver, 1948). Initially utilised to assess the overall efficacy of a new treatment for cancer, the measure was the first published instance of a medical appreciation of factors outside of disease progression and control.

Throughout the latter part of the 20th Century, research continued aimed at firming up both the concept and the measurement of the concept. With an increased emphasis on quality of life from within the medical fraternity and from the commercial sector, in the form of pharmaceutical corporations, the field expanded exponentially. Jacoby (2000) highlights this in her review of the topic by stating that a Medline search using the term "Quality of Life" for the years 1966-1970 yielded only 4 responses, whilst a similar search in 1995 produced 1000.

The rise in popularity of the topic has not been without controversy. Critics have argued that quality of life is often an overused term, vague in both its definition and its measurement (Bishop & Hermann, 2000). Betts (2000) challenges whether or not quality of life can be accurately measured and how relevant are the findings from studies using quality of life outcomes in determining the development of future medical care. He argues that there is a tendency for quality of life measures and outcomes to be used in terms of short-term outcomes applied to pharmacological trials. Correctly, he questions the relevance of a short term approach to examining and investigating quality of life, which can lead to a meaningless analysis of factors that will not contribute to the well-being of the patient. Betts (2000) advocates quality of life study and measurement as a means to further the understanding of the patient journey, thereby giving the clinician a more balanced and useful view of how therapy should be delivered.

1.3.2 Quality of Life in Epilepsy

There is a great deal of evidence to suggest that epilepsy can have a significant detrimental effect on the quality of life of those with the condition. From the physical effects of having the condition to the noted associations with psychosocial difficulties, the impact on the overall wellbeing of those with epilepsy can be both significant and detrimental.

Kendrick (1997) introduces factors that may impact on the quality of life of those with epilepsy. She conceptualises these factors into three domains of medical, social and psychological factors. Within the medical factors she cites the occurrence of the seizures (frequency & severity, medication intrusion and side effects) and hospitalisation. The social factors include stigmatisation, family factors such as overprotection, employment difficulties and legal restrictions including driving. Under psychological factors, she lists direct cognitive difficulties, intellectual decline and psychiatric difficulties.

Baker, Gagnon & McNulty (1998) investigated the relationship between quality of life and seizure type and frequency. Analysing data from the United Kingdom, France and Germany the authors found that both seizure type and seizure frequency were significant predictors of quality of life in the regression analysis with more severe seizures and more frequent seizures having a significantly poorer quality of life than those with infrequent or no seizures.

Leidy, Elixhauser, Vickrey, Means & William (1999) compared quality of life in people with a diagnosis of epilepsy and that of normal controls. Their study included an analysis of seizure frequency and its influence on quality of life within the epilepsy sample. The authors found that people with epilepsy who were seizure free had levels of quality of life similar to the age matched controls. Those who continued to experience seizures were found to have levels of quality of life significantly lower than both the seizure free group and the controls. Within the intractable epilepsy group, Leidy et al (1999) found that seizure frequency was a significant predictor of quality of life, with higher frequency negatively correlating with quality of life. Some weaknesses were apparent within the study. Patients who had a diagnosis of clinical depression were excluded on the grounds that their condition would have an impact on quality of life beyond that of the epilepsy alone. As stated previously, depression is a potentially co-morbid condition with epilepsy, and the exclusion of a potentially influential group of patients may have resulted in a bias within the sample towards those who were higher functioning. Also, the data for seizure frequency were categorised in the analysis into three 3 variables, rather than entered as raw scores. It could be that by using arbitrary cut-offs individuals were grouped inappropriately, resulting in possible bias.

The results of Leidy et al. (1999) were supported by a further study by Birbeck, Hays, Cui & Vickery (2002) who investigated the quality of life of individuals with epilepsy in various stages of seizure status. They found that improvements in quality

of life were most significant in those who had achieved seizure freedom. However, the authors were unable to detect a statistically significant difference in quality of life in terms of seizure frequency in those who did not achieve seizure freedom. This suggests that although seizure freedom is an important goal in treatment, it may be that in those for whom this is not possible, seizure frequency is less of an issue than was previously thought. The design of this study did not take into account any factors beyond seizure frequency. The authors concluded that seizure freedom was an imperative for any improvements in quality of life. However, this inference was based on the outcomes from measures solely focussed on quality of life and seizure frequency and did not take into account psychosocial variables. This study also excluded individuals who had an increase in seizure frequency of over 50% and as a result 5% of individuals were excluded from the final analysis. The authors did not report the reason for this decision, and it is possible that this may have made the sample unrepresentative.

Conceptually, the belief that good physical health equates to optimal quality of life is deep-rooted within the health professions. The assumption is that individuals with health problems are unable to achieve reasonable levels of quality of life (Albrecht & Devlieger, 1999). Albrecht & Devlieger examined the quality of life profile of 153 people with a wide range of disabilities from HIV/AIDS to mental health problems. Using a qualitative approach, the authors reported that 54.3% of people with serious disabilities had good or excellent quality of life. They compared this to the population with no disabilities who report good or excellent quality of life in 80-85% of cases. The analysis of the data indicated that common factors identified with better

quality of life in the disability sample were higher levels of social support, resilience and acceptance. This study was of good quality in terms of the scope of conditions that were included and also in terms of the high number of interviews that were analysed.

Gilliam & Kanner (2002) highlighted the importance of concentrating on factors beyond seizure frequency. They reviewed the data regarding the role of depression in the outcomes of quality of life for those with intractable epilepsy and concluded that much of the variance in the outcomes for those with epilepsy could be explained by disorders of mood, beyond any influence of seizure frequency.

This was confirmed by a study by Tracy, Dechant, Sperling, Cho & Glosser (2007), which investigated the contribution of depression and anxiety and seizure related variables in the quality of life of those with epilepsy. They examined the variables using stepwise linear regression and found that levels of depression accounted for the highest amount of the variance in quality of life, with only a small amount explained by the seizure related variables. The authors suggest that in any treatment model for epilepsy, psychological variables should be addressed as these can directly improve the individual's quality of life.

Gilliam, Kuzniecky, Meador, Martin, Sawrie, Viikinsalo, Morawetz & Faught (1999), analysed the outcomes from a group of 71 surgery patients and found that mood status provided the greatest account of the variance in the quality of life outcomes. Neither lower seizure frequency nor seizure freedom were associated with

improved outcomes. The results of this study indicate the difficulties in a treatment model that only examines the physical outcomes in epilepsy.

Bishop & Allen (2003) conducted one of the few qualititative studies to examine epilepsy and quality of life. Using a postal survey, 46 participants completed an open ended questionnaire that asked them to rate their quality of life and then to list aspects that they felt were important in helping them arrive at this rating, both positive and negative. Using an open-coding technique, the authors identified ten domains within three functional domains of intrapersonal, interpersonal and extrapersonal. The domains identified are listed in Table 3.

Intrapersonal	**Interpersonal**	**Extrapersonal**
Autonomy/Independence	Social Support	Work and Productivity
Physical Health	***Family Support***	Personal/Financial Security
Self Concept	Religion Spirituality	Leisure Activities
Mental Health		

Table 3: Domains identified from the participant's responses (Adapted from Bishop & Allen, 2003)

Further analyses were conducted to examine what issues were important contributors or detractors in quality to life to people with epilepsy. These items are listed, along with the number of participants who gave responses that were coded into each domain, in Table 4.

Contributors	Number of items	Detractors	Number of Items
Family Support/Relationships	***31***	Psychological Distress	16
Social Support/Relationships	18	Transportation Limitations	14
Religion/Spirituality	15	Stigma/Perceived Stigma	12
Leisure Activities	13	Restrictions on Freedom	12
Basic Needs Met	13	Seizures	10
Positive Self Concept	9	Cognitive Limitations	8
Employment	9	Seizure Worry	8
Health	8	General Health	8
Independence/Autonomy	7	Employment Restrictions	8
Seizure Control	5	Medication Effects	7
Helping Others	5	Health Care Problems	6
		Social Isolation	6
		Problematic Family Relationships	5

Table 4: Items identified as important contributors and detractors and the number of participants who reported them (Adapted from Bishop & Allen, 2003)

Participants in the study identified psychosocial factors as the primary factors that influence their quality of life, notably the influence of the family and the role played by psychological distress. Seizure control, health problems and the occurrence of seizures were less endorsed, but still relatively important. The results suggest that focus should be aimed at not only improving the clinical outcomes for people with epilepsy, but also in investing time in identifying those psychosocial factors that are important to the individual.

Johnson, Jones, Seidenberg & Hermann (2004) further examined the relationship of psychological variables in quality of life in epilepsy in comparison to seizure related variables. They found that the clinical variables (seizure frequency, seizure severity and duration of condition) did adversely affect quality of life in their sample. However when the psychological variables of anxiety and depression were included in the analysis, they became a more powerful predictor of the variance than the clinical variables. The authors concluded that any treatment of epilepsy must take into account the relative roles of psychological factors in order to provide the person with the best means to recovery.

Loring, Meador & Lee (2004) investigated the role of depression in quality of life. 115 patients with intractable epilepsy were identified and completed measures including the QOLIE-89, BDI-II and a measure of seizure worry. Regression analyses indicated that depression accounted for the greatest amount of variance within the sample ($R_2 = 0.45$), with seizure worry providing the next highest amount ($R_2 = 0.42$). Loring et al. (2004) reported that symptoms of depression and seizure worry are the two most important determinants of quality of life in intractable epilepsy.

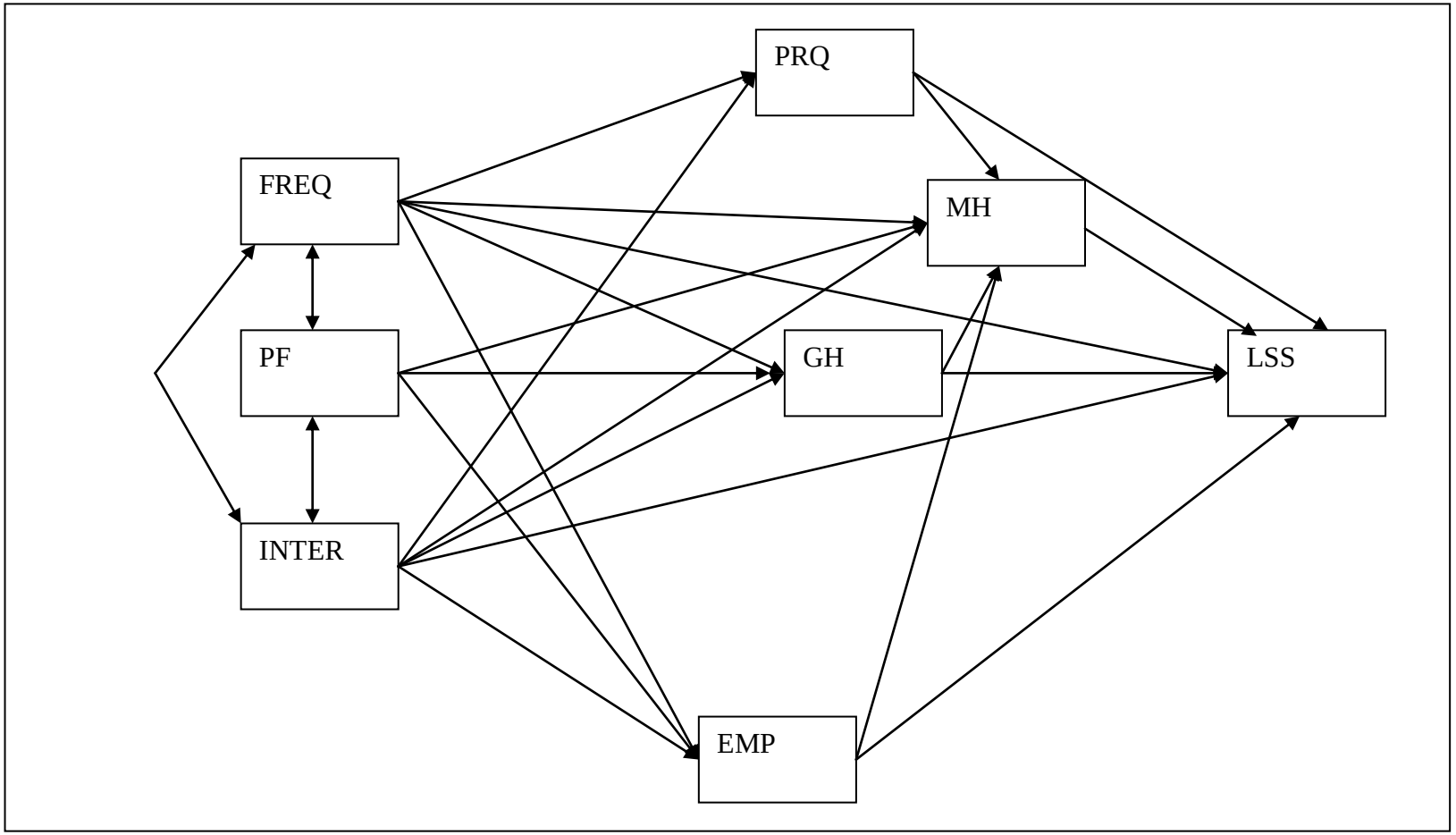
Jacoby & Baker (2008) explored the quality of life trajectory in people with intractable epilepsy. The trajectory of a condition is regarded as the course and likelihood of events occurring during the time scale of the illness. Using this model the authors examined the literature to identify the expected progression of quality of life. They argued that seizure frequency had little impact on levels of quality of life

and suggested that the severity of the seizures may be more important. It was also suggested that the quality of life of those with intractable epilepsy will likely rise and fall over the course of the condition. The likely cause of these changes would be the non-clinical aspects that are known to be associated with epilepsy, such as anxiety, depression and also resilience.

Bishop, Berven, Hermann & Chan (2002) evaluated an exploratory model of quality of life among adults with intractable epilepsy. They conducted a literature review to identify the pertinent physical, social and psychological variables that may affect quality of life. They included; perceived social support; physical function; perceived general health; mental health (freedom from anxiety or depression); employment status; seizure frequency and perceived interference by the seizures in daily life. In their initial model (Figure 2) they predicted that seizure frequency and seizure interference would be the strongest predictors of quality of life. The model was tested using path analysis and the relationships discovered between the variables prompted a revision of the model. Seizure frequency accounted for only 0.16 of the negative variance on quality of life, although it did have an indirect influence through its relationship with social support. Seizure interference had no direct relationship with quality of life, but did have an indirect influence through general health. The main direct contributors to quality of life were social support, general health and mental health. The study suffered from a low response rate (19%) meaning that the results may not be representative of the population with epilepsy. The measure used for quality of life was the Life Situation Survey (Chubon, 1995) and this scale is limited in that it focuses solely on situational factors of quality of

life. It may have been more appropriate to have used an epilepsy specific scale or a number of different scales.

Figure 2: Path Model of the interrelationships among seizure frequency (FREQ), physical function (PF), seizure interference (INTER), social support (PRQ), general health (GH), mental health (MH), employment (EMP) and quality of life (LSS). Reproduced from Bishop, Berven, Hermann and Chan, 2002.



Szaflarski, Meckler, Privitera, & Szaflarski (2006) conducted a regression analysis on data from a sample of 99 patients who had intractable epilepsy. The aim of the study was to examine the influence of the age of the patient, the age of onset of the seizures and the duration of the condition on their health related quality of life. Using the Quality of Life in Epilepsy-89 (Devinsky, Vickery, Perrine, Hermann, Meador, Hays, & Cramer, 1995), the authors found that current age was not a significant predictor of quality of life, but age at onset and duration of the condition were significant predictors. Seizure frequency also was not a significant predictor in their first regression model. However, they conducted further multiple regressions using measures of depression and adverse life events. When this was done, the inclusion of these variables accounted for all of the predictive relationship. Szaflarski et al. (2006) suggested that the focus of outcomes on the condition specific aspects of epilepsy, such as onset and seizure frequency, overlooks the influence psychosocial aspects and that of mood.

The evidence from this study highlights an important factor that may account for some of the observed trends in the literature. Although results concerning seizure type, frequency, duration of disease and many other factors have been found to have an association with quality of life in epilepsy, their influence may be masking the less obvious influence of psychological or psychosocial factors. The inconsistency of the results of these studies could be seen as an indication that there may be other explanations. Most of the studies discussed have neglected to include psychological or psychosocial factors. By focusing on the possible disease specific explanations of the observed variance of quality of life in those with epilepsy, perhaps the true causal

factors have been missed. This is not to exclude disease specific explanations of the variance, but is suggested merely to highlight that their influence may not be exclusive.

Suurmeijer, Reuvekamp & Aldenkamp (2001) examined the role of psychosocial factors in the quality of life of 210 outpatients with ongoing epilepsy. The aim of their study was to investigate the perceived differences in quality of life in epilepsy from a psychological perspective, in addition to the more traditional medical explanations of seizure frequency and perceived severity of seizures. In addition to measures of physical functioning, psychological distress was measured using the General Health Questionnaire (GHQ), self-esteem was measured using the Rosenberg Self-Esteem Scale (RSE). No specific measure of quality of life was used within the study. The scale that was used was the Visual Analogue Scale-Delighted-Terrible, which allowed participants to rate their quality of life on a ten point scale. The results of the investigation explained 44% of the overall variance in quality of life in their sample. Splitting the variables into three domains (physical functioning, social status and psychological status), the hierarchical regression showed that psychological status and social status explained 29% of the accounted variance, with physical functioning only accounting for 5%. The results are summarised in Figure 3.

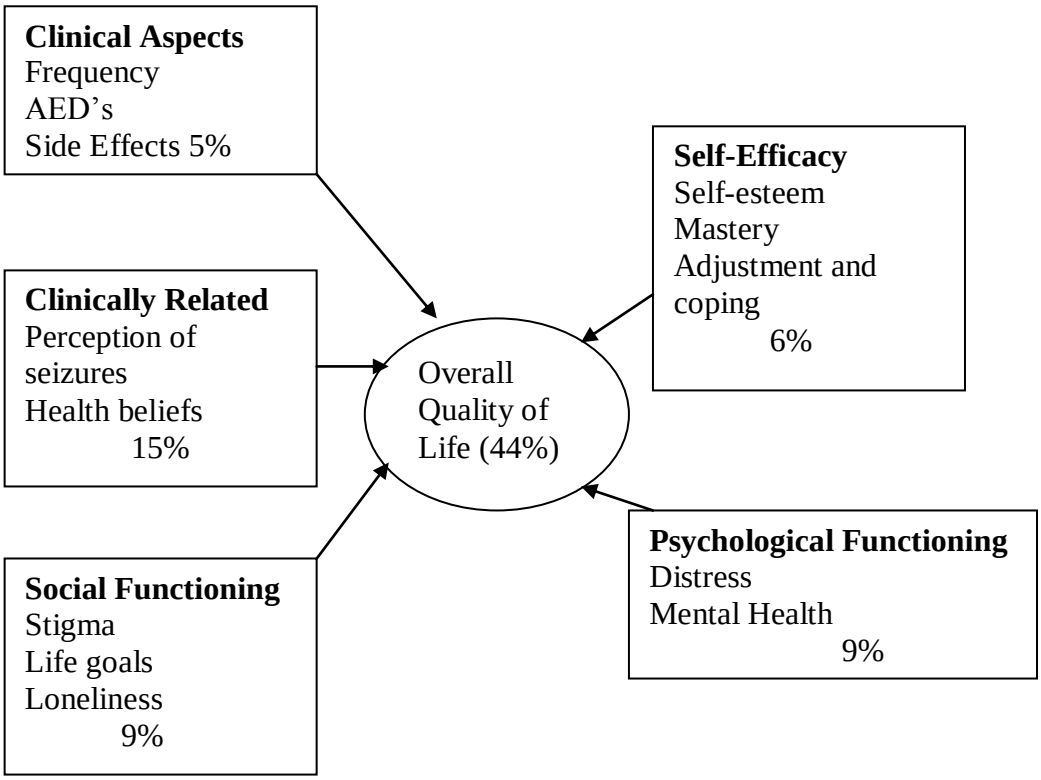


Figure 3: Variance explained by factors in study by Suurmeijer et al. (2001)

The results of the study by Suurmeijer et al. (2001) require careful interpretation due to methodological limitations. A visual analogue scale was used to assess quality of life. No reference for the scale was provided, meaning it was not possible to assess the suitability of the measure in this population. It may have been more appropriate to have used a more standardized scale to allow for future comparison.

The studies above have highlighted the limited impact of seizure frequency on quality of life in those whose seizures are intractable. They have also indicated that psychosocial variables may be important in the overall variance of quality of life. Therefore, it is important to examine which factors may impact negatively or

positively on quality of life. One are that has shown to have a significant impact on quality of life in those with epilepsy is stigma.

Stigma

Ann Jacoby, along with many of the other researchers in the field, has conducted a great deal of research into how stigma may impact on the quality of life of those with epilepsy. Although it is not possible to provide a comprehensive review of the conception of stigma, it can be loosely defined as the process by which an individual or group is deemed to be deviating from the societal or cultural norm, either in their behaviour or in their attributes. Some chronic health conditions can be viewed as stigmatising (Jacoby, Snape & Baker, 2005). Whilst diseases that are viewed to be outwith the individual's control are regarded in a more positive respect by others i.e. cancer, conditions where control is assumed to be more internally based are associated with higher levels of stigma (e.g. mental illness). Epilepsy can be viewed as stigmatising disorder, due to the relative lack of knowledge within the general public as to its causes and their fear of seizures and the subsequent deviation from societal norms (Temkin, 1971; Jacoby et al., 2005).

The process of becoming stigmatised for people with epilepsy appears to involve a process of two parts, both through the feelings associated with having a stigmatising disorder and with the actual process of being stigmatised (Jacoby et al., 2005).

That stigma impacts on quality of life in epilepsy is well documented. Jacoby, Baker, Steen, Potts & Chadwick (1996) investigated the link between stigma and quality of life and found a strong linear relationship (Jacoby et al., 1996). Further studies have also identified stigma as factor in quality of life in epilepsy (Hermann, Wyler, Anton. & Vanderzwagg, 1990; Baker, Brooks, Buck, & Jacoby, 2000). The notion of stigma has some relevance to the overall impact of psychosocial or psychological factors on quality of life. Stigma can be perceived as reducing an individual's acceptance of their condition and can be thought of as a moderating variable in their responses to epilepsy. Both of these factors are associated with the concept of resilience and may indicate that this concept may be implicated in the overall variance of quality of life.

In summary, the finding that the quality of life of those with intractable epilepsy can be diminished appears robust in the literature. However, the mechanisms of influence are less clear. It may be that stigma has a significant role, or it could be that many different factors combine to impact on quality of life. The intuitive approach would suggest that seizure frequency is the main moderator of quality of life. This is possibly supported by the reported evidence that suggests that those who are seizure free can achieve levels of quality of life similar to those without a chronic health condition. The difficulty in this approach can be seen with those who are not seizure free and still maintain high levels of quality of life. How can seizure frequency moderate this effect? Clearly, the role of seizure frequency in the quality of life of those with intractable epilepsy is less important than has previously been believed. It may be possible that factors similar to those reported by Suurmeijer et al (2001) could provide a better account

1.4 Resilience

The concept of resilience is a relatively under-researched within adult psychopathology. Recent advances have been made in the fields of chronic pain (Karoly & Ruehlman, 2006) trauma research (Davidson, Payne, Connor, Foa, Rothbaum, Hertzburg & Weisler, 2005) and sexual abuse (McClure, Chavez, Agars, Peacock, & Matosian, 2008) but the term still provokes some confusion within the health professions. The following chapter will present an outline of the history of resilience research, before examining some of the evidence from fields other than epilepsy. The section will end with an introduction to the mechanisms that may be at play if resilience is a factor in quality of life in epilepsy.

1.4.1 Historical Perspective

As a concept, resilience has been in the realms of academic research for many years. However, the difficulty in researching and defining such a wide-ranging concept has meant that only recently has the issue of resilience moved from the philosophical to the scientific.

Initial investigations into the concept of resilience were conducted in the field of the child development, specifically examining children of adults with schizophrenia. Garmezy's (1970, 1974) studies in this area were some of the first empirical investigations of people who displayed the trait of 'competence' in the face of extreme stressors (Luthar, Cicchetti & Becker, 2000). Out of this work, the focus of

the research regarding competence remained within the field of child development. There are many possible reasons for this, but the main issue appeared to be the traditional notion that the skills developed by children during the developmental phase, protected them from psychopathology in later life. It was felt that adults who presented with psychopathology had missed their opportunity to develop these skills, and therefore required treatment solely for their disorder, rather than examining the possibility that these competencies were amenable to lifelong change. This type of thinking regarding a fixed capacity for resilience typified what Richardson (2002) calls the first wave of resilience theory.

Dyer and Tusaie (2004) reviewed the literature concerning resilience. They explain that the development of the construct is rooted in two main areas of research. Firstly, psychological coping in the face of adversity laid the groundwork for interest in what factors mediated positive responses to psychological or environmental stress. Secondly, the increased understanding as to the physiological responses to stress meant that the interplay between physical symptomatology and psychological difficulties contributed to the idea that a concept could relate to both psychological and physical factors. Arguably, the two areas had previously been regarded as mutually exclusive. Therefore, the concept of resilience provides an overarching addition to the literature that attempts to explain the interplay between the psychological and physical responses to stress and adversity. Richardson (2002) states that the notion that resilience is a dynamic process in response to the presence of stress or adversity marks the arrival of the second wave of resilience theory.

Dyer and Tusaie (2004) go on to examine some of the literature behind the factors associated with resilience. They highlight two main areas of influence, namely intrapersonal and environmental factors. They state that the intrapersonal factors can be conceptualised as providing a protective shield from adversity or stress, with the environmental factors impacting on the development and action of the intrapersonal. These factors are listed in Table 5.

Intrapersonal and Genetic Factors	Environmental Factors
Optimism	Perceived Social Support
Intelligence	Life Events
Creativity	Parenting Style and Attachment
Humour	Marital Relationships
Positive Coping Strategies	Activities
Social Attractiveness	
Strong Belief System	
Strong Sense of Self	
Hardiness	
Educational Attainment	
Self-Esteem	
Stress Reactivity	

Table 5: Factors associated with resilience (Adapted from Dyer & Tusaie, 2004)

1.4.2 Resilience as a concept

As research into resilience continued, the concept of resilience moved away from the original theories of it being a fixed, finite resource into a more dynamic conceptualisation. As the theoretical progression continued, resilience began to replace many different concepts of positive reactions in the face of negative events, subsuming the notion of competence, unconscious defence mechanisms, risk vs. protection, hardiness and many others. As the concept continued to be more widely recognised through the late 20th Century, the rise of the movement of positive

psychology within psychological research began to expand the concept of resilience as a viable area of research across the lifespan and conditions. This idea of resilience as a concept can be viewed as the third wave of resilience theory (Richardson, 2002).

This third wave of resilience theory is typified by the understanding that an individual's resilience will wax and wane throughout the lifespan, depending on the outcomes of specific life events. This means that individuals and their systems can both foster and reduce levels of resilience (Richardson, 2002). Therefore, the conceptualisation is that although resilient qualities can be revealed by the presence of stress or adverse events, they are also a resource that reveals itself in everyday life and can be modified or damaged. This 'metatheory' of resilience marks the generally accepted thinking behind the concept at the current time. Therefore resilience can be defined as the possible outcome and the process by which an individual reacts to disrupting life events, either through positive adaptation, life stagnation or life digression (Kaminsky, 2006).

Bonanno (2005) discusses the importance of challenging the view that resilience is a relatively rare phenomenon. He states that resilience in the aftermath of trauma represents a distinct pathway in successful adaptation, separate from the pathways of recovery, chronicity or delayed reaction. The pathway to a resilient response involves a lower initial response to the stressor, followed by a continued return to normative functioning. Studies have shown that this pathway to resilience is the most common reaction to potentially traumatic experiences occurring in 35-55% of those who are

exposed (Bonanno, Moskowitz, Papa & Folkman, 2005; Bonanno, 2004; McFarlane & Yehuda, 1996)

1.4.3 Resilience across conditions and populations

As resilience has become more accepted as a definable and measurable concept, research into the application of the theory to areas across the medical, educational and commercial fields has expanded.

Davidson, et al. (2005) examined the effect of medication and CBT on levels of resilience in those who were being treated for post-traumatic stress disorder (PTSD). Ninety-two patients with chronic PTSD completed measures of resilience (CD-RISC, Connor & Davidson, 2003), trauma and disability. The sample were randomized into 4 groups[2] and following completion of treatment, pre/post total CD-RISC scores were analysed for the whole sample. The overall effect size for the group was 0.72, with Tigabine providing the highest improvement (ES = 1.06). They also reported improvements in the CBT group, albeit with a smaller effect size (ES = 0.55). However, they did report that the limitations of their study, namely a lack of a control and a small *n* mean that it is difficult to generalise the results. Also, the group receiving CBT did so as a 5 week adjunct following 10 of weeks of medication treatment. As well as being unable to separate the effects of the drug and the CBT, the limited duration of the psychotherapeutic input may mean that the effect size is perhaps less than it could have been.

[2] The groups were; Tiagabine, Fluoxetine, Sertraline and Sertraline followed by CBT

Karoly & Ruehlman (2006) investigated the role of resilience in the field of chronic pain. They conducted a comparison of the psychological correlates associated with resilience in two groups of individuals with matched levels of pain severity. The results indicated that the resilient sample showed significantly higher levels of positive coping, lower use of medication or medical services, lower levels of catastrophising and more adaptive attitudes to both their pain and their beliefs regarding the future. The authors couched the results of their study in terms of the self-regulatory approach to chronic illness (Bandura, 2005), suggesting that resilience can be viewed as the outcome of an adaptive process of integration of new goals within the framework of their ongoing health difficulties. One area where the authors highlighted a limitation with the study was in their assumption that levels of resilience would remain stable across the timeline of dealing with chronic pain. Karoly & Ruehlman suggest that the use of a longitudinal design could account for this deficiency. The method of recruitment in this study could also be criticised. Participants were contacted via random telephone number generation and screened for the presence of chronic pain using a standardised pain scale. If they provided responses above a designated cut-off, they were invited to take part in the study. At no point were the individuals interviewed regarding the cause of their pain or how their pain arose. It is possible that the sample selected may have been over-inclusive and may not have been a true representation of those with chronic pain.

Farber, Schwartz, Schaper, Moonen, & McDaniel (2000) examined the role of several factors within the concept of resilience (commitment, challenge and control) into the overall levels of psychological distress, quality of life and core self beliefs,

in a population of 200 patients with a diagnosis of HIV and AIDS. The results of the study indicated that the high levels of the resilience factors were associated with significantly lower levels of psychological distress, higher levels of quality of life and significantly more positive core beliefs. The conclusion made by the authors was that resilience has a strong influence on levels of psychiatric co-morbidity in people with HIV or AIDS.

Some research has examined the promotion of resilience within the workplace using a group-based treatment (Millear, Liossis, Shocet, Biggs & Donald, 2007). The authors examined the effect of an 11-week intervention based on a program entitled "Promoting Adult Resilience" (PAR). Twenty individuals taken from a workforce sample were allocated to the treatment condition, with a group of 51 volunteers from a work place well being program constituting the control group. Although no direct measure of resilience was used, outcomes included measures of coping self-efficacy and optimism, anxiety, depression, stress, life satisfaction and psychological well-being. Comparisons between the groups indicated that the PAR group improved significantly on measures of coping self-efficacy and optimism, depression and stress. The authors concluded that PAR program showed improvements on the factors associated with psychological resilience. Given that the sample was drawn from a non-clinical population, it is not possible to generalise the results to clinical cohorts. However, the results do suggest that treatment programs can be created that may have an effect on levels of resilience.

Coping

Although no studies exist that directly examine resilience and epilepsy, a number of investigations have been conducted into the influence of coping style, and how this can affect overall quality of life. Resilience is known to resemble the concept of coping, but the scale of the concept of resilience is much broader than that of coping (Karoly & Ruehlman, 2006). Both concepts share some commonality in terms of the self-awareness of an individual to make the best of their situation and these common factors would indicate that the literature on coping in epilepsy may inform as to the utility of applying the concept of resilience to the condition. Osterhuis (1999) examined the different types of coping in a population of adults with epilepsy and found that those who employed an active approach style of coping perceived their seizures as significantly less threatening. They were also less likely to have clinical symptoms of anxiety or depression.

Krakow, Buhler & Haltenhof (1999) investigated the coping behaviour of patients with intractable epilepsy. They examined the responses of 40 patients on measures of coping, depression, locus of control and psychosocial adaptation. The results of their analysis indicated that individuals who engaged in problem-focused and active coping strategies had better outcomes in terms of depression and psychosocial adaptation. The study suffered from a number of limitations. The sample used in the study were drawn entirely from an inpatient epilepsy population. This means that

results cannot be generalised to those in primary or secondary care. The study also used multiple correlations and it may be that a significance level of 0.01 would have been more appropriate than their chosen value of 0.05. Given that these styles of coping seem to correlate with the concept of resilience, it is clear that there is some utility in examining resilience in those with epilepsy.

1.4.4 Resilience and Quality of Life

The research literature indicates that the concept of resilience appears to be a reasonably acceptable possibility in providing an account of the reported variance seen in quality of life of people with epilepsy. All of the factors associated with resilience listed in Table 5, match well with those that are detailed to impact on the quality of life of those with the condition (Giovagnoli, Meneses & da Silva, 2006). Therefore, identifying those with epilepsy who have high or low levels of resilience, it may be possible to explain the reported discrepancies found in those whose seizure frequency does not appear to impact on their quality of life.

Lawford & Eiser (2001) examined the links between resilience and quality of life. They suggest that the concepts are similar in terms of their multi-dimensionality, variability, latency of the constructs and also in their component domains. They questioned whether the two constructs may be related, and if so, whether the relationship is one of mediation or has a more direct, causal effect. The argument put forward suggests that the concept of resilience should be included in any theoretical model of quality of life. The authors also highlighted the difficulties in examining

both concepts and the need for there to be a clear conceptual model allowing for an understanding of the relations between the factors that comprise the concept.

Jacoby & Baker (2008) outline the impact of quality of life "promoters" in epilepsy. They reported that the evidence suggests that factors associated with resilience, most notably optimism and positive affect greatly increase the likelihood of an individual having good quality of life. The authors suggest that these resilience factors will have a greater influence on the quality of life in those with intractable epilepsy.

In terms of how resilience can impact on quality of life in epilepsy, it may be useful to conceptualise this using the following model. The quality of life for an individual is threatened by many aspects including medical, social and psychological. These factors are then balanced by the strengths of the individual, be they internal or external. Although the balance of the system will be determined by the relative weights of the strengths and threats, the overarching concept of resilience will mediate the outcome. This model is based on the one proposed by Bishop, Berven, Hermann and Chan, (2002). If resilience is included in this model, the positive and detrimental factors may each be directly influenced by the levels of resilience. In some cases, resilience will negate the effect of the detrimental factors, thereby increasing the likelihood of a positive or stable response. In other cases, resilience will promote the impact of the positive factors, reducing the impact of the other factors. The quality of life of the individual will therefore be protected from negative experiences through the role of an individual's levels of resilience.

If resilience affects quality of life in epilepsy in this manner, the ability to predict how well an individual will cope with the intractability of their condition will provide a valuable tool in assessing future needs. Knowledge of this relationship will also allow for a better understanding of why some people with intractable epilepsy maintain reasonable levels of quality of life in spite of the chronicity of the condition. Finally, a better understanding of the relationship between resilience and quality of life would allow researchers to investigate whether changes in levels of resilience can bring about changes in quality of life.

1.5 Aims and Hypotheses

The aim of the study is to examine the role of resilience in the quality of life in those with intractable epilepsy. Levels of anxiety, depression and seizure frequency will also be investigated, as the literature indicates that these factors may also display a relationship with quality of life.

1.5.1 Hypothesis 1

Levels of psychological resilience will be significantly positively associated with quality of life in individuals with intractable epilepsy.

1.5.2 Hypothesis 2

Resilience will be a stronger predictor of quality of life in people with epilepsy than seizure frequency.

1.5.3 Hypothesis 3

Resilience will be negatively associated with measures of anxiety and depression.

CHAPTER 2: METHODOLOGY

2. Methodology

2.1 Design

The study incorporated a within subjects design with all participants completing the experimental questionnaires measuring quality of life, anxiety, depression, resilience, seizure frequency, employment and marital status, geographic location and educational attainment. Resilience, seizure frequency, and levels of anxiety and depression were included in the multiple regression on quality of life.

2.2 Ethical Issues and Approval

During the design of the project, a number of steps were taken in order to address ethical concerns. The main tool for providing potential participants with reassurance and information was through the use of a general information sheet. When creating the sheet, care was taken to ensure that potential participants were aware that their ongoing care would not be affected by participation in the study. It was also explained to potential participants that anonymity would be ensured and that the investigators would have no access to patient files. It was explained that the data collected would only be accessed by the main researcher and would be stored on NHS property on a password protected computer. The potential risks of participation were also highlighted and the availability of further support if required was explained. Individuals were considered to have given implied consent if they

returned their questionnaires as informed consent would have compromised anonymity.

Ethical approval for the study was sought from the Tayside Committee on Research Ethics (Study Reference: 08/s51401/11) and from the University of Edinburgh Clinical Psychology Course Organising Committee. A change was made to the procedure by the Tayside committee, through the inclusion of an emergency contact in case of the study causing distress to the participants. Both the lead researcher and his direct clinical supervisor were included as emergency contacts. Although contact through these means would compromise the anonymity of the participant, it was felt that the inclusion of this was essential to ensure adequate patient safety.

2.3 Participants

Individuals were offered an opportunity to enter the study if they were aged between 16-65, with a confirmed diagnosis of epilepsy and the presence of at least one seizure in the past six months, despite the use of anti-convulsant medication. Participants were excluded from the study if they had a current diagnosis of intellectual impairment or were actively psychotic. 223 patients were identified who met the inclusion criteria within the study period.

2.4 Measures

The participants completed three experimental questionnaires. These were: The Quality of Life in Epilepsy Inventory- 31 (Cramer, Perrine, Devinsky, Bryant-Comstock, Meader, & Hermann, 1998), The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Connor-Davidson Resilience Scale (Connor & Davidson, 2003). They also completed a general clinical and demographic information sheet. A pilot of the measures with five healthy controls indicated that the measures would take between 20-30 minutes to complete. The participants were also provided with an information sheet regarding the study, both in terms of the overall aims and explaining what would be done with the data collected. Measures and information sheets are included in Appendices I-IV.

2.4.1 The Quality of Life in Epilepsy Inventory-31

This Quality of Life in Epilepsy Inventory-31 (QOLIE-31, Cramer, Perrine, Devinsky, Bryant-Comstock, Meader. & Hermann, 1998) is based on the Quality of Life in Epilepsy Inventory-89 (QOLIE-89, Devinski et al., 1995). The QOLIE-31 was devised by examining the factor loading of those items that were rated as most commonly important to people with epilepsy. The scale consists of 31 items organised into seven subscales—Seizure Worry (5 items), Emotional Well-Being (5 items), Energy/Fatigue (4 items), Social Functioning (5 items), Cognitive Functioning (6 items), Medication Effects (3 items), Overall Quality of Life (2 items)—and an additional item assessing overall health status. The raw scores are rescaled from 0 to 100, with higher values reflecting better QOL. Scores on the QOLIE-31 can be converted into T-scores, with a mean of 50 and a standard deviation of 10. In the current study, the raw QOLIE-31 scores were used.

Reliability and validity are well established (Steinbuchel, Heel & Bullinger, 2000). The scale is widely used both in research and clinical practice and is the most frequently used assessment of quality of life in people with epilepsy (Cramer et al., 1998). Internal consistency has been reported as lying between 0.77 and 0.85, with test-retest reliability ranging from 0.64-0.85 (Cramer et al., 1998). Written permission for use of the QOLIE-31 was obtained from the author. The scale has been translated and normed into numerous languages including Portuguese (da Silva, Ciconelli, Alonso, Azevedo, Westphal-Guitti, Pascalicchio, Marques, Caoclo,

Cramer, Sakamoto & Yacubian, 2007) Italian (Beghi, Mauro, & Roncolato, 2005), German, Danish, Spanish, French & Swedish (MAPI, 1996).

2.4.2 The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a 14-item self-report questionnaire, commonly used to screen for symptoms of anxiety and depression. The 14-items can be separated into two 7-item sub-scales for anxiety and depression. Respondents are required to read each of the items and to indicate how much they agree with the statement on a 4 choice, 3-point scale. This provides a maximum score of 21 for each sub-scale. Scores can be placed on 4 ranges; 0-7 normal; 8-10 mild; 11-15 moderate; 16-21 severe (Snaith & Zigmond, 1994). The scale has been found to display good levels of concurrent validity, with a medium to large correlation with other measures of depression and anxiety, such as the BDI-II (0.62-0.73) and the STAI-S (0.64-0.81) among others (Bjelland, Dahl, Haug & Neckelmann, 2002).

Sensitivity and specificity levels have been reported to be approximately 0.80 when the scales use a cut-off score for anxiety and depression of greater than or equal to 8. Internal consistency has also been investigated and appears to be robust, falling in the range of 0.68-0.93 (Bjelland, Dahl, Haug & Neckelmann, 2002). The scale is used extensively in clinical practice and has been administered in numerous research studies involving people with epilepsy (Baker, Smith, Dewey, Jacoby & Chadwick, 1993; Jacoby, Baker, Steen, Potts & Chadwick, 1996). The HADS is also regarded as

a more accurate measure of mental health in people with epilepsy than other measures of depression and anxiety (BDI-II; BAI), due to its emphasis on the behavioural and emotional symptoms of mental health, rather than on the physical symptoms that could potentially be a consequence of epilepsy rather than a mood disorder.

2.4.3 The Connor-Davidson Resilience Scale

The Connor-Davidson Resilience Scale (CD-RISC) is a brief self-report measure of resilience, defined by the authors of the scale as embodying the personal qualities that allow an individual to thrive in the face of adversity. The development of the scale was an expansion of work by Kobassa (1979) on the concept of hardiness and from Rutter and Lyons' (Rutter, 1985; Lyons, 1991) research into strategy generation and stress coping.

The CD-RISC contains 25 items, all of which carry a 5-point range of responses, as follows: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4). The scale is rated based on how the subject has felt over the past month. The total score ranges from 0–100, with higher scores reflecting greater resilience. The authors of the scale report that it shows good levels of internal consistency (Cronbach's $\alpha = 0.89$), good levels of test-retest reliability ($r = 0.87$) and good convergent validity (Connor & Davidson, 2003). The development of the scale was conducted on both a sample from the general population and in a variety of

clinical conditions. Ahern, Kiehl, Sole & Byers (2006) evaluated the CD-RISC in comparison with 5 other measures of resilience and concluded that the scale is valid and reliable for use in the adult population.

The scale is widely used in the research community, with studies using it to examine resilience in post traumatic stress disorder (PTSD) with adults, children and in terms of psychological functioning in older adults (Lamond, Depp, Allison, Reichstadt, Moore, Golshan, Ganaits & Jestes, 2008; Davidson, Payne, Connor, Foa, Rothbaum, Hertzburg & Weisler, 2005). The scale has also been utilised with adult anxiety disorders and self-esteem (Benetti & Kambouropoulos, 2006; Campbell-Sills, Cohan & Stein, 2005, Pollack, Stein & Davidson, 2004), chronic pain, cancer (Karoly & Ruehlman, 2006; Aspinwall & MacNamara, 2005), HIV and many other health conditions.

Normative scores have been established for a number of conditions including individuals with PTSD, Generalised Anxiety Disorder, an inpatient psychiatric population, general psychiatric outpatients, general primary care populations and the general population (Connor & Davidson, 2003).

2.4.4 General Information Sheet

The general information sheet was created by the lead investigator in order to capture information regarding the clinical and demographic variables of the cohort.

Information regarding gender, age, marital status, educational achievement, seizure frequency, and area of residence were included within the sheet. The information for seizure frequency was obtained by asking respondents to self-report the number of seizures they experienced in the previous six months.

2.5 Site of Study

The Neurology Department of Ninewells Hospital provides neurological services for Tayside and part of Fife (population about 500,000) with clinics in Ninewells Hospital, Perth Royal Infirmary and Arbroath Infirmary. In Ninewells Hospital there is a 14 bed Neurological Unit with a full supporting staff in Physiotherapy, Occupational Therapy, Speech Therapy, Medical Social Work and Clinical Psychology. There is a full range of Clinical Neurophysiological and Neuroradiological services. In addition to general new and review neurological clinics, specialist clinics are held for epilepsy, with outpatient review supported by a specialist nurse in epilepsy. Epilepsy clinics are held on a weekly basis and internal departmental statistics indicate that in a three-month period (January-March 2008), 286 patients were seen for reviews of their condition. This projects to an average yearly capacity of 1144 patient contacts.

NHS Scotland provides specialist Neurology services in 4 areas (Tayside, Lothian, Greater Glasgow and Grampian). Although the composition of these services is heterogeneous in terms of staffing and facilities, the population coverage and staffing ratios are similar (NHS Scotland, Information Service Division, 2005).

2.6 Procedure

Individuals were recruited to the study through contact with their outpatient consultant neurologist in the Neurology Department at Ninewells Hospital, Dundee. All patients referred to the service would have experienced at least 1 seizure confirmed by EEG or through self-report, and would have undergone assessment by the consultant neurologist.

During their review appointment, potential participants were informed that they were invited to participate in a study examining quality of life in epilepsy. If the patient indicated a desire to participate, they were provided with an information pack detailing the background information of the study, contact details and the experimental measures. This pack was to be taken home for completion and the experimental measures returned to the main investigator by pre-paid envelope. Patients were informed that their responses would be entirely voluntary and would remain anonymous. They were also informed that should they feel that they wished to discuss the study, they would be able to contact the main researcher in the first instance, although this would break some of their anonymity.

The consultant screened for eligible patients during their preparation for the review appointments, and all of those who met the required criteria would be invited to take part in the study by either the consultant or the specialist nurse in epilepsy. Information was recorded by each clinician regarding the age, gender and diagnosis

of each patient who was provided with a pack, in order to record the overall characteristics of the invited sample for comparison with those who actually agreed to participate.

2.7 Data Analysis

All analyses were conducted using the Statistical Package for Social Sciences, Version 12. Hypothesis 1 stated that resilience would display a significant positive correlation with quality of life. To test this association, a Spearman's correlation was conducted on the data for resilience and quality of life. Hypothesis 2 stated that resilience would account for a greater level of the variance in quality of life than seizure frequency. A stepwise regression was conducted on the data for quality of life, with resilience, anxiety, depression and seizure frequency as the independent variables. Hypothesis 3 stated that resilience will be significantly negatively associated with levels of anxiety and depression Spearman's correlations were conducted.

The strength of the relationships between variables for the correlations was analysed in line with Cohen (1988), who suggested that a small relationship would fall in the range of r = .10 to 29. A medium effect would fall in the range r = .30 to.49 and a large association would be in the range of .50 to 1.0 (both positive and negative valences included).

2.8 Statistical Power

Statistical power was calculated using the package G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). For hypotheses 1 and 3, a sample of 85 was calculated as being acceptable for a parametric correlation to obtain a power of .8, with a medium effect size of .3 and an error probability of 0.05. As the correlations were non-parametric, this number was multiplied by 1.1 to obtain a required sample size of 94 (Clark-Carter, 1997). For hypothesis 2, the results of the power calculation indicated that for a power level of 0.8, with a medium effect size of 0.15, and an error probability of 0.05, the required number of participants would be 85. The calculation was conducted under the assumption that 4 variables would enter the regression analysis.

CHAPTER 3: RESULTS

Chapter 3: Results

3.1. Demographic Variables

Before conducting statistical analyses, the data were investigated in terms of demographics. 223 individuals were invited to take part within the study. Sixty individuals returned the questionnaires, giving a return rate of 26.9%. Of the 60 who participated in the study, 28 (46.7%) were female and 32 (53.3%) were male. The mean age of the participants was 37 (Standard Deviation = 11.2, range = 21-59). In order to evaluate whether the experimental group was representative of the available sample, data on age and gender was collected for all individuals who were invited to participate in the study. Table 1 demonstrates that age and gender for the experimental group was similar to that of the overall available sample. An unpaired samples t-test showed that the groups did not differ significantly in terms of age ($t = 0.062$, $p = 0.950$). Chi-square analysis confirmed that the groups did not differ significantly in terms of their gender ($x2 = 0.085$, $p = 0.770$).

	Whole Sample n = 233	Experimental Group n = 60
Age	Mean 36.9 SD 11.45	Mean 37.0 SD 11.17
Gender	126 female (56.5%) 97 male (43.5%)	28 female (53%) 32 male (47%)

Table 1: Means and percentages for the experimental group and the whole sample

Demographic data is outlined in Table 2. Of those who participated 56.7% were married, 33.3% single and 10% in a long-term relationship. Thirty percent of the participants had some secondary, 50% college education and 20% with a University education. Employment status was 46.7% employed full-time and 8% unemployed, whislt 36.7% were employed on a part-time basis. Geographically, the individuals who returned questionnaires were predominantly from the Dundee metropolitan area, although 22% resided in rural areas.

Gender	Male Female	n = 32 (53%) n = 28 (47%)
Age	Mean age SD = Range	37 11.167 21-59
Marital Status	Single Married Long-term partner	n = 20 (33.3%) n = 34 (56.7%) n = 6 (10%)
Educational Attainment	Secondary College University	n = 18 (30%) n = 30 (50%) n = 12 (20%)
Employment Status	Full Time Part Time Self Employed Student Homemaker Without Employment	n = 28 (46.7%) n = 22 (36.7%) n = 1 (1.7%) n = 2 (3.3%) n = 2 (3.3% n = 5 (8.3%)

Table 2: Demographic data for the experimental group

The means and standard deviations for the experimental group for measures of quality of life, seizure frequency, anxiety, depression and resilience are displayed in Table 3.

	Mean	Standard Deviation
Anxiety	7.31	4.35
Depression	5.37	4.75
Resilience	61.80	9.96
Seizure Frequency	14.98	9.97
Quality of Life	61.42	1.53

Table 3: Means and Standard Deviations for main experimental measures

3.1.2 Exploration of the Data

Prior to statistical analysis, the data were examined in terms of their distribution. The presence of skewness or kurtosis was examined for the variables of quality of life, depression, anxiety, seizure frequency and resilience. This was done by calculating the ratio of the possible skewness or kurtosis with its standard error. Depression and anxiety showed a positive skew. Resilience showed a significant level of kurtosis and visual examination of the data indicated a bi-modal distribution. Quality of life also displayed a slight bi-modal distribution. Seizure frequency was found to be normally distributed.

Given the deviations from normality demonstrated by the variables anxiety, depression, resilience and quality of life and their non-interval nature, non-parametric Spearman's correlations were used to test hypotheses 1 and 3.

In order to test Hypothesis 2, a stepwise regression was required. In order to enter the data for resilience into the equation, the data was recoded into two categories based

around the median of the score for the scale. The dichotomised data were used solely in the regression analysis, with all subsequent analyses including resilience using the raw scores. Depression and anxiety also showed elements of a non-normal distribution, but the decision was made that they were to be included in the regression due to the robustness of the test to violations. The distributions of the variables are displayed in Appendix VII.

3.2 Hypotheses Related Data Analysis

3.2.1 Hypothesis 1

Levels of psychological resilience will be significantly positively associated with quality of life in individuals with intractable epilepsy.

A Spearman's correlation was conducted on the data for quality of life, measured by the Quality of Life in Epilepsy Scale-31 (QOLIE-31) and resilience, measured by the Connor-Davidson Resilience Scale (CD-RISC). A large significant positive relationship was found ($r = 0.818$, $n = 60$, $p < 0.001$) indicating that higher levels of resilience are associated with higher levels of quality of life. A scatterplot of the relationship between quality of life and resilience is displayed in Appendix V.

3.2.2 Hypothesis 2

Resilience will be a stronger predictor of quality of life in people with epilepsy than seizure frequency.

A stepwise regression was conducted with quality of life as the dependent variable and resilience, seizure frequency, anxiety and depression as the independent variables. Correlations indicated that seizure frequency did not show a significant relationship with quality of life. However, the decision was made to include seizure frequency in the analysis as previous studies have found it to be a factor in quality of life. As mentioned previously, data on resilience were recoded into two categories around the median, in order to satisfy parametric assumptions. No multicolinearity was found within the data.

Stepwise regression identified two variables that accounted for approximately 79% of the variance in quality of life. Resilience accounted for 77% (R2 = .775) with depression accounting for 2% (R2 = 0.015). Neither anxiety nor seizure frequency were found to contribute to the model. Table 4 displays the standardised betas, t-values and significance levels for all the variables in the regression model.

	Standardised Beta	t statistic	Significance
Resilience	.748	8.383	<0.001
Depression	-.180	-2.016	<0.05
Anxiety	-.158	-1.198	>0.05
Seizure Frequency	.188	1.434	>0.05

Table 4: Betas, t statistics and significance levels for the stepwise regression on quality of life

3.2.3 Hypothesis 3

Resilience will be negatively associated with measures of anxiety and depression.

Spearman's correlations were conducted between resilience (CD-RISC), anxiety and depression, as measured by the Hospital Anxiety and Depression Scale (HADS). The results indicated that resilience and anxiety showed a large significant inverse relationship ($r = -.707$, $p < 0.001$) and resilience and depression also showed a large significant inverse relationship ($r = -.667$, $p < 0.001$). Scatterplots of the relationships between resilience and anxiety and depression are displayed in Appendix VI.

3.3 Exploratory Analyses

Further examination of the data was conducted to investigate the effects of levels of anxiety and depression on quality of life. The data were also investigated in terms of the demographic variables and their relationship with quality of life. A final analysis was conducted to investigate whether the group differed on measures of resilience and quality of life dependent on the presence of significant symptoms of anxiety or depression.

3.3.1 Anxiety, Depression and Quality of Life

Spearman's correlations were conducted between quality of life and both anxiety and depression. There was a large significant inverse relationship between anxiety and quality of life, ($r = -.706$, $n = 60$, $p < 0.001$). A similarly large significant inverse relationship was present between depression and quality of life, ($r = -.711$, $n = 60$ $p < 0.001$).

3.3.2 Marital Status and Quality of Life

Marital status was recoded into two variables; relationship or no relationship. A Mann-Whitney test was conducted to determine whether there were any statistical differences between those who were in a relationship and those who were not. The results indicated that there was no significant differences between the groups ($U = 397.5$, $p = 0.975$).

3.3.3 Education Level and Quality of Life

The relationship between education level and quality of life was examined by separating the group into three separate groups. These groups consisted of those who had only a secondary education, those who had a college education and those who had attended university. A Kruskal-Wallis test identified no statistically significant differences in quality of life across the three groups ($KW = 5.598$, $p = 0.0609$).

3.3.4 Employment and Quality of Life

The majority of the sample were in some form of employment (n = 50). Therefore, it was not possible to compare the group in terms of those who were employed and those who were not. However, analysis was conducted to investigate if there was any difference in quality of life of those who were employed full-time and those who were employed part-time. A Mann-Whitney test was conducted and the results indicated that there was no significant difference in quality of life between those who were in part-time employment and those who were in full time employment (U = 286, p = 0.674).

3.3.4 The Impact of Anxiety on Resilience and Quality of Life

The group was separated in terms of levels of anxiety into two groups; low anxiety or high anxiety. The Hospital Anxiety and Depression Scale currently has cut-off scores ranging from 0-7 for low symptoms, 8-10 for mild symptoms, 11-15 for moderate symptoms and >16 for severe symptoms. Individuals who scored 10 or less were placed in the low anxiety group and individuals who scored 11 or greater were placed in the high anxiety group. The medians and range for the groups are displayed in Table 4.

	Quality of Life	Resilience
High Anxiety (n 21)	Median 48.7 Range 44.3-67.2	Median 51 Range 44-72
Low Anxiety (n 39)	Median 68.0 Range 42.1-79.6	Median 68 Range 45-78

Table 5: Medians and ranges for the anxiety groups on measures of resilience and quality of life

A Mann-Whitney test revealed that the groups differed significantly in terms of quality of life, with higher levels of quality of life being found in the low anxiety group ($U = 83$, $p < 0.001$). A further Mann-Whitney test indicated that the groups differed significantly in terms of resilience, with higher levels of resilience being found in the low anxiety group ($U = 82$, $p < 0.001$).

3.4 Summary of Results

There was a large, positive significant association found between resilience and quality of life. Therefore higher levels of resilience were associated with higher levels of quality of life, supporting hypothesis 1.

The results of the regression analysis indicated that resilience was a statistically significant predictor of quality of life. Seizure frequency did not provide a significant account of the variance. Therefore resilience was a stronger predictor of quality than seizure frequency in the current sample, which supports hypothesis 2.

Resilience displayed large and statistically significant negative associations with both anxiety and depression. Therefore, higher levels of resilience were associated with lower levels of both anxiety and depression, which supports hypothesis 3.

CHAPTER 4: DISCUSSION

Chapter 4: Discussion

4.1 Summary of the Research

It has been suggested that factors beyond clinical symptoms may have an important role to play in the quality of life of those with epilepsy (Tracy et al., 2007; Johnson et al., 2004; Bishop et al., 2002). Researchers have estimated that psychosocial variables such as anxiety, depression, stigma, self-esteem and self-efficacy, may account for approximately 20-30% of the explained variance in the quality of life of people with epilepsy (Loring et al, 2004;Bishop et al., 2002; Suurmeijer et al., 2001).

One psychosocial factor that has not received attention in epilepsy is psychological resilience. Resilience can be regarded as the process and outcome of positive reaction to stressful events (Kaminsky, 2006). The utility of investigating the role of resilience in the quality of life of those with epilepsy is informed from studies examining resilience in other chronic health conditions (Karoly & Ruehlman, 2006; Faber et al. 2000). The research in other conditions has suggested that psychological resilience can play an important protective role in allowing people to maintain good levels of functioning in spite of their difficulties.

The primary aim of this study was to examine the role of psychological resilience in the quality of life of people with intractable epilepsy. Factors that may explain the variance in quality of life in those with epilepsy were investigated to determine whether resilience could explain a higher degree of the variance than seizure

frequency. The final aim of the study was to examine the relationship between resilience and anxiety and depression.

People with epilepsy were identified through contact with their neurology department and asked to complete questionnaires examining resilience, quality of life and levels of anxiety and depression. 223 individuals were invited to take part in the study, of which 60 completed and returned the measures. It was hypothesised that psychological resilience would display a significant, positive relationship with levels of quality of life. It was also hypothesised that resilience would be a stronger predictor of quality of life in people with epilepsy than seizure frequency. Finally, it was hypothesised that resilience would display a significantly negative correlation with levels of anxiety and depression.

4.2 Discussion of the Research Findings

4.2.1 Hypothesis 1

Hypothesis 1 predicted that levels of psychological resilience will be significantly positively associated with quality of life in individuals with intractable epilepsy

Psychological resilience is regarded as a possible protective factor in those with chronic health conditions (Karoly & Ruehlman, 2006). It is known that people with intractable epilepsy display lowered levels of quality of life compared to controls (Leidy et al., 1999). This lowered quality of life impacts negatively on both the individual's ability to cope with the condition and also on the overall impact of the condition in terms of health economics for society at large (Pugliatti et al., 2007). Resilience has been shown to be amenable to change and may possibly have an effect on levels of quality of life (Davidson et al., 2005).

In the current study, the relationship between levels of resilience and levels of quality of life was investigated in those with intractable epilepsy. A significant, positive relationship was found between the two concepts, indicating that higher levels of resilience are associated with higher levels of quality of life. Therefore, it was found that the hypothesis that levels of psychological resilience will be significantly positively correlated with quality of life could be accepted. The results support previous work investigating factors associated with quality of life in epilepsy.

Bishop et al. (2002) found that factors such as mental health and social support are strong predictors of quality of life. The association found in the current study would potentially explain a degree of this variance given the possible protective role that resilience may have in protecting individuals from pathology.

The finding that levels of psychological resilience display a large positive relationship with levels of quality of life, suggests that the two concepts show a strong association. Unfortunately, it is not possible to identify the nature of this relationship from the current study's findings as correlation does not imply causality (Clark-Carter, 1997). It could be that levels of resilience directly affect levels of quality of life or that levels of quality of life directly affect levels of resilience or that another factor influences both of the variables. A longitudinal study would allow for an investigation of the possible effect of resilience on quality of life. This could be done by measuring the relationship between the two concepts over a period of time to examine how the concepts change and whether an increase in one leads directly to increases in the other. If the nature of the relationship is causal (A causes B), then there is a possibility that by increasing levels of psychological resilience, levels of quality of life would also be increased.

4.2.2 Hypothesis 2

Hypothesis 2 stated that resilience would be a stronger predictor of quality of life in people with intractable epilepsy than seizure frequency.

Research has indicated that seizure frequency may have a significant negative relationship with levels of quality of life in those with intractable epilepsy (Birbeck et al., 2002; Leidy et al., 1999). However, these findings have not been reported consistently and it may be that psychosocial factors can provide a better account of the variance in quality of life (Bishop et al., 2002; Suurmeijer et al., 2001). It was hypothesised that levels of psychological resilience would be a stronger predictor of quality of life in people with epilepsy than seizure frequency.

In the present study, resilience was found to explain a significant amount of the variance in the quality of life of those with intractable epilepsy. Seizure frequency was not found to explain a significant amount of the variance. This indicates that levels of resilience were a better predictor of levels of quality of life than seizure frequency in this sample.

Seizure frequency did not correlate significantly with levels of quality of life and therefore no association between the variables was found. This does not replicate the findings of other studies into quality of life in epilepsy (Leidy et al., 1999). Additionally, the trend of the relationship between the seizure frequency and quality

of life was in a positive direction, which is the opposite from other studies examining the relationship between the two variables. Therefore it may be that the lack of a significant finding may invalidate the results of the analysis. The study suffered from a low *n* meaning that the chances of detecting a association was reduced and the possibility of making a type 2 error was increased. For this part of the study, it was calculated that for 2 variables entering the multiple regression analysis, an *n* of 98 was calculated to produce a power .80 for a medium effect size (.15). As the study did not reach the required level of power (*n* = 60), it is not possible to state unequivocally whether a true finding has been achieved.

The results of this section of the study indicate that resilience may provide a significantly better account of the variance in quality of life in those with intractable epilepsy, given the caveats mentioned previously. Although it would be premature to suggest that resilience is the primary predictor of quality of life, it would certainly warrant further investigation. This result also goes some way to explaining why seizure frequency has been a somewhat inconsistent predictor of quality of life. Other studies that have examined quality of life in terms of seizure frequency have found that when psychosocial factors are included in the analysis, the effects of seizure frequency are negated (Johnson et al., 2004).

The overall effect of seizure frequency on quality of life was small and statistically not significant and in the opposite direction than would be expected based on previous research.

A further possibility is that there may be a publication bias in the literature, with studies that found an association between seizure frequency and quality of life more likely to be published than those that did not.

4.2.3 Hypothesis 3

Hypothesis 3 stated that resilience will be negatively associated with measures of anxiety and depression.

The research into mood disorders in those with epilepsy indicates that those with the condition have a significantly elevated risk of developing anxiety or depression (Harden, 2002; Piazzini et al., 2001). Anxiety and depression are both linked to lower levels of quality of life (Cull & Goldstein, 1997). Therefore, in terms of examining the utility of the concept of resilience in quality of life in epilepsy, it was important to identify the relationship of resilience to these two factors. By examining this relationship, it will be possible to begin to model the possible mechanisms by which resilience impacts on quality of life. If there is a significant relationship between anxiety and depression and resilience, it may indicate that the effect of resilience on quality of life is an indirect one; resilience may mediate levels of anxiety and depression, which in turn, could impact on an individual's quality of life.

The results of the study indicated that levels of resilience displayed a significant negative correlation with levels of anxiety and depression, with large effect sizes for both. These results suggest that higher levels of resilience are associated with lower

levels of anxiety and depression, and vice versa. As with hypothesis 1, it is not possible to assume a causal relationship between the variables as a result of only correlational analysis. Therefore it would be necessary to further investigate the relationship between the variables through the use of a longitudinal study design, where the movement within the variables across time could be further examined.

4.3 Explanations to Account for the Research Findings

4.3.1 Research Design

The design of this study involved recruiting patients from a secondary care service. Although this provided the optimal means to access the greatest number of patients in the shortest time, it may have influenced the level of severity of the experimental sample. It may be that those managed in secondary care experience more severe epilepsy than those who are managed in primary care. Consequently, the results of the study are more generalisable to individuals with epilepsy attending secondary care than to those attending primary care.

It also well documented that a significant number of people with epilepsy may be unaware of their condition (MacDonald et al, 2000) and that a number of individuals with the condition are not currently in the care of a medical professional (NICE, 2004). It was not possible to gain access to this population in the current study due to time limitations and financial constraints. Future studies could attempt to include these individuals through advertisements in the press or in non-clinical sites.

In order to ensure that the sample used in the study were as representative as possible of individuals with epilepsy attending secondary care, data for age and gender of all of those who were eligible to be invited into the study was collected. This allowed the researcher to examine the representativeness of the experimental group. As seen in the Results chapter, the experimental sample and the invited sample did not differ in terms of their age and gender, suggesting that the experimental sample was representative of those with intractable epilepsy who are managed in secondary care. As seen in the Methodology chapter, the service at which participants were recruited is similar to other services in terms of patients seen and staffing levels (NHS Scotland, Information Services Division, 2005).

A postal survey was used in order to recruit as many participants as possible. It may be the case that by not having direct contact with the participants, the possibility of interviewer bias was reduced. However, it is still possible that the participants may have made inferences regarding the type of person or organisation that have provided the questionnaire and then altered their responses to satisfy these assumptions (Oppenheim, 1992).

4.3.2 Response Rate

Research using postal questionnaires is often fraught with difficulties in obtaining a reasonable number of returns to satisfy the demands of statistical power and also in gaining an adequate number of returns to ensure that the group as a whole is represented. For studies with low response rates there is always the possibility that the individuals who do return their data are in some way biased. For example, those who return the questionnaires may be highly motivated or have less severe symptoms of a condition and than those who do not return questionnaires (Oppenheim, 1992).

In this study, the response rate was 26.9%, which can be considered low (Barker et al., 1994). Moran et al. (2004) used a postal survey in a study examining seizure frequency and quality of life in people with intractable epilepsy and reported a response rate of 48%. Cramer, Blum, Reed & Fanning (2003) also utilised a postal survey examining depression and quality of life and reported a response rate of 41%. Bishop et al. (2002) used a postal survey design examining the factors contributing to quality of life in epilepsy, and reported a response rate of 19%. Therefore, the response rate in the current study can be considered low in comparison with the majority of the literature.

The possible reasons for a low response rate are multiple and some participants may have had difficulty in reading and completing the questionnaires due to problems with literacy. Although the questionnaires were designed to be uncomplicated, this factor cannot be ruled out, and it could be that the sample were biased by their

literacy skills. A further issue is that of the cognitive difficulties commonly experienced in this population, which may have impacted on the participant's ability to concentrate on completing the measures (Aldenkamp, 2006).

Participants were also required to complete the questionnaires at home and participants consequently did not have someone involved with the study nearby to discuss the questionnaires with or have questions answered Contact details for the main researcher were provided and it was explained to the participants that should they have questions they could contact their consultant neurologist or the main researcher. However, by not providing a direct, face-to-face contact for clarification at the time of completion, it may have been that the sample were biased by their intellectual ability, with those who found the information easier to understand more likely to complete the measures.

In order to try and increase the response rate in this study, various methods were utilised. Questionnaire packs included a pre-paid, pre-addressed envelope in order to increase the likelihood of a return. Also, clear statements regarding confidentiality were explicitly included in each section of the study. These statements included information regarding who would have access to the information and what would be done with the information following its collection. It was hoped that this would provide participants with a sense of reassurance regarding their data, thereby increasing the likelihood of the participant returning their data. Anonymity was also provided for the participants. This was done to not only protect the identity of the clients and satisfy data protection and ethical concerns, but also in the hope that it

would increase the likelihood of a return due to participants feeling more at ease with the protection of their identity. However, this also limited the ability to follow up non-responders. All of the methods mentioned above are recommended as methods to improve response rate in a postal survey (Oppenheim, 1992).

A further possibility in explaining the response rate is that although all attempts were made to try and provide the participant with as much information as possible regarding the study, it may be that the overall length of the information sheets and experimental measures reduced the likelihood of a response. Oppenheim (1992) suggests that although the length of a questionnaire is a potentially confounding factor in completion rates, this tends to interact with the relevance of the information to the participant. It is possible that the information provided to the participants may have resulted in a level of fatigue and therefore a lower overall response rate. However, the information provided in the questionnaires was deemed necessary by the Ethical Committee and it was hoped that the relative importance of the condition to the individual would counteract the effect of the length of the questionnaires.

It was estimated that reading the information sheets and completing the questionnaires would take between 30-40 minutes, with 20-30 minutes of that time being questionnaire completion. Most studies do not provide data regarding the time taken to complete their questionnaires, although the choice of questionnaires was similar to that of other comparable studies (Harden, Maroof, Nikolov, Fowler, Sperling, Liporace, Pennell, Labar & Herzog, 2007).

It may have been that by using a postal survey design, valuable data were lost in terms of allowing participants to freely discuss the impact of epilepsy on their quality of life. A qualitative design would have provided the participants with the necessary freedom to inform the researcher of the areas that they feel impact greatest on an individual basis. The decision was made to use a quantitative design for two reasons. Firstly, the greater statistical power of the design allows for a better analysis of the relationships between the variables (Barker, et al., 1994). As this was the key aim of the study, a qualititative design would have been less appropriate as the smaller number of participants would have potentially clouded whether a real relationship was being observed. Secondly, the design was chosen to inform future theory which could be elucidated further by a secondary study using a qualitative approach. The detection of whether there is actually a relationship between the variables in the first instance, allows for a basis on which to inform a more in depth analysis through qualitative methods (Barker et al., 1994).

The low response rate and potential biases amongst those who returned questionnaires would have to be considered when generalising the results from this study to other epilepsy populations. However the results from this study are likely to have some generalisability at least to other secondary care epilepsy services.

4.3.3 Statistical Power

For Hypotheses 1 and 3, non-parametric correlations were used. The required sample size for the detection of a medium effect with power of .8 and an $\propto$ <0.05 was 94. The current study had 60 participants. Therefore, the study was underpowered. This means that the results must be interpreted with caution and the hypotheses cannot be fully supported. However, given the size of the effects noted and the relative proximity of the sample to the required level of size, it would seem reasonable to infer that the noted relationships may have some validity.

For the stepwise regression used to test hypothesis 2, an *n* of 85 was required to find an effect size of .15 at the .80 level of power, for an $\propto$<0.05. As only 60 participants were recruited, the analysis was underpowered. As a consequence it may be that the inability to detect an effect for seizure frequency may have come about due to a lack of power, rather than as a result of a true interaction. The reasons for the lack of statistical power are threefold. Firstly, as outlined in the previous section, the response rate for the postal survey was lower than had been expected.

Secondly, it may have been that the data collection window was not long enough to adequately allow for the return of a large enough sample of data. Although every effort was made to provide an adequate period of time to collect a large enough sample of data, a delay in receiving ethical permission to begin the study resulted in a 7-week delay in data collection.

A final point is that of the studies reliance on third parties to administer the surveys. The design of the study meant that the consultant neurologists within the epilepsy service would present participants with the measures. Although their input was essential to the study, valuable data collection time was missed as a result of poor communication between the main researcher and the consultants. However, given the proximity to the required level of power, the interpretation of the results appears relatively valid.

For hypotheses 1 and 3, the use of non-parametric Spearman's correlations reduced the overall power of the findings. Given the non-normative distributions observed within the samples, it was not possible to satisfy the assumptions of parametric tests, even after conversion through algebraic means. Although the use of non-parametric tests is a valid means of hypothesis testing (Clark-Carter, 1997), their lack of power in comparison to parametric analyses means that their results are less likely to provide powerful result.

The non-normative distribution of measures of depression and anxiety could potentially have limited the regression to two variables. It was not possible to convert the data using algebraic means. As resilience had already been converted into a dichotomised variable, neither depression nor anxiety could be dichotomised to enter the regression. The literature indicates that mental health may play an important role in the variance of quality of life in epilepsy, so their inclusion was warranted borth in terms of theory and statistical robustness.

4.3.4 Main Measures

The reasoning behind the choice of the questionnaires chosen as the main measures is discussed in the Methodology chapter. A further examination of the main measures is required as it could be that the choice of the measures may have had a direct influence on the results of the study.

The Quality of Life in Epilepsy Scale- 31 (QOLIE-31)

The QOLIE-31 is a well-validated measure of quality of life in those with epilepsy (Steinbuchel et al., 2000). The decision to use the 31 item scale in this study was a compromise between the length of time taken to complete the scale and the depth of information obtained. The main difficulty in measuring quality of life is whether or not the selected scale has an acceptable level of construct validity (Steinbuchel et al., 2000). It may have been more appropriate to have used the QOLIE-89 (Devinsky et al., 1995) in place of the shorter version, as it provides more items and gives a greater number of factors. However, the relative brevity of the QOLIE-31 in comparison to the QOLIE-89 outweighed the benefit of a more inclusive measure, as the concerns listed above regarding length of questionnaire detail. Also, the QOLIE-31 is widely used in clinical research and is considered by the authors to provide an acceptable trade-off between content validity and ease of completion (Cramer et al., 1998). The QOLIE-31 has also been found to correlate significantly with the QOLIE-89 (Cramer et al., 1998). Consideration was also given to the possibility that the

length of the QOLIE-89 may have further reduced response rates. Therefore, it would appear that the choice of the scale was appropriate.

It may have been appropriate to have included a battery of measures rather than a single scale in the measurement of quality of life. Given the difficulties in formalising the concept and attempting to measure quality of life as a single entity, inclusion of a measure such as the Liverpool Health Related Quality of Life Battery in Epilepsy (Baker, Jacoby, Smith, Dewey, Johnson & Chadwick, 1994) may have been warranted. Also, the inclusion of other more general measures of quality of life, such as the WHOQOL (Skevington, 1999) or the EuroQol (The EuroQol Group, 1992), would have provided a more balanced view of quality of life. However, whilst it may be important to include multiple measures in terms of evaluating treatment effects, the practicality of conducting research means that a single measure may be acceptable (Steinbuchel et al., 2000)

Connor-Davidson Resilience Scale (CD-RISC)

The CD-RISC was chosen as the main measure of psychological resilience. This was done for a number of reasons. It is brief and simple to complete and, most notably, it displays strong psychometric qualities in terms of content validity and reliability (Connor & Davidson, 2003). Furthermore, the scale was chosen due to its ease of interpretation for the researcher.

In terms of its suitability for use with the epilepsy population, the authors of the scale do state that the CD-RISC does have utility in assessing coping in individuals who are experiencing reactions to highly stressful situations. Given that a diagnosis of epilepsy can be viewed as a threat to both the self and one's health, it was felt that the scale could be appropriate for this population and would provide a valid measure of resilience.

As outlined in the Introduction, (1.4.2) resilience is not a unitary construct and comprises a multi-dimensional structure. Therefore, it may have been appropriate to have included multiple measures of the factors associated with the concept of resilience. These could have included measures of self-esteem and coping (Dyer & Tusaie, 2004). This would have allowed for a more in-depth analysis of the participants levels of resilience and may have produced a better understanding of the concept than would be found with the use of a single measure.

The CD-RISC provides a "snapshot" of an individual's levels of resilience. As mentioned in section 1.4.2, resilience can be viewed as a dynamic concept that will fluctuate over the lifespan (Richardson, 2002). It is possible that levels of resilience were not representative of the true situation for some of the participants, and may have been affected by current situational demands (such as martial stress or financial pressures). It may have been useful to have sampled levels of resilience over a number of time frames in order to counteract the effects of temporary stressors. Unfortunately the limitations of the timeframe of the study meant that this was not possible. In spite of the limitations listed above, the decision to use the CD-RISC

was made as the time taken to complete the scale is short, and it displays a high level of validity and reliability.

Hospital Anxiety and Depression Scale (HADS)

The HADS was chosen as the main measure of anxiety and depression for a number of reasons. As mentioned in the Methodology chapter, the scale has been widely used in populations with epilepsy and has acceptable validity and reliability. Also, the scale is brief and is relatively simple to score and interpret.

Other scales that could have been utilised were both the Beck Depression Inventory II (BDI-II, Beck et al., 1996) and the Beck Anxiety Inventory (BAI, Beck & Steer, 1990). Both scales have good psychometric properties and have been well used in clinical populations. However, some of the items included in the BDI-II may overlap with the physical symptoms of epilepsy and thereby produce a false representation of the true levels of depression Therefore, the BDI-II was discounted.

A further issue may be that the use of a single measure for anxiety and depression, without the inclusion of a clinician rated scale may not have measured the true level of anxiety and depression within the sample. However, both the anxiety and depression scales of the HADS have shown good levels of construct validity in comparison to clinician-administered scales 0.86, (Bjelland et al., 2002). The inclusion of a clinician rated scale would have required the main researcher to

interview each participant individually, thereby reducing the likelihood of achieving a sample size large enough to have reached statistical power. Also, to have incorporated this design aspect would have required that participant anonymity be compromised, a design that would have been unlikely to receive ethical approval.

Self-Report Measures

General concerns exist regarding the use of self-report measures in research. The tendency for individuals to engage in behaviours such as acquiescence and providing socially desirable responses is well documented (Barker et al., 1994). Although efforts were made to ensure that the scales used in this study took these tendencies into account, it is not possible to guarantee that our sample was not biased in terms of these factors.

4.3.5 Seizure Type and Severity

Previous research has investigated the influence of seizure type and severity on quality of life (Baker et al., 1998). It may be that these variables could provide an explanation of a degree of the variance in quality of life. Unfortunately, it was not possible to collect this data in the current study due to the difficulties in satisfying both ethical issues and the limited capacity of the study. To do this would have required careful examination of patient records, thereby negating patient anonymity. Although it may have been possible to collect this information within the general

information forms that were sent to patients, the lead clinician of the Neurology service recommended against this due to concerns regarding the patient's knowledge of their conditions. Whilst this was agreed at the time, it may be that questions regarding patient diagnosis and self-perceived seizure severity should have been collected.

In summary, the observed experimental effects can be accounted for by a number of factors including the design of the study, the characteristics of the sample, the measures chosen and the analyses conducted. The current study has attempted to control for these confounds in order to provide an accurate account of the hypothesised phenomena.

4.3.6 Seizure Frequency

Data for seizure frequency were collected via self-report in the general information sheet. Reliance on a self-report was required due to the protection of anonymity inherent in the study design. It could be argued that the use of this method may have led to an inaccurate estimate of the actual occurrence of seizures and formal monitoring could have provided a more accurate estimate. Leidy et al. (1999) suggest that although this type of method would possibly be more accurate, most studies in epilepsy rely on self-report of seizure count.

4.4 Future Research and Implications

The current study has examined the role of psychological resilience in the quality of life of those with intractable epilepsy. Given the research findings there are a number of possible areas for future expansion and examination that move on from the present question.

4.4.1 Treatment in Intractable Epilepsy

Current treatment models in those who continue to experience seizures are based firmly in medical attempts to gain freedom from seizures (NICE, 2004). Although this aim should remain at the heart of any treatment for the condition, it may be that by introducing further adjuncts to treatment, outcomes may improve, not only in terms of the clinical sequelae of the condition, but also in the more psychological factors. There is little evidence that a reduction in the frequency of seizures greatly improves quality of life (Pulsipher, Seidenberg, Jones & Hermann, 2006). Indeed much of the research has emphasised the importance of factors such as anxiety and depression in the quality of life of those with epilepsy (Szaflarski & Szaflarski, 2004; Cramer et al., 2003). In addition, both anxiety and depression are possibly more amenable to change than seizure frequency in those with intractable epilepsy.

Some research has examined the promotion of resilience within the workplace using a group-based treatment (Millear et al., 2007). As this study was conducted within a workplace population, the merits of this type of approach are unknown within a clinical sample. Therefore, it may be that trials of this type of group-based therapy may be warranted within the field of epilepsy. This would allow for a more causal

analysis of how treatment aimed at fostering levels of resilience affects levels of quality of life in epilepsy.

Improvements in resilience have been noted following intervention using a mindfulness based cognitive behavioural therapy approach. Hughes, Jordan & Schiraldi (2007) examined the effects of teaching resilience skills to a group of healthy young adults. Significant improvements were noted on measures of resilience, depression and anxiety. The authors concluded that resilience could be improved through the use of direct interventions using mindfulness-based techniques. This is further supported by Reibel, Gresson, Brainard & Rosenzweig (2001) who suggest that mindfulness promotes a significant level of cognitive appraisal, which in turn leads to improvements in psychological resilience.

There is some evidence that the use of acceptance-based interventions can improve resilience. Kratz, Davis & Zatura (2007) investigated the impact of levels pain acceptance in a population with fibromyalgia. They found that levels of acceptance were positively associated with levels of positive affect. The authors indicate that this increased acceptance could be directly linked to a greater level of resilience against negative emotional states.

Acceptance and Commitment Therapy (ACT) appears to be one type of treatment that may fit into a resilience model of quality of life in epilepsy. Hayes et al. (1999) define ACT as a contextually based of therapy designed to assist individuals in

modifying their behaviour from styles that encourage experiential avoidance of internal states, to ones that allow the client to experience these states without making judgments and decisions on the content of these thoughts or feelings. Some evidence regarding the development of ACT based treatments in epilepsy is beginning to emerge and the results appear to be promising (Lundgren et al., 2006). This area would appear to be one warranting further attention, and it may be that a group-based approach using ACT principles may directly affect the quality of life of those with epilepsy by increasing levels of psychological resilience.

Another area where resilience and ACT may be incorporated into current treatments for epilepsy is by assisting patients in preparing them for the difficult time period following diagnosis of intractability. It is known that patients who receive a diagnosis of a chronic condition can foster feelings of resentment, anger and hostility both towards clinicians and the condition itself (Parker, Dumat & Booker, 1994). This can make it difficult for the patient to move on from the diagnosis towards a state of adaptation to the condition. Increasing an individual's level of resilience at this point could result in better adaptation.

There is some evidence that by screening for resilience at the early stages of receiving a diagnosis of a chronic health condition, potential psychopathology can be identified and addressed. Connor & Davidson (2003) suggest that their scale may provide a useful tool in early identification of those who are exposed to highly stressful life events and may not have the coping skills or internal attributes to maintain normative functioning. The diagnosis of epilepsy and the subsequent

sequelae of the condition can be intensely stressful and de-stabilising (Baker, 1997). Therefore, research into how best to identify those who are most at risk of subsequent psychopathology would allow for a proactive approach for service planners and better follow up for the patient. However, the use of a screening questionnaire would need to be informed by additional factors such as clinical opinion, as it may be that there is a natural lowering in resilience levels following a diagnosis, and that these would recover in time. It could be that intervention at this stage could actually interfere with the natural recovery, as has been noted in the field of trauma research (Bisson, McFarlane & Rose, 2000).

The links between resilience, anxiety and depression merit further investigation. The significant correlations found between these variables suggests that there may be interplay between the three variables. Depression and anxiety are more common in those with epilepsy (Gaitatzis et al., 2004) than those in the general population. Traditional therapeutic techniques have focussed on using cognitive-behavioural techniques to bring about symptom relief through behaviour change and challenging negative thinking styles (NICE, 2004). By investigating the effects of treatment aimed at treating anxiety and depression on levels of resilience, it would be possible better understand the relationship. A further question would be whether treatment aimed at fostering resilience could bring about improvements in anxiety and depression.

Future research should also be aimed at examining further psychosocial factors and their influence on quality of life in intractable epilepsy. Given the low number of participants that were recruited in the current study, it was not possible to increase

the variables in the analyses, without reducing the power of the results. Variables such as adverse life events, depression, stigma, self-efficacy (Szaflarski, et al. 2006; Jacoby et al., 2005; Suurmeijer et al., 2002) have shown an effect on quality of life. As the research continues to identify the importance of psychosocial variables, further work should examine the mechanisms of the effects of each variable. This would allow for a model of quality of life to be constructed where the interplay between those factors that have a direct influence and those with an indirect influence could be better understood. This type of study would require a significant, multi-site design and lay beyond the scope or capacity of the current study.

4.4.2 Clinician Knowledge of Quality of Life and Resilience in Epilepsy

As the emphasis on outcomes beyond clinical factors has increased, clinicians are required to care for their patients in a more holistic fashion (Jacoby, 2000). Given that epilepsy has a number of negative psychosocial correlates, quality of life will be an area where clinicians may need to devote a degree of attention (Betts, 2000). Whilst most clinicians working in the field of epilepsy will be aware of the need to focus on quality of life, they may be less aware of what can done to improve the situation for their patients. As they may not be aware of interventions or advice that could be offered to their patients to help improve their condition, some clinicians may increase their focus on the areas where they feel that they have more of an influence, namely medical outcomes. It would be of interest to examine clinician's knowledge of what can be done to assist their patients in terms of quality of life. If a lack of knowledge is discovered, it could be that providing information regarding the

possible ways in which resilience could positively impact on quality of life could fill the knowledge gap.

4.4.3 Clinical Issues in the Management of Epilepsy

The NICE guidelines (2004) on the treatment and management of the epilepsies recommend the most efficacious treatments for the condition and offer advice to clinicians in terms of what information can and should be given to patients. The tone of the guidance is increasingly focussed on psychosocial aspects associated with quality of life. Of interest, were the recommendations that individuals with epilepsy should be informed of the increased likelihood of developing anxiety or depression. However, in the National Health Service, access to psychological therapies is limited and not all patients with epilepsy at risk of developing anxiety or depression will be able to access therapy in a timely fashion. It may be that little can be done to assist patients in dealing with the possible development of psychopathology other than referral on to a specialist adult mental health service or clinical health psychology service. However, if further investigation improves the explanation of the relationship between resilience and anxiety and depression in epilepsy, it may be that consultant neurologists and clinical nurse specialists would be able to provide information to the patient regarding behaviours or techniques that they could be using to foster their levels of resilience. This would provide a practical solution to the difficulties faced by an oversubscribed service under increasing pressure from governmental targets.

4.5 Summary and Conclusions

This study examined the relationship between resilience and quality of life in individuals with intractable epilepsy. The hypotheses being tested were whether resilience and quality of life displayed a significant association, whether resilience could account for a greater amount of the variance in quality of life than seizure frequency and whether resilience demonstrated a significant relationship with measures of anxiety and depression. The results of the study upheld all of these hypotheses.

The results of the research would suggest that there is a need for further investigation of the factors involved in levels of quality of life in patients with intractable seizures. As epilepsy is a heterogeneous condition requiring many different types of treatment, it would intuitively make sense to find ways in which the multiple outcomes of seizure frequency, seizure severity, seizure intrusion and quality of life can be improved. If resilience can assist either in improving quality of life or levels of anxiety and depression, then it may be a useful addition to the options available to services.

Currently, the evidence base for therapies aimed at fostering resilience is in its infancy in the United Kingdom. Current guidance for the implementation of therapies requires that there should be a significant evidence base before treatments can be recommended as a frontline intervention. Therefore, considerable literature on

both efficacy and effectiveness of resilience-based therapies will be required before they can be incorporated.

CHAPTER 5: REFERENCES

Alanis-Guevara, I., Pen˜a, E., Corona, T., Lo´pez-Ayala, T., Lo´pez-Meza E. & Lo´pez-Go´mez, M. (2005). Sleep disturbances, socioeconomic status, and seizure control as main predictors of quality of life in epilepsy. Epilepsy and Behaviour, 7, 411-415

Albrecht, G. & Devlieger, P. (1999). The disability paradox: high quality of life against all odds. Social Science & Medicine, 48, 977-988

Aldenkamp, A. (2006). Cognitive impairment in epilepsy; State of affairs and clinical relevance. Seizure, 15, 219-200

Aldenkamp, A & Hendriks, M (2000). Managing Cognitive and Behavioural. Consequences of Epilepsy. In Baker, G & Jacoby, A., (eds) *Quality of life in epilepsy: Beyond seizure counts in assessment and treatment*. Harwood.

Aldenkamp, A., Baker, G. & Meador, K. (2004). The neuropsychology of epilepsy: what are the factors involved? Epilepsy and Behavior, 5, S1-S2

Ahern, N., Kiehl, E, Sole, M. & Byers, J. (2006). A review of instruments measuring resilience. Issues in Comprehensive Pediatric Nursing, 29, 103-125

Annegers, J. & Coan, S. (1999). SUDEP: Overview of definitions and review of incidence data. Seizure, 8, 347-352

Aspinwall, L. & MacNamara, A. (2005). Taking positive change seriously. Cancer, 104, 2549-2556

Attarian, H., Valhe, V., Carter, J., Hykes, E. & Gilliam, F. (2003). Relationship between depression and intractability of seizures. Epilepsy and Behavior, 4, 298-301

Baker, G. (1997). Psychological Responses to Epilespy. *In Cull, C. & Goldstein, L. (eds) (1997) The Clinical Psychologist's Handbook of Epilepsy. Routledge*

Baker, G., Brooks, J., Buck, D. & Jacoby, A. (2000). The stigma of epilepsy: a European perspective. Epilepsia, 41, 98-104

Baker, G., Gagnon, D. & McNulty, P. (1998). The relationship between seizure frequency, seizure type and quality of life: findings from three European countries

Baker, G. & Jacoby, A. (eds) (2000). *Quality of Life in Epilepsy: Beyond seizure counts in assessment and treatment*. *Harwood Academic Publishers*

Baker, G., Jacoby, A., Smith, D., Dewey, M. and Chadwick, D. (1994). Development of a novel scale to assess life fulfilment as part of the further refinement of a quality-of-life model for epilepsy. Epilepsia, 35, 3, 591-596

Baker, G., Smith, D., Dewey, M., Jacoby, A. & Chadwick, D. (1993). The initial development of a health-related quality of life model as an outcome measure in epilepsy. Epilepsy Research, 16,65-81

Bandura, A. (2005). The primacy of self-regulation in health promotion. Applied Psychology, 54, 245-254

Barker, C., Pistrang, N. & Elliot, R. (1994). *Research Methods in Clinical and Counselling Psychology. Wiley*

Beck, A. & Steer, R. (1990). Beck Anxiety Inventory. Pearson Education

Beck, A. Steer, R. & Brown, G. (1996). Beck Depression Inventory-II. Pearson Education

Beghi, E., Mauro, N. & Roncolato, M. (2005). Validity and reliability of the Italian version of the Quality-of-Life in Epilepsy Inventory (QOLIE-31). Seizure, 14, 452-458

Benetti, C. & Kambouropoulos, N. (2006). Affect-regulated indirect effects of trait anxiety and trait resilience on self-esteem. Personality and Individual Differences, 41, 341-352

Betts, T. (2000). A physician reflects on quality of life. *In Baker, G. & Jacoby, A. (eds) (2000) Quality of Life in Epilepsy: Beyond seizure counts in assessment and treatment. Harwood Academic Publishers*

Birbeck, G., Hays, R., Cui, X. & Vickery, B. (2002). Seizure Reduction and Quality of Life Improvements in People with Epilepsy. Epilepsia, 43, 535-538

Bishop, M. & Allen, C. (2003). The impact of epilepsy on quality of life: a qualitative analysis. Epilepsy & Behavior, 4, 226-233

Bishop, M., Berven, N., Hermann, B. & Chan, F. (2002). Quality of Life Among Adults with Epilepsy: An exploratory model. Rehabilitation Counseling Bulletin, 45, 87-95

Bishop, M. & Hermann, B. (2000). Impact of Epilepsy on Quality of Life: A review. *In Baker, G. & Jacoby, A. eds (2000). Quality of Life in Epilepsy: Beyond seizure counts in assessment and treatment. Harwood Academic Publishers*

Bisson, J., McFarlane, A. & Rose, S. (2000). Psychological Debriefing. *In Foa, E., Keane, T & Friedman, M. Effective Treatments for PTSD. Practice Guidelines from the International Society for Traumatic Stress Studies. The Guildford Press*

Bjelland, I., Dahl, A., Haug, T. & Neckelmann, D. (2002). The validity of the Hospital a Anxiety and Depression Scale: An updated literature review. Journal of Psychosomatic research, 52, 69-77

Blumer, D., Montouris, G., Davies, K., Wyler, A., Phillips, B. & Hermann, B. (2002). Suicide in epilepsy: psychopathology, pathogenesis and prevention. Epilepsy and Behaviour, 3, 232-241

Bonanno, G. (2005). Resilience in the face of potential trauma. Current Directions in Psychological Science, 14, 135-138

Bonanno, G. (2004). Loss, Trauma and Human Resilience: Have we underestimated the human capacity to thrive after extremely aversive events? American Psychologist, 59, 20-28

Bonanno, G., Moskowitz, J., Papa, A. & Folkman, S. (2005). Resilience to loss in bereaved spouses, bereaved parents and bereaved gay men. Journal of Personality and Social Psychology, 88, 827-843

Buck, D., Jacoby, A., Baker, G. & Chadwick, D. (1997). Factors influencing compliance with antiepileptic drug regimes. Seizure, 6, 87–93

Campbell-Sills, L., Cohan, S. & Stein, M., (2005). Relationship of Resilience to Personality, Coping and Psychiatric Symptoms in Young Adults. Behaviour Research and Therapy, 44, 585-599

Camfield, P. (2007). Problems for people with epilepsy beyond seizures. Epilepsia, (S9), p1-2

Chadwick, D. (1998). Rational Drug Therapy for Epilepsy. *In: Laidlaw, J, Richens, A. & Chadwick, D. (eds) The Epilepsies, Butterworth Heinemann*

Christensen, J., Vestergaard, M., Mortensen, P., Sidenius, P. & Agerbo, E. (2007). Epilepsy and Risk of Suicide: A Population Based Case-Control Study. The Lancet Neurology, 6, 693-698

Chubon, R. (1995). Manual for the Life Satisfaction Survey. Columbia, University of South Carolina

Clark-Carter, D. (1997). *Doing Quantitative Psychological Research: From Design to Report. Psychology Press*

Clinical Standards Advisory Group (2000). Services for patients with epilepsy: report of a CSAG Committee chaired by Professor Alison Kitson.

Connor, K. & Davidson, J. (2003) The Development of a New Resilience Scale: The Connor-Davidson Resilience Scale (CD-RISC). Depression and Anxiety, 18, 76-82

Cockerell, O., Hart, Y., Sander, J., Goodridge, D., Shorvon, S. & Johnson, A. (1994). Mortality from epilepsy: results from a prospective population based study. Lancet, 344, 918-921

Commission on Classification and Terminology of the International League Against Epilepsy (1993). Guidelines for epidemiologic studies on epilepsy. Epilepsia, 34:592–596

Cramer, J., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meader, K. & Hermann, B. (1998). Development and Cross-Cultural Translations of a 31-Item Quality of Life in Epilepsy Inventory. Epilepsia, 39, 81-88

Critchley, M. & Critchley, E. (1998). *John Hughlings Jackson: The Father of English Neurology. Oxford University Press*

Cull, C. & Goldstein, L. (1997). *The Clinical Psychologist's Handbook of Epilepsy. Routledge*

da Silva, T., Ciconelli, R., Alonso, N., Azevedo, A., Westphal-Guitti, A., Pascalicchio, T., Marques, C., CaBoclo, L., Cramer, J., Sakamoto, A. & Yacubian, E. (2007). Validity and Reliability of the Portuguese Version of the Quality of Life in Epilepsy Inventory (QOLI-31) for Brazil. Epilepsy & Behaviour, 10, 234-241

Davidson, J., Payne, V., Connor, K., Foa, E., Rothbaum, B., Hertzburg, M. & Weisler, R. (2005). Trauma, Resilience and Saliostasis: effects of treatment in post-traumatic stress disorder. International Clinical Psychopharmacology, 20, 43-48

Devinsky, O., Vickery, B., Perrine, K., Hermann, B., Meador, K., Hays, R. & Cramer, J. (1995). Development of the quality of life in epilepsy inventory. Epilepsia, 36, 1080-1104

Dyer, J. & Tusaie, K. (2004). Resilience: A historical review of the construct. Holistic Nursing Practice, 18, 3-10

Eadie, M. & Bladin, P. (2001). A Disease Once Sacred: A History of the Medical Understanding of Epilepsy. John Libbey Eurotext

The EuroQol Group (1992). EuroQol: a new facility for the measurement of health related quality of life. Health Policy, 20, 321-328

Farber, E., Schwartz, J., Schaper, P., Moonen, D., & McDaniel, S. (2000). Resilience factors associated with HIV disease. Psychosomatics, 41, 140-146

Faul, F., Erdfelder, E., Lang, A.G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behavior Research Methods, 39, 175-191.

Forsgren, L., Beghi, E., Oun, A. & Sillanpaa, M. (2005). The epidemiology of epilepsy in Europe: a systematic review. European Journal of Neurology, 12, 245-253

Gaitatzis, A., Carroll, K., Majeed, A. & Sander, J. (2004). The Epidemiology of the Comorbidity of Epilepsy in the General Population. Epilepsia, 45, 1613-1622

Garmezy, N. (1970). Process and reactive schizophrenia: some conceptions and issues. Schizophrenia Bulletin, 2, 30-74

Garmezy, N. (1974). The study of competence in children at risk for severe psychopathology. *In Anthony, E. & Koupernik, C. (eds), The child in his family: children at psychiatric risk. New York, Wiley*

Gilliam, F. & Kanner, A. (2002). Treatment of Depressive Disorders in Epilepsy Patients. Epilepsy and Behavior, s2-s9

Gilliam, F., Kuzniecky, R., Meador, K., Martin, R., Sawrie, S., Viikinsalo, M., Morawetz, R. & Faught, E. (1999). Patient-oriented outcome assessment after temporal lobecotmy for refractory epilepsy. Neurology, 53, 687-694

Giovagnoli, A., Meneses, R. & da Silva, A. (2006). The contribution of spirituality to quality of life in focal epilepsy. Epilepsy and Behavior, 9, 133-139

Harden, C. (2002). The Comorbidity of depression and epilepsy: epidemiology, etiology and treatment. Neurology, 59, 48-55

Harden, C., Maroof, D., Nikolov, B., Fowler, K., Sperling, M., Liporace, J., Pennell, P., Labar, D., & Herzog, A. (2007). The effect of seizure severity on quality of life in epilepsy. Epilepsy & Behavior, 11, 208-211

Hauser, W., Annegers, J. & Kurland, L. (1991). Prevalence of epilepsy in Rochester, Minnesota: 1940-1980. Epilepsia, 32, 429-445

Hauser, W., Annegers, J. & Kurland, L. (1993). Incidence of epilepsy and unprovoked seizures in Rochester, Minnesota: 1935-1984. Epilepsia, 34, 453-468

Hayes, S., Strosahl, K & Wilson, K. (1999). *Acceptance and Commitment Therapy; An experiential approach to behavior change. The Guildford Press*

Hermann, B., Whitman, S., Wyler, A., Anton, M. & Vanderzwagg, R. (1990). Psychosocial predictors of psychopathology in epilepsy. The British Journal of Psychiatry, 156, 98-105

Hughes, T., Jordan, J. & Schiraldi, G. (2007). A college course to build resilience and prevent mental disorders in functioning adults. Poster Presentation, American Public Health Association Annual Meeting

Jacoby, A. (2000). Theoretical and Methodological Issues in Measuring Quality of Life. *In Baker, G. & Jacoby, A. (eds) Quality of Life in Epilepsy: Beyond seizure counts in assessment and treatment. Harwood Academic Publishers*

Jacoby, A. & Baker, G. (2008). Quality of life trajectories in epilepsy: A review of the literature. Epilepsy and Behavior, 12, 557-571

Jacoby, A., Baker, G., Steen, N., Potts, P. & Chadwick, D. (1996). The clinical course of epilepsy and its psychosocial correlates: findings from a UK community study. Epilepsia, 37, 148-161

Jacoby, A., Gorry, J., Gamble, C. & Baker, G. (2004). Public knowledge private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. Epilepsia, 45, 1405-1415.

Jacoby, A., Snape, D. & Baker, G. (2005). Epilepsy and Social Identity: the stigma of a chronic neurological disorder. Lancet Neurology, 4,171-178

Johnson, E., Jones, J., Seidenberg, M. & Hermann, B. (2004). The Relative Impact of Anxiety, Depression, and Clinical Seizure Features on Health-related Quality of Life in Epilepsy. Epilepsia, 45, 544-550

Jones, R., Butler, J., Thomas, V., Peveler, R. & Prevett, M. (2006). Adherence to treatment in patients with epilepsy: associations with seizure control and illness beliefs. Seizure, 15, 504-508

Kaminsky, K. (2006). Resilient Leaders: Leveraging emotional intelligence, leadership vision & social capital resources to achieve outcome success through disruption. Unpublished Doctoral Thesis, Cape Western University

Kanner, A. (2003). Depression in epilepsy: prevalence, clinical semiology, pathogenic mechanisms and treatment. Biological Psychiatry, 54, 388-398

Karnovsky, D., Abelmann, W. & Craver, L. (1948). The use of nitrogen mustards in the palliative treatment of carcinoma. Cancer, 1, 634-656

Karoly, L. & Ruehlman, P. (2003). Psychological "resilience" and its correlates in chronic pain: Findings from a national community sample**.** Pain, 123, 90 - 97

Kendrick, A. (1997). Quality of Life. *In Cull, C. & Goldstein, L. (Eds) (1997). The Clinical Psychologist's Handbook of Epilepsy. Routledge*

Kobassa, S. (1979). Stressful events, personality and health: An inquiry into hardiness. Journal of Personality and Social Psychology, 37, 1-11

Krakow, K., Buhler K., Haltenhof, H. (1999) Coping with refractory epilepsy. Seizure, 8, 111–5

Kratz, A., Davis, M. & Zautra, A. (2007). Pain acceptance moderates the relation between pain and negative affect in female osteoarthritis and fibromyalgia patients. Annals of Behavioral Medicine, 33, 291-301

Lamond, A., Depp, C., Allison, M., Langer, R., Reichstadt, J., Moore, D., Golshan, S., Ganaits, T & Jeste, D. (2008). Measurement and predictors of resilience among community-dwelling older women. Journal of Psychiatric Research, In press.

Lawford, J. & Eiser, C. (2001). Exploring links between the concepts of Quality of Life and Resilience. Pediatric Rehabilitation, 4, 209-216

Leidy, N., Elixhauser, A., Vickrey, B., Means, E. & Willian, M. (1999). Seizure frequency and the health-related quality of life of adults with epilepsy. Neurology, 53, 162-166

Leppik, I. (1990). How to get patients with epilepsy to take their medication. The problem of non-compliance, Postgraduate Medicine, 88, 253–256

Loring, D., Meador, K. & Lee, G. (2004). Determinants of quality of life in epilepsy. Epilepsy and Behaviour, 5, 976-980

Luders, H. & Comair, Y. (2001). *Epilepsy Surgery. Lippincott, Williams & Wilkins*

Lundgren, T., Dahl, J., Melin, L. & Kies, B (2006). Evaluation of Acceptance and Commitment Therapy for Drug Refractory Epilepsy: A Randomised Controlled Trial in South Africa-A Pilot Study. Epilepsia, 47, 2173-2179

Luthar, S., Cicchetti, D. & Becker, B. (2000). The construct of resilience: A critical evaluation and guidance for future work. Child Development, 71, 543-562

Lyons J. (1991). Strategies for assessing the potential for positive adjustment following trauma. Journal of Traumatic Stress, 4, 93–111

Mac, T.L., Tran, D., Quert, F., Odermatt, P., Preux, P.M. & Tan, C.T. (2007). Epidemiology, aetiology and clinical management of epilepsy in Asia: a systematic review. The Lancet *Neurology*, 6, 533-43

MacDonald B., Cockerell O., Sander J. & Shorvon S. (2000). The incidence and lifetime prevalence of neurological disorders in a prospective community-based study in the UK. Brain 123, 665-676

Matthews, W. & Barbaras, G. (1981). Suicide and epilepsy: a review of the literature. Psychosomatics, 22, 515-524

MAPI Research Institute (1996). Cultural adaptation of the QOLIE-31 into UK-English, Italian, Spanish, Canadian French, French, German, Danish and Swedish. Lyon.

McClure, F., Chavez, D., Agars, M., Peacock, J. & Matosian, A. (2008). Resilience in Sexually Abused Women: Risk and Protective Factors. Journal of Family Violence. 23, 81-88

McFarlane, A. & Yehuda, R. (1996). Resilience vulnerability and the course of post-traumatic reactions. In Van der Kolk, McFarlane, A. & Weisaeth, L. (eds) Traumatic Stress, Guildford

Millear, P., Liossis, P., Shochet, I., Biggs, H., Herbert, C. & Donald, M. (2007). Promoting adult resilience in the workplace: Synthesising mental health and work-life balance approaches. In Proceedings of the 42nd Annual Conference of the Australian Psychological Society, Brisbane

Moran, N., Poole, K., Bell, G., Solomon, J., Kendall, S., McCarthy, M., McCormick, D., Nashef, L., Sander, J. & Shorvon, S. (2004). Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilisation and impact on life in 1652 people with epilepsy. Seizure, 13. 425-433

National Institute of Clinical Excellence (2004). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE

NHS Scotland, Information Services Division (2005).
http://www.datadictionaryadmin.scot.nhs.uk/isddd/17546.html

Oosterhuis, A. (1999). Coping with epilepsy: the effect of coping styles on self-perceived seizure severity and psychological complaints. Seizure, 8, 93-96

Oppenheim, A. (1992). *Questionnaire Deign, Interviewing and Attitude Measurement. Pinter Publishers*

Parker, H., Dumat, W. & Booker, C. (2000). The Pain Management Program. *In Main, C. & Spanswick, C. (2000). Pain Management – An Interdisciplinary Approach, , (eds), Churchill & Livingstone: Edinburgh.*

Piazzini, A., Canevini, M., Maggiori, G. & Canger, R. (2001). Depression and Anxiety in Patients with Epilepsy. Epilepsy and Behaviour, 2, 481-489

Pollack, M., Stein, M. & Davidson, J. (2004). New challenges for anxiety disorders: Where treatment, resilience and economic priority converge. CNS Spectrums, 9, 1-10

Preux, P.M. & Druet-Carbanac, M. (2005). Epidemiology and aetiology of epilepsy in sub-Saharan Africa. The Lancet *Neurology,* 4, 21-31

Pugliatti, M., Beghi, E., Forsgren, L., Ekman, M. & Sobrocki, P. (2007). Estimating the Cost of Epilepsy in Europe: A Review with Economic Modelling. Epilepsia, 2224-2233

Pulsipher, D., Seidenberg, M., Jones, J. & Hermann, B. (2006) Quality of life and comorbid medical and psychiatric conditions in temporal lobe epilepsy. Epilepsy and Behaviour, 9, 510-514

Ramaratnam, S., Baker, G. & Goldstein L. (2005). Psychological treatments for epilepsy. Cochrane Database of Systematic Reviews 2005, Issue 4

Reibel, D., Gresson, J., Brainard, G. & Rosenzweig, S. (2001).Mindfulness-based stress reduction and health related quality of life in a heterogeneous patient population. General Hospital Psychiatry, 23, 183-192

Richardson, G. (2002). The Metatheory of Resilience and Resiliency. The Journal of Clinical Psychology, 58, 307-321

Richens, A. & Perucca, E. (1993). Clinical Pharmacology and Medical Treatment. *In Laidlaw, J., Richens, A. & Chadwick, D. (eds) A textbook of epilepsy, 4th Edition, Churchill Livingstone*

Robertson, M., Trimble, M. & Townsend, H. (1987). Phenomenology of depression in epilepsy. Epilepsia, 28, 364-372.

Robertson M., Channon S. & Baker J. (1994). Depressive symptomatology in a general hospital sample of outpatients with temporal lobe epilepsy: a controlled study. Epilepsia, 35, 771–777

Rutecki, P. (1990). Anatomical, Physiological, and Theoretical Basis for the Antiepileptic Effect of Vagus Nerve Stimulation. Epilepsia, 31, s1-s6

Rutter, M. (1985). Resilience in the face of adversity: protective factors and resistance to psychiatric disorders. British Journal of Psychiatry, 147, 598–611

Sander, J. & Shorvon, S. (1996). Epidemiology of the epilepsies. Journal of Neurology, Neurosurgery and Psychiatry, 61, 433-443
.
Scottish Intercollegiate Guidance Network (2003). Diagnosis and Management of Epilepsy in Adults. SIGN

Semah, F., Picot, M., Adam, C., Broglin, D., Arzimanoglou, A., Bazin, B., Cavalcanti, D. & Baulac, M. (1998). Is the underlying cause of epilepsy a major prognostic factor for recurrence? Neurology, 51, 1256-1262

Shorvon, S. (1991). Chronic epilepsy. The British Medical Journal, 302, 363-366

Shorvon, S., Fish, D., Perucca, E. & Dodson, W. (2004). *The treatment of epilepsy. 2nd Edition, Blackwell Publishing*

Skevington, S. (1999). Measuring Quality of Life in Britain: An Introduction to the WHOQOL-100. Journal of Psychosomatic Research, 47, 449-459

Snaith, R. & Zigmond, A. (1994). HADS: Hospital Anxiety and Depression Scale. Windsor, NFER Nelson

Spector, S., Tranah, A., Cull, C. & Goldstein, L. (1999). Reduction in seizure frequency following a short term group intervention for adults with epilepsy. Seizure, 8, 297-303

Speilberger, C. (1967). Manual for the State-Trait Anxiety Inventory. Consulting Psychologist Press.

Steinbuchel, N., Heel, S. & Bullinger, M. (2000). A review of currently available quality of life measures. *In Baker, G. & Jacoby, A. (eds) Quality of Life in Epilepsy: Beyond seizure counts in assessment and treatment. Harwood Academic Publishers*

Suurmeijer, T., Reuvekamp, M. & Aldenkamp, A, (2001). Social Functioning, Psychological Functioning and Quality of Life in Epilepsy. Epilepsia, 42, 1160-1168

Swarztrauber, K., Dewar, S. & Engel Jr, J. (2003). Patient attitudes about treatments for intractable epilepsy. Epilepsy & Behavior, 4, 419-25

Szaflarski, M., Meckler, J., Privitera, M. & Szaflarski, J. (2006). Quality of life in medication-resistant epilepsy: The effects of patient's age, age at seizure onset and disease duration. (2006). Epilepsy and Behavior, 8, 547-551

Szaflarski, J. & Szaflarski, M. (2004). Seizure disorders, depression and health related quality of life. Epilepsy & Behavior, 5, 50-57

Taylor, J. (1931). *Selected Writings of John Hughlings Jackson. Volume II, Hodder & Stoughton*

Temkin, O. (1971). *The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology. John Hopkins Press*

Toone, B. (2000). The psychoses of epilepsy. Journal of Neurology, Neurosurgery and Psychiatry, 69, 1-4

Tracy, J., Dechant, V., Sperling, M., Cho, R. & Glosser, D. (2007). The association of mood with quality of life ratings in epilepsy. Neurology, 68, 1101-1107

Vickrey, B, Berg, A, Sperling, M., Shinnar, S., Langfitt, J., Bazil, C., Walczak, T., Pacia, S., Kim, S. & Spencer, S. (2000). Relationships between seizure severity and health related quality of life in refractory localization-related epilepsy. Epilepsia, 41, 760-764

Wiebe, S., Blume, W., Girvin, J. & Eliasziw, M. (2001). A randomized, controlled trial of surgery for temporal-lobe epilepsy. The New England Journal of Medicine. 345, 311-318

Whitman, S., Hermann, B. & Gordon, A. (1984). Psychopathology in Epilepsy: How great is the risk? Biological Psychiatry, 19, 213-216

World Health Organization, (2001). Epilepsy: A historical review. World Health Organization

Yuen, A., Thompson, P., Flugel, D., Bell, G. & Sander J. (2007). Mortality and morbidity rates are increased in people with epilepsy: Is stress part of the equation? Epilepsy & Behavior, 10, 1-7

Zigmond, A. & Snaith R (1983). The Hospital Anxiety and Depression Scale. Acta PsychiatriaScandinavia67,361-70

APPENDIX I

Information Sheet for Participants

TAYSIDE PARTICIPANT INFORMATION SHEET

Quality of Life in Epilepsy in Adults: The role of psychological resilience

My name is ********* and I am completing my final year of clinical psychology postgraduate training at the University of Edinburgh. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you firstly understand why I am doing it, and secondly, what it would involve if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to contact your consultant neurologist with any questions you may have.

Background to the project

This project is a joint project between the University of Edinburgh and NHS Tayside. We are looking at some of the factors that may be important in living with epilepsy. In particular, I am interested in which factors can account for better quality of life in those with the condition.

What does the study entail?

The study will involve you completing 3 questionnaires and filling out a basic information sheet regarding your condition and some historical details. There would be no need to meet directly with myself, as I will provide all the material by mail for return by pre-paid envelopes. The questionnaires are multiple choice and should take no more than 25-35 minutes to complete. You will not need to provide your name on the questionnaire. Once you have sent off the questionnaires, you have completed the study. You will not be contacted in the future.

Do I have to take part?

It is up to you whether or not you take part. Only once you have read the information sheet and if you consent to participating, you need to complete the questionnaires and send them to me in the Stamped Addressed Envelopes. Taking the pack from the appointment does not mean that you have to take part. You are free to withdraw at any time and without giving a reason. A decision to withdraw at anytime, or a decision to take part, will not affect the standard of care you receive. This study is entirely separate from any contact you may be having with the NHS.

What are the discomforts or risks?

Some questions in the questionnaires may identify areas of difficulties or feelings that you had not fully considered before. If this happens and you are having difficulty coping with them, please let your neurologist know or feel free to contact your GP.

What will happen to the information you collect about me?

If you are willing to take part in the study, all the information about you and the responses that you give on questionnaires will be confidential with no names being asked of you. No personal information will be used in the write up of the study. The responses you give to the questionnaires will be collated with other participants' responses to assess the factors that influence quality of life in epilepsy. All data will be stored on a password-protected computer with no personal identifiable information. Access to the questionnaires will only be granted to the principle researcher.

What are your rights?

Participation in the study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any point without having to provide a reason. Your decision whether or not to participate in the study will have no influence on any current or future

psychological or medical care you receive. It will also have no influence on your relationship with any healthcare staff you are involved with.

The Tayside Committee on Medical Research and Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. The committee will also receive regular reports from NHS Tayside Monitors who will examine the records of research while it is in progress.

If you are willing to take part in this study please the questionnaires and information sheet and return them in the Stamped Addressed Envelope.

What happens if I am injured or have a complaint as a result of taking part in this study?

If you believe that you have been harmed in any way by taking part in this study you would have the right to pursue a complaint and any resulting compensation through the University of Edinburgh who are acting as the research sponsor. Details about this would be available through the research team. Also, as a patient of the NHS, you would have the right to pursue a complaint through the usual NHS process. To do so, you could submit a written complaint to the patient liaison manager, Complaints Office, Ninewells Hospital (Freephone 0800 027 5507). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Tayside, but you may have to pay your legal costs.

Can I talk to someone regarding this study?

If you would like more information regarding the study, you can get in touch with your consultant neurologist at Ninewells. You can also contact the main researcher, at the number listed above.

What happens if I feel upset or worried after I have completed the questionnaires?

Although there has been no indication that completing the questionnaires could cause any problems, if you have any difficulties, you should contact the main researcher, **********, who would be available to arrange further advice and support. If you do wish to contact Mr *******, please be aware that this would result in a loss of anonymity.

This study is sponsored by the University of Edinburgh who have taken out insurance cover for this purpose. Therefore, you may receive compensation in the event you are harmed by something unforeseen, i.e., when there is no negligence on the part of those conducting the study. This will depend upon review of the circumstances that led to harm or injury and the likelihood it was linked to your participation in the study. Such complaints should take this up initially with the lead investigator who is in charge of the study locally.

Thank you for taking the time to read and consider the above information. If you are willing to take part in the study, please take time to carefully read and complete the questionnaires and general information sheet.

APPENDIX II

General Information Sheet

General Information Sheet

Please fill in the following as accurately as you can. This information is used to look at general factors associated with people with epilepsy, and will not be used to identify you.

Age:

Gender *(circle one)*: **Male Female**

Marital Status *(circle one):* **Single Married Long-term partner**

Education Level *(circle the highest level):* **Secondary College University**

Employment Status *(please circle the main category if you belong to more than one)*

Full time employed **Part-time employed** **Self-employed**

Student **Homemaker** **Without employment**

Voluntary worker **Other *(please state):*** _____

Please enter the first 4 digits of your postcode (i.e. DD2 1):

When did you last have a seizure *(please circle one)*?

In the last week? **Last month?** **More than a month?**

Approximately, how many seizures do you have in a typical 6 months? ☐

Thank you. Please continue with the rest of the questionnaires.

APPENDIX III

Quality of Life in Epilepsy-31

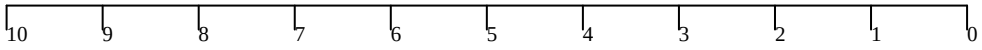
Instructions

The QOLIE-31 is a survey of health related quality of life for adults with epilepsy. This questionnaire should only be completed by the person who has epilepsy (not a relative or friend) because no one else knows how you feel.

There are 31 questions regarding your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3….). If you are unsure about how to answer a question, please give the best answer you can.

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

(Circle one number on the scale below)



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

How much of the time during the **past four weeks…..**

(circle one number on each line)

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

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

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

15. The following question is about memory. In the **past 4 weeks** have you had any trouble with memory? *(circle one number)*

Yes a Great Deal	Yes Somewhat	Only a Little	No, Not at All
1	**2**	**3**	**4**

Circle one number for how often in the **past 4 weeks** you have had trouble remembering or how often this memory problem has interfered with your normal work or living.

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

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

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

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

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
19. Leisure time	**1**	**2**	**3**	**4**	**5**	**6**
20. Driving	**1**	**2**	**3**	**4**	**5**	**6**

The following questions relate to the way you **FEEL** about your **seizures.**

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

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

		Very Worried	Somewhat Worried	Not Very Worried	Not at all Worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that Medications that you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS** circle one number for how much they bother you on a scale of 1 to 5 where 1 = not at all bothersome and 5 = extremely bothersome.

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

31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 10 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. Please consider your epilepsy as part of your health when you answer this question.
(Circle one number on the scale below)

10 9 8 7 6 5 4 3 2 1 0

Best Imaginable Health State — Worst imaginable Health State

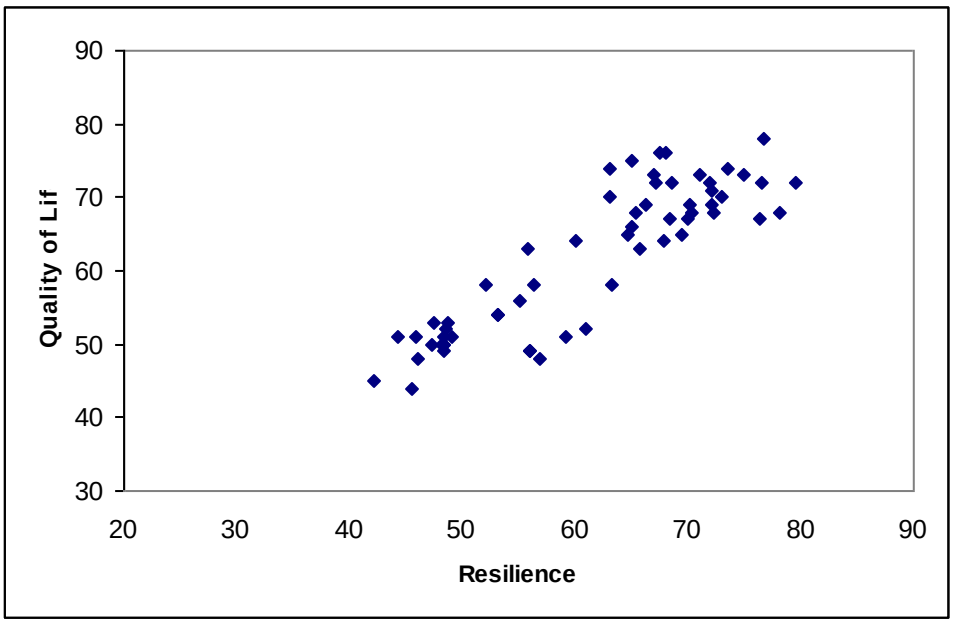
APPENDIX IV

Connor-Davidson Resilience Scale

(The Connor-Davidson Resilience Scale is protected by copyright and may not be used or reproduced without permission from the authors.)

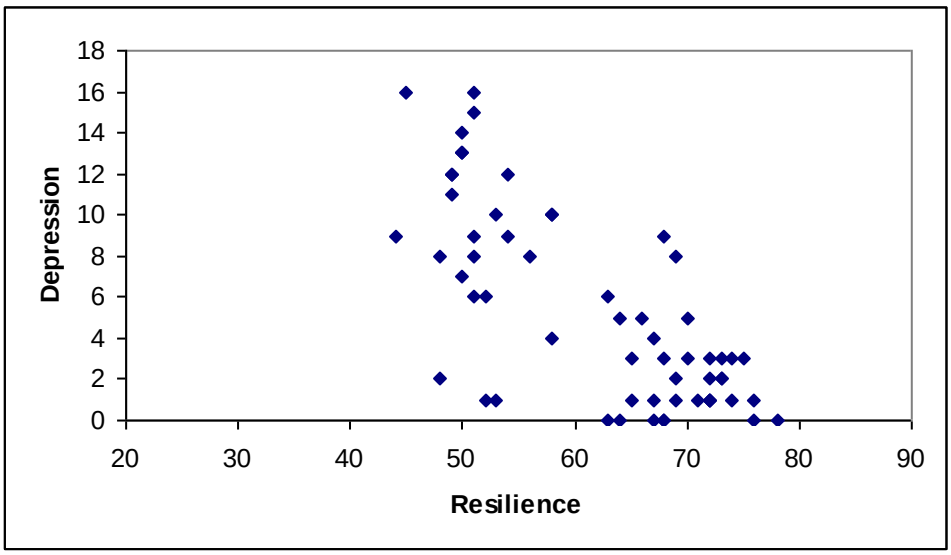
APPENDIX V

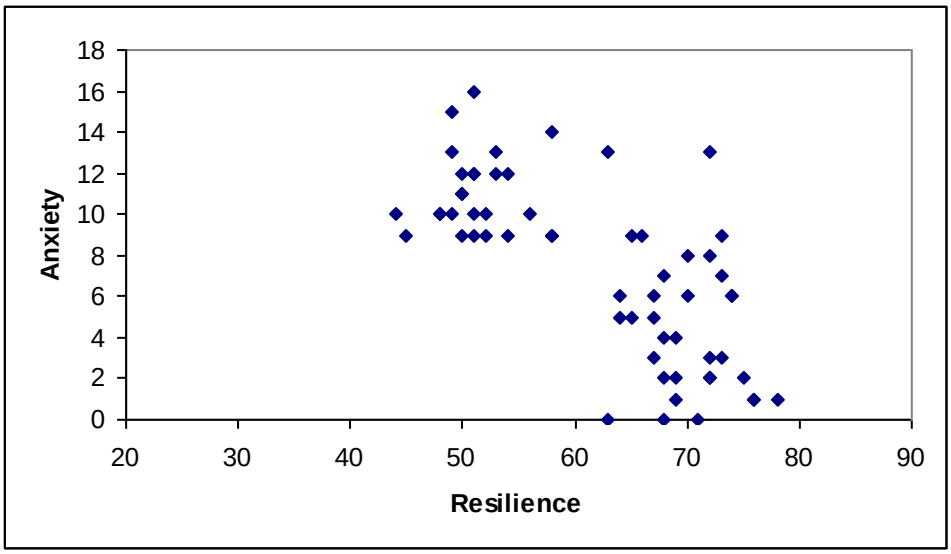
Scatterplot of Relationship Between Quality of Life and Resilience


90
80
70
60
50
40
30
Quality of Lif
20
30
40
50
60
70
80
90
Resilience

APPENDIX VI

Scatterplots of the Relationships Between Resilience and Anxiety and Depression

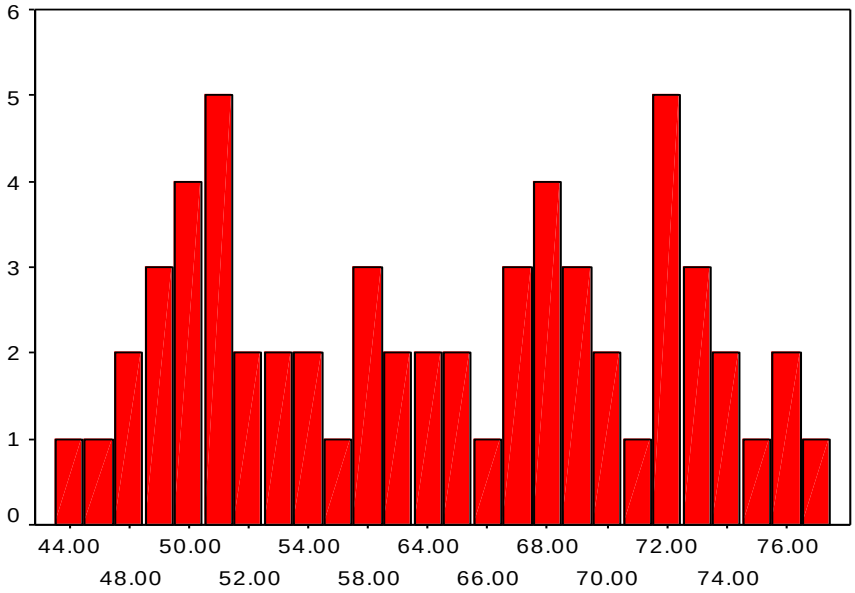

Depression
18
16
14
12
10
8
6
4
2
0
20
30
40
50
60
70
80
90
Resilience


Anxiety
18
16
14
12
10
8
6
4
2
0
20
30
40
50
60
70
80
90
Resilience

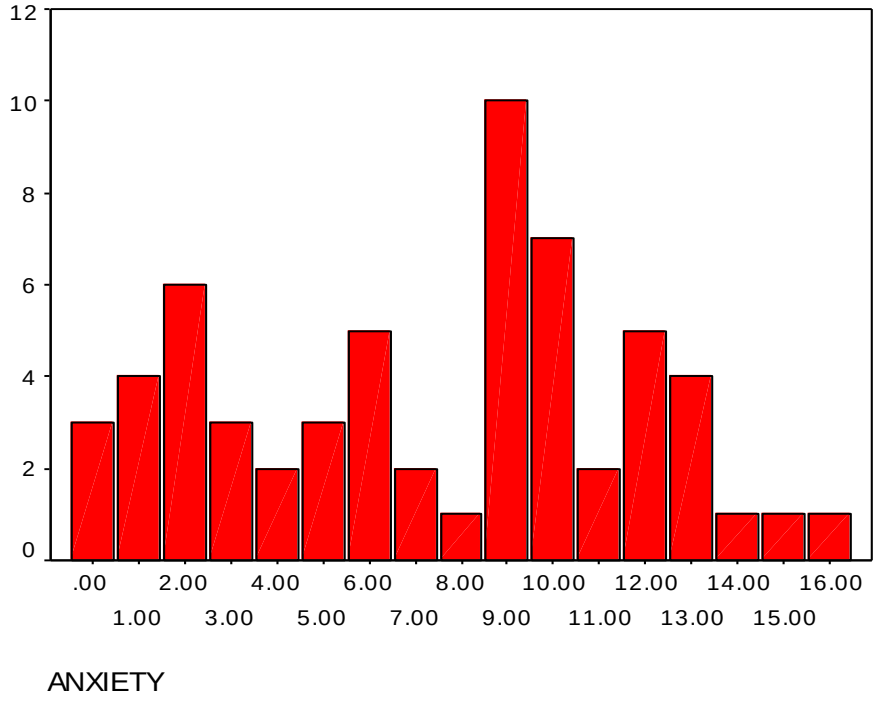
APPENDIX VII

Distributions of the main experimental measures

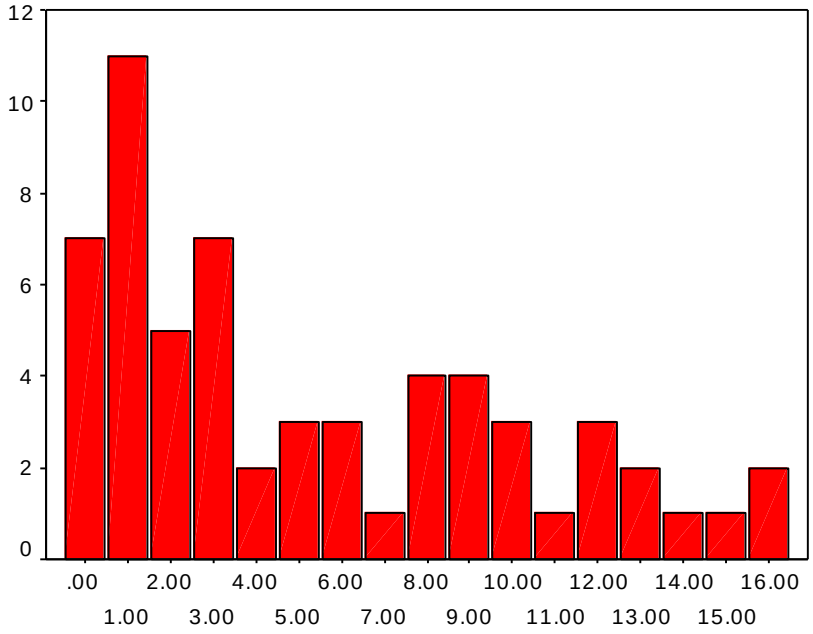
Distribution of Resilience Scores



Distribution of Anxiety Scores



Distribution of Depression Scores



Distribution of Seizure Frequency