SELF PERCEPTION AND PSYCHOSOCIAL FUNCTIONING IN PEOPLE WITH INTRACTABLE EPILEPSY

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SUMMARY

It has long been recognised that many people with poorly controlled epilepsy suffer from significant inter-ictal psychosocial problems. Yet there is little consensus on appropriate treatment for such difficulties. It is argued that this has been due to an overconcentration on seizure control in treatment practice and a lack of professional agreement on potential aetiological factors or of consistent appropriate definitions of psychological and social difficulties.

Recent research on patients' perceptions of their condition has indicated that such perceptions may be a more potent predictor of psychosocial functioning than objective information such as seizure type or frequency. If such perceptions were found to vary in a consistent and predictable manner, this would have considerable assessment and treatment implications.

Analysis was made of the literature on patient perceptions. Four main conceptual areas were implicated: The perceived social effects of epilepsy, the perceived physical effects of epilepsy, perceived control over epilepsy and its effects, and knowledge of epilepsy.

From this analysis a hypothetical "perception of epilepsy" model was developed: From this, it was suggested that patients' perceptions vary between "adaptive" perceptions, and "maladaptive" perceptions. It was proposed that "adaptive" perceptions were typified by good knowledge, high

efficacy beliefs, high perceived control over seizures and health related behaviours, low fear of seizures and low perceived social limitations imposed by epilepsy. Conversely, "maladaptive" beliefs were typified by poor knowledge, low efficacy beliefs. external control beliefs, high perceived social limitations and high fear of seizures. It was hypothesised that if this model proved to be valid, the more maladaptive an individuals perception, the greater the psychosocial risk.

A further supplementary hypothesis was made concerning "underadaptive" perceptions which, it was speculated, would result in passivity and dependency.

Clearly an integral component in an evaluation of this model would be the availability of a valid and reliable assessment of knowledge of epilepsy. However, no such questionnaire was avalable. Therefore as a prerequisite to an analysis of this conceptual model, an epilepsy knowledge questionnaire was developed. Two scales were developed reflecting general knowledge of epilepsy (E.K.P.-G) and specific knowledge about the individuals own condition (E.K.P.-P). Fifty five true/false items (34 medical knowledge items,21 social items) were selected by a range of experts in the field of epilepsy for the E.K.P.-G. A clinical trial was then completed by 82 people with epilepsy attending a city centre outpatient clinic. Results indicated that the scale had both good internal reliability and test retest reliability. Also the range of scores indicated that it is sensitive to differences in knowledge. Potential uses

of the questionnaire are discussed. A similar process was carried out with regards to the development of the E.K.P.-P. Results suggested that this complementary measurement provides a valid and comprehensive assessment profile which has considerable practical applications.

Results of the detailed analysis of 109 individuals with intractable epilepsy provided support for the perception model: With the exeption of perceived control of seizures, measures of perception were significantly related in the hypothesised direction. Also measures of perception accounted for a strong and highly significant proportion of variance in measures of anxiety and depression. Measures of perception were also found to be related to expressed social difficulties.

However, no supportive evidence was found for the supplementary "underadaptive" model.

Further analysis of the practical applicability of this model was made by providing detailed assessment of a series of case studies before. during and after a brief intensive epilepsy education programme. Results indicated that this conceptual model proved to be an effective framework for the understanding of the nature of individual differences in people with epilepsy, and that it has considerable care and treatment implications.

Full discussion of results is provided and potential uses and future developments of the model are considered.

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CHAPTER 1

PROBLEMS WITH THE ASSESSMENT AND TREATMENT OF INTER-ICTAL PSYCHOSOCIAL PROBLEMS IN PEOPLE WITH EPILEPSY

INTRODUCTION

It has been suggested that the history of epilepsy provides a microcosm of the history of medicine (1). Hippocrates was the first person to provide an accurate description of epilepsy as a disorder of the brain in about 400 B.C. In fact the words epilepsy and epileptic are from the Greek word "epilambenein" meaning to seize, possess or attack (1,2). Unfortunately, until relatively recently the treatment and care of people with epilepsy has frequently been less than enlightened. However, advances in neurology in the eighteenth and nineteenth centuries re-established the central role of brain dysfunction as the cause of epilepsy and laid the foundations for current understanding of the condition. Perhaps the greatest influence of this time is the work of Hughlings Jackson who considered epilepsy to be "*an occasional, excessive and disorderly discharge of nerve tissue*" (Hughlings Jackson in Shorvon,p.1(3)). This is a description which will still suffice today.

Epileptic seizures may take many forms and may be caused by a variety of pathological processes in the brain. Chadwick (1990) described a seizure as "*a brief and usually unprovoked stereotyped disturbance of behaviour, emotion, motor function or sensation*" (Chadwick,p.15(4)), while Meldrum (1990) stated "*the clinical components are determined by the site of origin and the pattern and spread of the abnormal discharge*" (Meldrum,p.11(5)).

The prevalence of epilepsy in the general population has

been found to vary depending on the definitions of epilepsy and assessment methods used. However, there is some consensus that about 5% of the population will experience a non-febrile epileptic seizure which will probably recur in over half of this group. Of these, between 70% and 80% will be well controlled on anti-convulsant drugs (6). Once remission is achieved it is usually permanent and 50% of this group will be able successfully to withdraw medication. It has been estimated that only one in two hundred will have active or chronic epilepsy (3,7). It is also of interest to note that less than 5% of those with chronic epilepsy will require long term institutional care, and this is often because of associated neurological disability (3).

It has been recognised that, for many people with epilepsy, it is not the seizures, per se, that are the most serious aspect of the condition. Rather, it is the psychological and social implications which frequently accompany epilepsy that may cause the greatest disruption (8). The nature of such difficulties will be discussed in the following section.

THE PREVALENCE AND TYPE OF PSYCHOSOCIAL PROBLEMS IN PEOPLE WITH EPILEPSY

The consistent conclusion of the substantial literature examining the relationship between epilepsy and psychosocial functioning is, as Betts (1993) stated "*it is probable that psychiatric disturbance of all kinds is commoner in people with epilepsy than in the general population*" (Betts,p.397(8)), while investigations into the social consequences of having epilepsy have indicated that many people with epilepsy incur significant social difficulties

(9,10). In fact, it has been suggested that such accompanying problems may be more disabling than the seizure disorder itself (9,11).

The following section will provide a brief introduction to the range and type of issues addressed in the epilepsy/psychosocial functioning literature. While it has been recognised that certain psychiatric symptomatology can occur as phenomena of seizure activity, such as pre ictal anxiety or psychotic states, these have been well documented elsewhere. The present review will concentrate on inter-ictal psychosocial problems. (For detailed reviews, see Sands 1982(12), Hermann and Whitman 1984(13), 1986(14), Levin et al 1988(15), Betts 1993 (8)).

There have been numerous reports indicating higher rates of general psychopathology in people with epilepsy. A seminal study by Pond et al (1960) found that 29% of a sample of people with epilepsy from a general practice population had "psychological difficulties", while individuals with complex partial seizures were found to have higher rates of severe personality change and psychosis (16). While it has been suggested that this survey contained significant methodological flaws (8), a more recent and accurate General Practitioner survey by Eden and Toone (1987) has also shown elevated rates of psychiatric morbidity in people with epilepsy (18).

Similarly, Rodin et al (1977) found that more than half of their sample of people with epilepsy seeking specialist

medical attention exhibited some form of psychosocial dysfunction (18). Comparable levels of disturbance were found in an extremely comprehensive study of people with epilepsy by Zeilinsky (1974) in Warsaw. Results indicated 58% demonstrated "mental abnormality" while around 3% exhibited psychotic symptoms (19).

Studies of pediatric and adolescent populations have found broadly similar results. Graham and Rutter (1968) for example found that approximately one third of children with epilepsy examined had significant psychiatric and behavioural disturbance. This was found to be double the prevalence in children with other chronic non-neurological disorders such as asthma (20).

While reports of adult populations indicate that people with epilepsy incur more mental health and social problems than comparable healthy populations, figures do not appear to differ significantly when compared to non-neurological chronic illnesses or neurological disorders other than epilepsy. However, when psychopathology is present, there are indications that it tends to be more severe and psychotic in nature (21).

A broad range of areas have been studied under the somewhat non specific headings of psychiatric disorder, psychopathology and psychosocial functioning. However, the majority of the literature can be subsumed into the following areas of investigation: Psychosis, sexual dysfunction, social, interpersonal and vocational problems, personality and behaviour problems and affective disorders.

These will each be given brief consideration.

Psychosis

Descriptions of the phenomenology of inter-ictal psychosis can be traced back to the seventeenth century (21). Since this time there has been an implicit recognition of a relationship between epilepsy and psychoses which, most typically "*have either affective, paranoid or schizophrenia like symptoms, with affective and schizophrenia like symptomatology being the most commonly occurring. There seems in this category of patients to be a tendency to an intermittency in symptoms with a recurrent course, while the schizophrenia like or paranoid psychoses have a more chronic course.* " (Bolwig p.6(21)).

Empirical research behind such a relationship has, however, proven equivocal. Literature reviews (13,15) highlight three contrary schools of thought. Firstly, there are the proponents of an "affinity" hypothesis, i.e., that there is a positive relationship between epilepsy and psychosis. Alternatively there has been research indicating an antagonism, i.e. an inverse relationship, between epilepsy and psychosis. Finally there are those who adhere to a so called coincidence theory which suggest that rates of psychosis in epilepsy are no more than would be expected in the general population.

Hermann and Whitman (1984) suggested that this remains an extremely complex and contentious area, where many issues remain to be resolved. While many studies are inconclusive,

the overall evidence suggests that the "affinity" theory has most support and coincidence least (13). (For a detailed discussion of the literature, see Toone,1981(22) and Trimble 1982(23))

Sexual Dysfunction

While many reports tend to be anecdotal or are based on single case studies, there appears to be enough convincing evidence to indicate the prevalence of high levels of sexual dysfunction in people with epilepsy. The most commonly reported problem is hyposexuality which has been found to occur with decreased libido, reduced interest in "libidinous aspects of life" such as erotic fantasies and dreams, and also impotence and frigidity. While much of the work has concentrated on males, and in particular male testosterone levels (8), Demerdash et al (1991) also found high levels of hyposexuality in females (24). Studies have shown that incidences of sexual dysfunction have ranged from 12% to 72% depending on the epilepsy population studied and dependent measures used (15,13,25).

Personality and Behaviour Problems

A variety of personality traits have been associated with epilepsy, leading some to suggest the existence of an "epileptic personality". People with epilepsy have, for example, been thought more likely to be distractable, quick tempered, hypercritical, hypochondriacal, pedantic, circumstantial, religious and egocentric (8,26). While there are those who still persuasively argue for the existence of some of these traits (e.g., Waxman and Geshwind 1975 (27),

Bear and Fedio 1977 (28), Blumer 1982 (29)) the concept of the global "epileptic personality" has fallen into disfavour. Dodrill (1982) suggested that "*such a view of individuals with seizure disorders is highly oversimplified, and it could hardly be expected that a group of disorders as complex as this would demonstrate universal characteristics of any type*" (Dodrill,p.111(30)), while Betts (1993) asserted that "*the epileptic temperament, if it exists, or when it occurs, is the result of multiple handicap- childhood, environmental and physical deprivation, brain damage and perhaps the chronic effect of anti epileptic drugs*" (Betts, p.438(8)).

There is, however, a general belief that people with epilepsy tend to be more aggressive than those without epilepsy. While there is broad agreement that ictal aggression is an occasionally observed phenomenon, the literature on inter-ictal aggression is far more equivocal (31). On reviewing the literature on epilepsy and aggression, Dam and Dam (1986) concluded that most studies showing a positive relationship between epilepsy and aggression were biased towards groups with severe, intractable forms of epilepsy which tended to have high incidences of concomitant psychiatric symptoms and neurological deficits (26). Controlled studies of prisoners have failed to detect higher levels of violence in prisoners with epilepsy as compared to prisoners without epilepsy (13), while in unselected populations of people with epilepsy, no increased incidence of violent behaviour has been found (26, 32).

Social, Interpersonal and Vocational Problems

High rates of isolation and social withdrawal, with associated problems in social interaction, have been well documented in people with epilepsy (15,33,34,35). Children with epilepsy have been reported to have fewer friends and outside activities than comparable healthy children (36), or children with diabetes or asthma (10). Such difficulties have been found to continue into adulthood. Thompson and Oxley (1989) found that in a sample of people with severe epilepsy, 67% were dissatisfied with their current level of social and leisure activity. Sixty three percent also admitted to having no personal friends (10).

Much of the literature has focused on low rates of marriage in people with epilepsy. Recent research by Kurtz (1991) indicted that marriages involving people with epilepsy were more likely to end in separation and divorce (37), while in the Thompson and Oxley sample, 78% were not currently in a relationship and 50% indicated that they had never been in a relationship. Forty nine percent indicated dissatisfaction with this situation (10). In a Canadian study, Danski et al (1980) compared Marriage rates between 1941 and 1971. In 1941 both males and females had lower marriage rates. However, interestingly, in 1971 only males were found to have a lower rate of marriage (38).

With regards to vocational status, a considerable body of literature has developed, which has highlighted elevated rates of both unemployment and underemployment for people with epilepsy (9,10,15,39). The extent of this

problem was indicated in a recent survey by the British Epilepsy Association (1990) which found that 72% of those surveyed rated employment as presenting some, or serious problems to them (40).

It has proven difficult to provide accurate figures of unemployment and underemployment as rates vary depending on the group studied, the area the sample was drawn from and the economic circumstances at time of assessment. It has also been recognised that the reluctance of many people with epilepsy to disclose their diagnosis may influence figures (42). Reported frequencies have ranged from between 10% and 15% (Lehtovaara 1983(41)) to 67% (Thompson and Oxley 1989(10)).

With regards to underemployment, Scambler and Hopkins (1980) reported career inhibitions in 42% of their sample (42). Thompson and Oxley (1989) found that the majority of their sample who were in full time employment indicated dissatisfaction with their jobs which tended to be unskilled despite the majority having academic and vocational qualifications (10). A possible knock on effect of vocational problems is the increased incidence of poorer financial status among people with epilepsy (15).

Affective Disorders

Perhaps the most commonly experienced inter-ictal problems for people with epilepsy are those of anxiety and depression (8,13,43). Trimble and Perez (1980), for example, found that in a group of 281 non psychiatric selected patients,

mean anxiety and depression scores on the Middlesex Hospital Questionnaire were not only significantly higher than a normal population, but were equivalent to a psychiatric population (44). Similar results were found by Arnston et al (1986) on the Hopkins Symptoms Checklist. Thirty nine percent of their sample indicated symptoms of anxiety as compared to 9% of a normative sample, while 25% indicated symptoms of depression as opposed to 9% of the normative sample (45).

With regards to inter-ictal anxiety, Betts (1989,1993) suggested that while the presence of generalised anxiety states in people with epilepsy is not uncommon, phobic anxiety and in particular agoraphobia is particularly prevalent. He proposed that an unfortunate consequence of patient's fear of having a seizure in a public place is that anxiety and panic may increase seizure frequency which consequently may reinforce and increase anxiety levels (8,46).

Depression appears to have been the most frequently elevated subscale on measurements of personality and psychopathology, such as the Minnesota Multi-phasic Personality Inventory (M.M.P.I) (13,47). Both reactive (i.e., a reaction to external life events) and endogenous (No obvious external precipitant) are prevalent (8,13,47). Interestingly, it has also been noted that depression is particularly likely to occur in people with epilepsy when there is a decrease in seizure frequency (46,8,47).

As would be expected from such a relationship between

depression and epilepsy, the majority of studies suggest suicide and self harm are more common in people with epilepsy than healthy controls (8,13,47). For example, from a review of 11 reports of mortality in epilepsy, Barraclough (1981) found that the risk of suicide was 5 times greater than would be expected (48). (For a detailed discussion of the literature, see Betts,1993 (8) and Robertson and Trimble 1983 (47)).

It has been demonstrated in this section that people with epilepsy are more susceptible to a broad range of psychological and social problems than comparable healthy individuals and in many cases, than people with other chronic illnesses.

Yet such findings seem to be of limited practical use: Literature on the development of effective treatment of such problems is sparse and reviews of medical and psychological treatment interventions indicate that the vast majority of published studies have targeted clinical seizure frequency as the main dependent variable with little or no reference given to associated psychosocial difficulties (49,50,51,52). The following section will examine why this should be the case.

THE TREATMENT OF PSYCHOSOCIAL PROBLEMS IN PEOPLE WITH EPILEPSY

Limitations of the Medical Model

The growing awareness of the psychological and social consequences of epilepsy has been paralleled by developments

of medical assessment and treatment. The modern history of both can be traced to the late 19th century: While bromides were first found to be useful for the treatment of epilepsy towards the end of the last century, the modern era of drug treatment began with the introduction of phenobarbital in 1912. The next major development was the recognition of the anti convulsant effect of phenytoin in the 1930s.

This period also saw considerable changes of the perception of the relationship between epilepsy and psychopathology. Guerrant et al (1962) described the period towards the end of the last century as one of "epileptic deterioration" which assumed that epilepsy was the result of a progressive hereditary degenerative condition which would necessarily result in deterioration of personality and behaviour. The period from the turn of the century to the 1930s was highly influenced by psychosomatic medicine and Freudian psychodynamics. This period of the "epileptic character" suggested that the epilepsy itself and associated behavioural change could be traced to an "epileptic constitution" which could be identified in patients prior to onset of seizures (53). Guerrant et al suggested that from the midpart of the century to the present day, two alternative viewpoints have developed. The first of these suggests that people with epilepsy are essentially normal and the development of psychosocial problems are secondary to factors such as head injury, prolonged drug treatment, fear of seizures or social stigma. The alternative viewpoint has proposed that people with temporal lobe epilepsy are particularly vulnerable to psychopathology and the most

important determinant is the site and type of epileptic discharge (53). Gibbs for example, has suggested that patients with epileptogenic foci above the Sylvian fissure tend to present to neurologists while those with foci below tend to present to psychiatrists (Reported in Sherwin 1982(54)).

This period has also witnessed considerable medical and technical developments which have lead to significant advances in the understanding and treatment of epilepsy. A number of new, more effective anti-convulsant drugs have been introduced, more effective surgical techniques have been developed and significant advances have been made in the development of less intrusive and more accurate assessment procedures, such as the development of C.T. scans in the 1950s and M.R.I. scans in the 1980s and 1990s, and also the refinement of E.E.G. techniques such as the development of video telemetry and ambulatory recording (3,55).

From this brief review it can be seen that there has been a clear division between treatment on the one hand, which has been almost exclusively medical or surgical, and the assessment of psychopathology on the other. The implicit assumption would appear to be that if seizures were controlled, associated psychosocial difficulties would disappear or be significantly reduced.

Ryan et al (1980) and Collings (1990) have suggested 2 models to account for psychosocial problems in people with

epilepsy (56,57). The first, the "medical model" is as described above; "*non medical problems are almost inevitable and severity covaries directly with the severity of the medical condition*" (Collings p.418(57)). Alternatively, the "sociopsychological model" assumes that other individual and social characteristics mediate the degree of problems suffered by the individual (56,57).

While psychological research has provided considerably more validity for the latter model, it is still the former which tends to be adopted in clinical trials. Binnie (1990) stated "*all too often theraputic interventions such as the use of new anti epileptic drugs or surgical treatment, are assessed chiefly in terms of seizure frequency with a scant regard for outcomes other than obvious adverse experiences or cognitive deficits*" (Binnie p.30 (51)).

Reviews of psychological treatment programmes have, somewhat surprisingly, revealed that the vast majority of reported studies have also adhered to the medical model and targeted clinical seizure frequency as the main dependent variable to be influenced by the formulation of seizure abatement or prevention techniques, based predominantly on behavioural and cognitive behavioural principles (49,8,59). Despite appeals for such studies to provide some degree of social validation of treatment outcome, with a few notable exeptions (e.g. Dahl et al 1987 (60), Rousseau et al 1985 (61), Tan and Bruni 1986 (43), Gillham 1990 (62)) the social and psychological consequences of treatment have largely been ignored.

Morrow and Baker (1993) suggested that seizure frequency is an attractive endpoint, firstly as it is the basis of epilepsy and secondly as it can be expressed numerically, thereby allowing the application of statistical methods (52). Yet, there are considerable difficulties in using such a limited point of reference. It has clearly been demonstrated that there is not a linear relationship between seizure frequency and psychopathology. There is considerable variability of type of seizures experienced. For example, a brief absence cannot be regarded as disabling as a generalised tonic clonic seizure. There is also considerable variability of the perceived severity of seizures. Some individuals are able to lead comparatively normal lives with a fairly high seizure frequency, and in fact Betts (1993) suggested that some individuals actually felt a marked sense of relief if they were able to have a controlled seizure, while others may live in constant dread of infrequent and unpredictable seizure occurrence (8,51,52). Also, many people with epilepsy have multiple problems of a long standing nature which are not a direct consequence of the present severity of the seizure disorder. Not only is the concentration on seizures ineffectual in dealing with such difficulties, but as Thompson and Oxley (1989) stated "*failure to identify their needs at an appropriate time, often due to an overconcentration on the purely medical aspects of the condition, will often lead to a slow but inexorable descent down the dependency spiral*" (Thompson and Oxley,p.128(10)).

SUGGESTED REASONS FOR THE FAILURE TO DEVELOP COHERENT TREATMENT PROGRAMMES FOR PSYCHOPATHOLOGY IN EPILEPSY

Scambler (1993) suggested that the paucity of studies on how epilepsy affects quality of life when compared with other chronic illnesses such as diabetes was "*perhaps understandable given the nature of epilepsy, namely its striking varied and intermittent symptomatolgy and general unpredictability, with or without treatment*" (Scambler,p.733(63)). However, perhaps the major reason for the limited effectiveness of research is that not only have definitions and means of assessment of psychosocial difficulties varied considerably, but also a bewildering variety of competing aetiological factors have been hypothesised for the development of psychopathology in people with epilepsy.

Hermann and Whitman (1986) suggested that research concerning causal factors of psychopathology in epilepsy can be subsumed into 3 major hypotheses: the neuroepilepsy, the psychosocial and the medication hypotheses (14) (See Table 1).

The neuroepilepsy hypothesis relates to the "period of psychomotor peculiarity" outlined above. This proposes that behavioural and psychiatric abnormalities are a function of central nervous system dysfunction related to the site of epileptic discharge. Hermann and Whitman (1986,1990) revealed that the majority of empirical research over the last 20 years would be subsumed under the neuroepilepsy hypothesis. However, significantly, when empirical research has been conducted, it has suggested that neuroepilepsy

variables have had little more than modest explanatory power (14,64).

With regards to the medication hypothesis, there has been some interest in the potential behavioural and cognitive side effects of anti convulsant therapy. For example, Reynolds (1981) has reported adverse psychological effects of toxic blood serum levels of anti convulsants (65). However, there appears to be comparatively little empirical

Table 1- High Risk Variables for Psychopathology in Epilepsy, Grouped According to Hypothesis

Neuroepilepsy	Psychosocial
Age at onset	Fear of seizures
Seizure control	Perceived stigma
Duration of disorder	Perceived discrimination
Seizure Type	Adjustment to epilepsy
Multiple seizure types	Locus of control
Etiology	Life event changes
Type of aura	Social support
Neuropsychological status	Socioeconomic status
	Childhood home environment
Medication	
Number of medications	
Serum levels	
Medication type	
Folic acid levels	

(In Hermann and Whitman,p.9(14))

research in this area. On reviewing the literature, Hermann and Whitman (1986) found that only 3% of variables empirically evaluated as risk factors for inter ictal psychopathology were medication related, and that a major difficulty in such research was the confounding effect of subject's neurological condition (14).

Finally, with regards to the psychosocial variables, there has long been recognition of the specific psychosocial risk factors associated with epilepsy such as those outlined in table 1 (9,12,13,15). However, only in recent years has research been conducted on how such factors predispose people with epilepsy to psychopathology. For example Hermann et al (1990) found that 3 independent psychosocial predictors (increased number of stressful life events in the last year, poor adjustment to epilepsy, financial stress) were related to psychopathology as indicated by elevated General Health Questionnaire (G.H.Q.) scores (64).

While it seems reasonable to assume that factors from each of these hypotheses contribute to the development of psychopathology in people with epilepsy, Hermann and Whitman (1986) suggest that there is considerable competition between the proponents of each of these schools of thought. While such competition is not uncommon in scientific research, and has frequently been found to act as a catalyst for future research developments, Hermann and Whitman have suggested that this has not been the case with regards to epilepsy. They suggested that in many cases proponents have argued for the prominence of their position at the expense of others. "*The opinions are frequently strong, often dogmatic, and not uncommonly stated with an air of authority and finality... For some reason the scientific development of the epilepsy/psychopathology field has been arrested in this state for over 25 years*" (Hermann and Whitman,p.11(14)).

Such dogmatism creates 2 problems. Firstly, specific predictor variables have not consistently been linked to specific areas of psychopathology. There in fact appears to be an implicit assumption that such predisposing factors will have a universal effect across all identified areas of psychopathology. Hermann and Whitman (1986) found that factors from each hypotheses, such as seizure type, stigma or medication were considered by many to be as potent predictors of, for example, sexual dysfunction and affective disorders as they were for psychosis (14). However, from their review they did find some suggestions that aetiological factors did vary as a function of the area of psychopathology under consideration. For instance, psychosocial factors tended to be related more to affective disorders and neuroepilepsy variables tended to correlate more with psychotic disturbance (14).

The second problem is that strict adherence to a narrow scientific paradigm precludes effective examination of the interaction between predictor variables. Recent research has proven to be somewhat more encouraging. For instance, Hermann and Whitman (1986), at the end of their review described a model for the evaluation of the relative significance of variables from each of the 3 hypotheses (14). Devellis and Devellis (1986) have also provided a hypothetical model of how social, psychological and biological variables relate to each other and to the development of psychopathology (66). Progress has also been made on the nature of interactions on specific areas of psychopathology. For instance, from a review of the

literature on depressive illness in people with epilepsy, Robertson and Trimble (1983) concluded that onset has multiple causes and indicated an intention to look at the intercorrelation between such causal factors (47).

In summary, understanding of the relationship between epilepsy and psychosocial functioning has come a long way since Guarrant's description of the "period of epileptic deterioration" at the turn of the century (53). However, it would appear that understanding of the aetiology of such difficulties and consequently the development of effective treatment has been hampered by scientific dogma, in conjunction with limited and in some cases inadequate, research. Recent research has attempted to address such difficulties by attempting to provide multifactorial hypotheses for the development of psychosocial difficulties.

INDIVIDUAL DIFFERENCES IN PSYCHOPATHOLOGY: THE IMPORTANCE OF PATIENTS' PERCEPTIONS

The development of multi-factorial research clearly provides a valuable contribution to the understanding of this complex area. However, it is suggested that while this may provide a meaningful description of populations of people with epilepsy, it is of limited practical use for understanding the individual. Mittan (1986) stated that "*it should be noted that the clinical interpretation of a group profile is at once representative of everyone and no one. Caution should thus be exercised when applying...results to individual patients*" (Mittan,p.113(34)).

The development of a conceptual model of individual differences of adjustment in people with epilepsy would evidently be of considerable practical benefit. However, the level of psychosocial adjustment necessarily reflects the interrelationship between a number of factors in any person with epilepsy. Morrow and Baker (1993) suggested that "*the complexity of problems produced as a result of having epilepsy needs to be understood in terms of the interaction of the psychological, social and physical wellbeing of the patient.* (Morrow and Baker,p.727(52)). Binnie (1990) illustrated this by highlighting that the factors involved in adjustment will, for instance, be significantly different for a barrister with epilepsy, than for a child with learning difficulties (51).

Arangio (1979), on providing a review of variables which should be considered for effective assessment and treatment of the individual with epilepsy, appeared to be somewhat pessimistic as to the possibilty of the development of a treatment model of individual differences for people with epilepsy: "*It would be impossible to review all the interventive psychosocial strategies that have been developed or should be developed. Simply stated, that strategy which is most meaningful is the one which is suggested by the information gathered*" (Arangio, p.123 (67)).

Perhaps the most encouraging recent development has been the work of Dodrill and his associates (1980) who developed a scale, the Washington Psychosocial Seizure Inventory

(W.P.S.I.), which was designed to asses both individual and group profiles of psychosocial adjustment in people with epilepsy (68). However there has been doubts cast about the validity and practical applicability of the scale (69,70). These will be discussed in more detail in chapter 8.

It appears evident that the failure to develop a psychosocial adjustment model of individual differences resides in the enormous complexities in assessing all relevant variables. However, perhaps a more promising approach is provided by recent developments in cognitive-behavioural psychology. From this, it has been suggested that it is not external and internal physiological events per se, but the individuals interpretation of these which can determine the nature and chronicity of psychological adjustment. Beck and his colleagues (1970,76) have suggested that experience leads to the formation of assumptions or "schemata" which are used to organise perception and consequently govern and organise behaviour. Consequent information is thereafter distorted in line with this pre-existing framework. While this model was developed with specific reference to emotional problems, it has been suggested that the same qualitative thought processes develop in all individuals (71,72).

In recent years there has been growing awareness in epilepsy research of the importance of patients' perceptions of their condition. In line with Beck's model, it has been suggested that the perceptions the person with epilepsy has about his/her condition and about him/her self in relation to

his/her condition are more important predictors of adjustment than more objective measures such as seizure type or frequency (52,56,57,69).

As has been outlined above, the aetiological factors involved in the development of such cognitive structures may vary considerably. However,the appeal of examining patients' perceptions is that it focuses on the current reality of the disorder for the individual, rather than concentrating on potentially redundant causal factors (73). If patient perceptions were found to vary in a consistent and predictable manner, this would have considerable assessment and treatment implications: Not only does such an approach have the potential to increase the range of treatment programmes for people with epilepsy, it also may help match available treatments to patients more effectively. Further, it may also provide a valuable insight into a group seldom examined in epilepsy research; the majority of individuals who appear to cope well with their epilepsy (15). However, at present, there has been no detailed consideration of individual differences in patient perceptions. While much of the literature on patient perceptions has focused on the concept of stigma, a number of other cognitive processes have also been examined in some depth. It is suggested that all relevant research can be subsumed within 3 broad subheadings: Perceived physical and social effects of having epilepsy, perceptions of control and knowledge of epilepsy.

The components of each of these areas will be given consideration in the following chapters. Based on this

research, a hypothesised model of how such factors interact between individuals will be proposed and empirically evaluated.

SUMMARY

It has been recognised that many people with epilepsy have significant inter-ictal psychosocial problems. However such findings have been of limited practical use, with the majority of medical and psychological treatment programmes focusing on the seizure disorder as a somewhat limited point of reference. It has been implied that the reason for the omission of psychological and social factors is that, not only have definitions of psychosocial difficulties varied considerably, but also a variety of competing factors have been suggested for the development of such problems. Also, while research may provide accurate descriptions of populations of people with epilepsy, this has been of limited value in understanding the individual.

Recent work on the perceptions people with epilepsy have about their condition has indicated that such perceptions may be a more potent predictor of psychosocial functioning than objective information such as seizure type or frequency. Such work has considerable assessment and treatment implications, yet there has been no empirical evaluation of the interaction between factors comprising self perception in people with epilepsy.

CHAPTER 2

THE PERCEIVED SOCIAL AND PHYSICAL EFFECTS OF EPILEPSY

INTRODUCTION

The importance of patients' perceptions of the effects of any chronic illness was emphasised by Sacks (1985) who stated that "*A disease is never a mere loss or excess- There is always a reaction on the part of the affected individual to restore, to replace, to compensate for and preserve his or her identity*" (Sacks in Richards and Reiter,p.84(55)). These comments are particularly salient with respect to epilepsy. Jacoby (1991) argued that patients' feelings concerning the potential social ramifications of being "epileptic" and specific fears about aspects of their seizure disorder may be as important in helping them cope with epilepsy as the control of seizures by medication (74).

In this chapter, two conceptually different areas of patients' perceptions will be considered- Firstly the challenge to self image as a consequence of being diagnosed as having epilepsy and secondly, the growing awareness of patients' fears concerning the potential physical consequences of epilepsy, principally through the work of Mittan and his colleagues.

The aim of this chapter is to provide a review of each section with a view to developing a conceptual model of individual differences in patients' perceptions of their condition. The structure of each section will therefore reflect this aim: Firstly, a review of the relevant literature with specific reference to the development and maintenance of cognitions will be provided. Secondly, the psychosocial impact of such cognitions will be considered.

Finally the literature will be reviewed for evidence of individual differences in cognition and consequent psychosocial adjustment.

SOCIAL AND PERSONAL IDENTITY: THE PERCEIVED EFFECTS OF HAVING EPILEPSY

Background

Much of current understanding of the perceived effects of being diagnosed as having epilepsy comes from the extensive literature on the concept of stigma.

Until comparatively recently, the orthodox model of research on this topic was lead by the assumption that people with epilepsy learned that having epilepsy was in some way discreditable through overt acts of discrimination. Therefore, emphasis was placed on levels of rejection and disapproval from others (75,76). However, recent research has challenged the legitimacy of this explanatory model and has suggested an alternative model based on patients' perception of stigma. Central to such a model is the work of Goffman (1968) who posited that stigma referred to any deeply discrediting attribute. However, the attribute, in this case having epilepsy, only becomes relevant if the individual perceives it to be discrediting (77).

In line with cognitive theory outlined in the previous chapter, Scambler and Hopkins (1988) suggested that people with epilepsy have a degree of commonality of learning experiences regarding their epilepsy which shapes and distorts their interpretation of past, present and future events. They proposed that the foundation of this "special

view of the world" is perceived stigma (75).

Scambler and Hopkins made an important distinction between "enacted" and "felt" stigma. Enacted stigma refers to the attitudes and beliefs held by others which result in acts of discrimination. This excludes instances of "legitimate" stigma such as driving bans. Felt stigma refers to the fear of encountering enacted stigma, and also the negative self image held by the person with epilepsy.

Inherent in the development of felt stigma is the belief that on being diagnosed as having epilepsy, an individual is transformed from being a "normal" person into an "epileptic". This is analogous to Goffman's concept of "spoiled identity" which results in feelings of fear and shame with the consequent belief that "normal" people will actively discriminate or distance themselves from the person with epilepsy (63,72,75,76).

Two broad explanations have been highlighted in the literature to account for the perception that to have epilepsy is to possess a deeply discrediting attribute; the historical residue of the deviant status of epilepsy and the potential reaction of others to seizure occurrence.

The relevance of the historical perspective was well articulated by a subject in Schneider and Conrads' (1980) study. "*Its implications are enormous. The historical implications of epilepsy are fantastic. I'm lucky to have been born when I was. If I had been born at the beginning of this century I would have been discarded...Probably locked*

away somewhere" (Schneider and Conrad,p.35(76)).

The abberant nature of epilepsy can be traced back to ancient Greece where two gods, Pan and Hecate, both of whom were associated with the sinister and savage side of human nature, were considered the Gods of epilepsy (63).

In christian times epilepsy was associated with demonic possession and in fact reference is made in the bible to what would appear to be people with epilepsy possessing "unclean spirits" (55).

In the middle ages the view of possession and evil persisted. This is perhaps most notably demonstrated in the Salem witch trials where many people with epilepsy were tried and put to death for the crime of having epilepsy (55).

In the 18th and 19th centuries "epileptics" tended to be regarded in the same categories as "mad", "feebleminded" or "imbeciles", and in fact a considerable proportion of those placed in the early mental asylums were incarcerated as they had epilepsy. Such an association was implicitly recognised by many physicians in the 19th century who, for example, regarded the potentially serious side effects of bromides as "better than having epilepsy" (55,78).

Such a background laid the foundation for considerable legal and social prejudice in the 20th century: Eugenics laws in the United States in the first quarter of the century lead to the prohibition of marriage of people with epilepsy

(incredibly this law was only overturned in Missouri in 1980) and sterilisation of people in "socially inadequate classes", of which people with epilepsy were included. Laws have also been implemented prohibiting the immigration of people with epilepsy, and the adoption of children, whereby a child who developed epilepsy in the first 5 years of life could be returned and the adoption annulled in the same way one would return faulty goods to a shop (78).

Dell (1986) suggested that such legislation "*Support the perception that people with epilepsy are undesirable, dangerous, or somehow mentally deficient and capable of passing that deficiency to their offspring. The reasoning becomes that therefore no children should be born to people with epilepsy, so they are forbidden to marry, sterilised or institutionalised and certainly no potential adoptive parent would want to adopt a child with epilepsy*" (Dell,p.189(78)).

Surveys of public attitudes towards people with epilepsy have found considerable ignorance hostility and prejudice. For example, a 1971 survey found only 57% felt people with epilepsy should be employed and 32% said they would object to their child playing with someone with epilepsy (O.H.E. In Betts(8)). Bagley (1972) suggested that levels of discrimination towards people with epilepsy were broadly comparable with levels of racial discrimination (79). Recent surveys have indicated that attitudes may be changing for the better. However critics have argued that such surveys exert pressure for people to voice socially acceptable opinions and that what people say and what they do may not

necessarily coincide (8,56,76).

In summary, it would appear that there is a trend towards more positive and open attitudes towards people with epilepsy. However, as Schneider and Conrad (1980) stated "*The historical residue of the deviant status of epilepsy remains central to the conditions current social reality*" (Schneider and Conrad,p.34(76)), while Richards and Reiter suggested that "*Both the person who has the seizure and society believe at a deep level that a seizure means to be taken over by some irresistible evil force. Today as a religious view has declined and a scientific view dominates, epilepsy is seen not so much as an evil, but as a negative, something that should be wiped out*" (Richards and Reiter,p.112(55)).

A second, and in many respects related, explanation of the perceived discrediting nature of epilepsy concerns the potential social ramifications of seizure occurrence. Betts (1993) graphically highlighted this with a patient's description of his seizure. "*To awake...lying in a filthy gutter,wet and messy because I have soiled myself, my thoughts confused, surrounded by strangers who are half curious, half disgusted. This is the nightmare with which I have to live*"(Betts,p.401(8)). Not only can the physical manifestations of seizure occurance be extremely disconcerting to observers, but such confusion and loss of control tends to be associated in the public mind with, for example, alcoholism or drug abuse.

Schneider and Conrad (1980) have suggested that, at best,

seizures in social situations are akin to such involuntary *faux pas as* breaking wind or belching. One of their subjects described seizure occurrence as like "*having your pants fall down in public*" (Schneider and Conrad,p.35(76)). The social meaning behind such behaviours for people with epilepsy may therefore be regarded as "*a threat to their status as normal and competent members of society*" (Schneider and Conrad,p.36(76)).

Recent research has provided a valuable insight into the social processes underlying the development of stigma. However, prior to a discussion of this research, it is suggested some caution must be taken concerning the general applicability of results as much of the work on this area is based on qualitative depth interviews on comparatively small numbers of people with epilepsy.

Research has indicated that people with epilepsy learn such negative perceptions through interaction with significant others who act as "stigma coaches" (76). Scambler (1993) proposed three main catagories of significant others-

1- Lay culture- As has been outlined above, despite recent encouraging changes in public attitudes towards epilepsy, the evidence is still suggestive of significant levels of public ignorance and discrimination towards people with epilepsy.

2- Medical professionals-The importance of this group cannot be underestimated. Not least of all as "*communication of the diagnosis of epilepsy by a physician confers the social and*

legal status of "epileptic" on the diagnosed" (Scambler,p.736(63)). Physicians failure to provide adequate relevant information has been implicated as a major factor in the development of felt stigma and patient dissatisfaction. This topic will be considered in greater detail in chapter 4.

3- The family- As many people with epilepsy develop their condition in childhood, the family, and in particular parental attitudes, appear instrumental in the development of the individuals perception of his/her condition. The more parents think of epilepsy as something "bad" and not to be discussed, the more likely the person with epilepsy is to see it as something to be ashamed of (63,75).

West (1992) identified parents who acted as "stigma coaches" by reacting with open hostility to the person with epilepsy in the belief that the stigma associated with the child may be extended to other family members. Therefore, such "stigma by affiliation" or "courtesy stigma" ascribes not only a sense of shame, but also a sense of responsibility for potential problems of other family members (80). Many families also adopted a lay theory of "epileptic defect" whereby parents would describe their child in terms of the "epileptic personality" (see chapter 1): "*There's something missing in her. She keeps doing things others don't. There's another boy like her and he's epileptic too.. Remember their minds aren't like yours or mine*" (West,p.14(80)). West suggested such attitudes remove responsibility from family members for what has gone on and further justifies hostile

conduct (80).

Perhaps the more commonly occurring parental strategy is one of overconcern and overprotection. It has been proposed that many parents extend "sensible" precautions such as those regarding swimming or cycling, to restrictions on almost any area of family life (35,63,75,76,80).

Psychosocial Consequences of Perceived Stigma

Given the strong sense of shame and self degradation that frequently accompanies a diagnosis of epilepsy, it is of little surprise that perceived stigma has been associated with elevated rates of psychopathology (45;64).

Scambler's (1993) "hidden distress model" provides a useful explanatory framework for such difficulties. This model comprises three stages-

1- Having epilepsy is seen as a social and personal liability. From this view, fear of enacted stigma predominates.

2- This results in a strategy of concealment and attempts to pass as "normal".

3- Non-disclosure results in reduced opportunities to encounter enacted stigma in social and vocational situations. However,this reinforces felt stigma which may result in potentially elaborate information management strategies which can prove to be a source of significant distress (63).

The potential deleterious effects of concealment have been well documented. West (1993) makes a useful distinction

between "successful" and "failed" concealers. "Successful concealers" managed to conceal their diagnosis from almost everyone outside of their immediate family. Not only did this strategy appear to reaffirm the perceived shamefulness of epilepsy, but the avoidance of social, vocational and recreational activities may potentially result in dependence, social and functional skills deficits, low self esteem, anxiety and depression (35,63,75,78,80).

"Failed concealers" had, at one time been "successful concealers". However, this strategy failed following a witnessed seizure. The perceived negative reaction of others served to reinforce felt stigma, which consequently lead to a redoubling of efforts to conceal their condition, which resulted in even greater restrictions in lifestyle (80).

Individual Differences in the Perceived Social Impact of Epilepsy

There was an implicit assumption in much of the early research that people with epilepsy are universally stigmatised by their condition. However, this appears to be far from the truth. Ryan (1980) found that approximately 70% of his sample felt they were not unreasonably limited or treated differently by others due to their epilepsy and 81% felt they had been treated fairly by employers (56). Studies of patients' perceptions of their conditions have also found that many people with epilepsy believe they possess many positive attributes and are the equal of people without epilepsy in many respects (81,82).

Such perceptions clearly have implications for psychosocial

wellbeing. Collings (1990) found that the discrepancy between current self perceptions and anticipated self without epilepsy was an extremely important predictor of psychopathology. Those who felt their self image would be little different if they did not have epilepsy tended to be better adjusted (57).

Such adapted perceptions tend to be typified by a sense of openess and control, which results in the ability to neutralise the actual or perceived negative impact of epilepsy on the individuals life (63).

While some adopt a policy of total disclosure, more commonly a policy of selective disclosure (which tends to be enacted in reaction to a witnessed seizure, or when it is highly probable that a seizure will be witnessed in the near future) is adopted. Scambler (1993) stated that "*by combining selective disclosure with a scepticism about the possibility of others negative judgements were they to know, the pragmatist sustains a relatively normal life*" (Scambler,p.738(63)). Such perceptions are based on the belief that epilepsy is "no big thing" and therefore need not be source of discrimination, or conversely a source of special treatment and sympathy (63,75,76,80). The implications of such strategies are that the individual is potentially less anxious in social situations and is therefore less likely to avoid them. Also, the individual is more likely to have a set of experiences broadly in line with the general population. As such, there will be little or no similarity between the individual and the commonly

held image of the "epileptic". West (1992) suggested that "*in the process of disclosing epilepsy, then, is created the possibility of altering the meaning of epilepsy and being judged as normal*" (West,p.15 (80)).

Such perceptions are in clear contrast with those of individuals who perceived their condition to have had a pervasive negative impact on their lives and had striven to offset the impact through concealment and avoidance. An extreme version of this model is described by Schneider and Conrad (In Scambler (1993)) who state that for this "debilitated" subtype "*epilepsy floods ones identity and life with meanings and behaviour that figuratively constipate the social self*" (Schneider and Conrad in Scambler p.739 (63)). Similarly, Scambler (1993) found a minority of people who allowed their epilepsy to become an obsession and felt themselves cursed (63).

Summary

Much of current understanding of the perceived social effects of having epilepsy is based on Goffman's (1968) concept of stigma which proposed that stigma applies to any attribute which is deeply discrediting (77). However, stigma is only relevant if the individual perceives it as so. Scambler and Hopkins have termed such perceptions with regards to epilepsy "felt stigma" (75). It has been demonstrated that high levels of felt stigma have considerable deleterious consequences. However, it has been suggested that there are considerable individual differences in levels of perceived stigma, and in fact many people with

epilepsy appear to cope perfectly well with the social implications of their condition.

THE PERCEIVED PHYSICAL EFFECTS OF EPILEPSY: FEAR OF SEIZURES

Background

It has already been indicated that the physical characteristics of epilepsy do not directly covary with psychopathology, and that a more fruitful line of inquiry concerns examination of the patients' subjective perceptions of his or her condition (52,69). In the previous section the psychosocial implications of seizure occurrence were discussed with reference to the perceived shame and embarrassment of seizures in social situations. However there is growing evidence to suggest that another perceptual aspect to seizure occurrence, patients fear of the physical consequences of seizures, may be an equally important predictor of psychosocial adjustment.

That people with epilepsy may be afraid of seizures comes as little surprise, yet Hermann and Whitman (1990) observed that "*the fears that patients have about their seizures and/or medical misinformation, are seldom assigned a significant role in discussions of behavioural adjustment*" (Hermann and Whitman,p.485(13)). Current understanding of patient fears is based, almost exclusively, on the work of Mittan and colleagues (1986). Mittan stated that prior to his research "*with occasional deference to organic variables, the psychosocial problems of epilepsy have simply, speculatively and summarily been ascribed to stigma*" (Mittan,p.91(34)). He suggested that such uncritical

acceptance of the stigma model has impeded new approaches.

From a sample of 373 adults with epilepsy, Mittan (1986) found not only pervasive fear of seizures, but that the intensity of fears were such that stigma never eclipsed the threat of seizures in importance (34).

The major perceived fear, which affected approximately two thirds of the sample, was fear of death due to seizures. This was thought possible through a variety of causes such as suffocation, accidents precipitated by seizures or heart attacks. Virtually all the sample had multiple fears and most believed that such events were not only possible but likely (34).

Fears of brain damage as a result of a seizure were also prevalent. Sixty per cent believed their seizures would cause progressive memory loss and 78% of the white subsection of the group believed epilepsy compromised their ability to think clearly. Additionally, over one third of the total sample were afraid of the physical and mental harm they thought were a likely consequence of anti-convulsant medication (34).

Mittan did not speculate in any detail on the aetiology of such fears. However, it seems reasonable to suggest that such perceptions of physical risk may develop in the same manner as perceptions of the social implications of epilepsy described in the previous section; namely through interaction with friends, associates, family and medical professionals. For example, parental strategies of

overprotection and reluctance to openly discuss epilepsy may well result in the individual overemphasising potential risks (63,75,76,80). Also, the failure of medical professionals to address patients fears and misconceptions tends to make the individual "fear the worst" and construct his or her own lay theories about the potentially devastating causes and consequences of seizures (83) (This will be discussed in greater detail in Chapter 4).

Psychosocial Consequences of Fear of Seizures

The most commonly reported consequence of such fears was continual dread and anxiety regarding a potential seizure. As a consequence, over three quarters were found to be depressed because of their epilepsy and some had considered suicide "*to put an end to the unpredictable terror of seizures*" (Mittan,p.100(34)).

In order to offset the perceived consequences of such fears, many went to great lengths to avoid potential accidents or seizure precipitants. While a proportion of strategies appeared rational reactions to the severity of the individuals condition, many were phobic and ritualistic in nature. For example over one fifth of the sample were afraid to leave home because of the possibility of a seizure. It was recognised that such self isolation was similar to the phobic avoidance found with respect to stigma and may have equivalent deleterious social and psychological effects (34).

Fear of epilepsy was also found to result in significant vocational limitations. Many were afraid of seizure related

job accidents and also that specific work environments and activities, such as physical exertion, loud noise or flashing lights might trigger seizures. In addition, over 80% were concerned that work related stress may cause seizures. This was proposed as not only a significant factor in failure to seek employment, but also failure to obtain employment (34).

Individual Differences in Patient Fears

In order to assess the relationship between patient fears and psychopathology, Mittan (1986) split his sample into "high" and "low" fear groups. From this procedure it was found that the high fear group were subject to significantly greater psychopathology and impaired social functioning. Further, the high fear group was found to be suffering from severe and clinically significant psychopathology as indicated by scores on every one of sixteen scales and subscales measuring psychopathology. The low fear group conversely fell within normal levels of adjustment (34).

Mittan contended that while causality was not established, there was little evidence to suggest support for the notion that patients fears grew out of pre-existing psychopathology. He therefore proposed that individual differences in patients' fears are a useful predictor of psychosocial functioning (34).

Summary

The fears that people with epilepsy have about their condition have been given little consideration in the

scientific literature. However, the work of Mittan and his colleagues has indicated that multiple fears of death and brain damage are widespread among people with epilepsy and that these fears are related to considerable impairment in psychosocial functioning.

There appears to be considerable individual differences in the intensity of such fears, which in turn appears to be directly related to levels of psychosocial functioning: People with high levels of fears about epilepsy have considerable psychological and social adjustment problems, while those with few epilepsy related fears appear to have comparatively normal levels of psychosocial adjustment (34).

With respect to both the perceived social effects of epilepsy and fear of the physical properties of epilepsy, a major recurring theme is the unpredictability of seizures and perceived lack of control. This aspect of patients' perceptions will be considered in the next chapter.

CHAPTER 3

PERCEIVED CONTROL AND HELPLESSNESS IN PEOPLE WITH EPILEPSY

Page Number

INTRODUCTION

It has been proposed that perceived control constitutes a fundamental need, which has implications for psychological wellbeing and physical health. Fiske and Taylor (1984) argued "*without a sense of both our own and others' predictability, the world would seem random. We would be unable to understand the responses of others and plan our own reactions*" (Fiske and Taylor,p.100(84)).

Psychological control appears to be particularly important under stressful or aversive circumstances. Laboratory studies in which subjects face stressors such as shock or loud noises where no information is available about the timing or onset of events and no action can be taken to alter the event, have produced high subject reactivity to stress (e.g. Glass and Singer 1972 (85), Rothbaum et al. 1982 (86), Fiske and Taylor 1984(84), Baron and Byrne 1984 (87)).

Chronic illness has been proposed as a naturally occurring stressful life event which results in loss of perceived control and an increased dependency on others. Such feelings of powerlessness have been associated with fear, anger and helplessness (87). Epilepsy is perhaps unique among chronic illnesses in its ability to engender feelings of lack of control: Not only is perceived control diminished through dependency on health professionals and medication and through considerable social, legal and economic restrictions. Also seizures, by their very nature, present a temporary and unpredictable loss of control

(45,66,69,88,89,90). Goldin and Margolin (1976) stated "*no matter how well the person's seizures are controlled, there is always the remote possibility that a seizure will strike. Moreover the time, place and social circumstances in which the seizure will take place are unknown. Hence, goal direction and...Functioning of the epileptic are cloaked in some degree of ambiguity with concomitant anxiety*" (Goldin and Margolin, in Arangio,p.109(67)).

In this chapter, it will be demonstrated that people with epilepsy as a group tend to have less perceived control over many aspects of their lives and that this may have considerable deleterious psychosocial consequences. However, it will also be revealed that there are considerable differences in perceived control within this group and that this may be a strong contributory factor in differential levels of adjustment.

THE RELATIONSHIP BETWEEN EPILEPSY, PERCEIVED LOSS OF CONTROL AND PSYCHOSOCIAL FUNCTIONING

It was indicated in the introduction that a central component of control is the need to confer predictability to the behaviours of oneself and others. This is particularly important for people with epilepsy. Scambler (1993) described the individual's need to make sense of the threatening, dramatic and intrusive symptoms of epilepsy and develop appropriate coping strategies as common dimensions of the perspectives of people with epilepsy (63). However, it has been argued that the episodic and unpredictable nature of seizures deprives people with epilepsy of the constant opportunity to develop adaptive reactions to the

disability (90).

The psychosocial implications for such perceived loss of control accompanying seizures are considerable as it has been suggested that this may generate to feelings of powerlessness in other aspects of voluntary behaviour (91). The theoretical basis behind this contention comes from cognitive attributional models of helplessness, and in particular Seligman's (1975) theory of "learned helplessness" (92). This suggested that when an individual's efforts at control repeatedly fail, he/she does not only cease trying to cause that particular outcome, but also, this may lead to a more stable underestimation of existing coping abilities. Consequently he/she may avoid or fail to exert control in novel situations where control is possible (92).

Maier and Seligman (1976) contended that learned helplessness creates three major deficits; motivational, cognitive and emotional. As the individual does not have the motivation to take steps necessary to change outcomes, he/she fails to learn and develop appropriate responses, which results in anxiety and depression. This, in turn, may result in further motivational and cognitive deficits (93).

Clearly, such a model has considerable similarity to the episodic and unpredictable loss of control experienced by people with epilepsy. It therefore appears reasonable to suggest that people with epilepsy may have a propensity to attribute general outcomes to external causes, with

concomitant emotional disturbance.

Research on both children and adults has provided empirical support for this position. Matthews and Barabas (1986) compared children with epilepsy to children with a chronic illness with relatively stable symptomatology; diabetes, and a control group of healthy children (90). Results indicated strong support for the above hypotheses: "*Regardless of the outcome, the competency domain, or the realm of reference, children with epilepsy invariably displayed the greatest perception of an external source of control relative to other children*" (Matthews and Barabas,p.170(90)). For example, the children with epilepsy were significantly more likely to attribute their own successes or various factors in social functioning to unknown sources. The authors also proposed that as a consequence, the children with epilepsy had a lower self concept and greater anxiety and depression than children with diabetes or healthy controls. Such perceptions were also thought to have considerable educational implications. Both good and bad school performance tended to be attributed to some unknown source of control. Therefore, it was suggested that "*those with epilepsy might be missing out on an important mediator of good school performance, namely an expectancy of success following effort*" (Matthews and Barabas,p.128(90)).

As external perceptions were most pronounced in the social sphere, Matthews and Barabas proposed that it was not simply perceived lack of control over seizures that engendered feelings of helplessness. Consideration was given to the key

role of significant others. For example, schoolmates may continue to react negatively to either a witnessed seizure or simply being "epileptic" regardless of the strategies adopted by the child to combat such reactions. The child may consequently attribute social failure (with some justification) to external causes. Also parental attitudes were implicated: In the previous chapter it was indicated that there is a tendency of parents of a child with epilepsy to overprotect, or in some cases punish or reject the child with epilepsy (75,80). It is suggested that a consequence of such parental strategies is that the child will fail to learn that outcomes are contingent on his/her behaviour: For the overprotected child the opportunity to take responsibility for his/her actions is denied. For the child who is punished or rejected, he/she may feel that such responses are based on an aspect of the child's life which he/she has little or no control over.

Devillis et al. (1980) found broadly similar perceptions of control in an adult population. Subjects with epilepsy were substantially less internal and believed their health was significantly more a matter of chance or fate and were more depressed than published norms of healthy populations (88).

Arnston (1986) also found pervasive feelings of helplessness which were significantly related to self esteem, life satisfaction, anxiety, depression and increased concern about somatic symptoms (45). Arnston once again emphasised that it was not the seizure frequency *per se* which was the significant factor in the development of helplessness, but

rather the perceived severity and unpredictability of seizures in social situations which was most pertinent (45).

INDIVIDUAL DIFFERENCES IN PERCEIVED CONTROL

Some indication of the nature of differences in perceived control was highlighted in the previous chapter. It has been demonstrated that many people with epilepsy appear well adjusted to their condition. Schneider and Conrad (1981) suggested that a central feature of such adjustment is a sense of control, while those who are unadjusted appear to be overwhelmed by the physical properties and social meaning of the condition (76).

Reviews of control based interventions to offset stress indicate that the various mechanisms employed can be reduced to two basic techniques: Taking some action with respect to an aversive situation (behavioural control) and thinking about that situation differently (cognitive control) (84,86). Both are of direct relevance to epilepsy and provide a useful framework for discussing the nature of individual differences.

Individual differences in behavioural control

In the Devillis et al. (1980) study outlined above, further to the main hypothesis that people with epilepsy will have less expectancies of control than a normal population, the relationship between seizure predictability and controllability and levels of helplessness and depression within this group was examined (88).

Subjects were asked how often they could tell a seizure was

about to occur, if seizures were more likely to occur in certain situations and whether they could stop a seizure that was about to happen. Results indicated that those who did not experience an aura and described seizures as less controllable and less predictable had significantly greater external beliefs about health and general behaviour, and greater levels of depression than those who perceived themselves to have some degree of seizure control (88).

Such findings have considerable psychosocial implications for the efficacy of the growing numbers of psychological self control techniques for seizure reduction (49,58,59). Betts (1989) suggested that somewhere in the region of 30% of people with epilepsy are capable of developing methods of preventing, aborting or modifying seizures (46). Yet it has been indicated that such programmes rarely provide social and psychological validation of treatment outcomes. The available evidence is, at best, mixed, but generally supportive of treatment resulting in increased general perceptions of control and better psychological and social adjustment. For example, Gillham (1990) reported that those who experienced a decrease in seizure frequency through self control techniques, had greater self confidence and were better able to plan their time from day to day (62).

However, many remain unable to predict or control their seizures and even in those reported cases where seizures are reduced, in only an extremely small percentage of reported cases is total control of seizures obtained. This presents significant difficulties for those who remain anxious and

fearful of potential seizure occurrence. Baker (1990) suggested that "*even a 75% reduction can hardly be considered a success if a patient remains disabled by his/her seizures*" (Baker,p.3(50)). As an integral component of such treatment is self monitoring for cues of seizure propagation, if only partial control is available to prevent seizures, for some, this may heighten perceptions of the aversiveness of the seizure. Perhaps a more adaptive response is to restructure the meaning of the seizure experience. For instance, Betts (1989) suggested that in patients who cannot fully control their seizures, it often useful to help them lose their fear of seizures through behaviour therapy programmes aimed at desensitizing them to fear of seizures in specific situations such as the street or supermarket, or possibly through showing the patient a video recording of his/her own seizure (46). The theoretical basis behind cognitive control, and the nature of individual differences will be considered in the next section.

Individual Difference in Cognitive Control

An interesting response to the learned helplessness model was put forward by Fogle (1978) who argued that active control methods may not always be the most adaptive behaviour, and conditions such as insomnia or sexual difficulties are frequently maintained or aggravated through the anxiety caused by attempts to deal with these problems. Fogle termed this problem "learned restlessness" (Fogle in Seltzer 1986(94)).

As it has been convincingly argued that there is an intimate

relationship between stress and seizure occurrence (e.g. Temkin and Davis 1984 (95), Betts 1989,1993 (8,46)), this may be of particular relevance for people with epilepsy.

Seltzer (1986) argued that "*in such cases where instrumentally effective coping strategies may not be available, learned helplessness may indeed be seen as an adaptive reaction; that is, what cannot be controlled externally is better disregarded,left alone or endured*" (Seltzer,p.70(94)). In support of this strategy of "instructed helplessness" Fogle cited experimental evidence where a negative stimulus is perceived as less aversive when voluntarily tolerated than when voluntarily terminated. It was proposed that such experiences may disconfirm calamitous expectations and alternatively may foster a more benign perception of the event (94).

This model may be extremely useful for people with epilepsy. In the previous chapter it was demonstrated that there are considerable differences in the perceived aversiveness and severity of seizures; some are able to cope well with frequent unpredictable seizures while others remain disabled with comparatively few seizures (34,52). It would therefore appear that individuals differ in the cognitive and behavioural resources necessary to relinquish control. This has lead to speculation that the concepts of self efficacy or resourcefulness are extremely important factor in the functioning of people with epilepsy (52).

Bandura (1977,89) has suggested that perceived self efficacy is a central cognitive mechanism linking psychosocial

influences to health functioning, which refers to "*the beliefs in ones capabilities to mobilise the motivation. cognitive resources and courses of action needed to meet given situational demands.*" (Bandura,p.1(97)) (96.97). He proposed that if an individual believes that he/she cannot control an inescapable aversive situation, this will be a source of initial anxiety. However, such "dysfunctional cognitions" are not distressing if one can exercise cognitive control so that they do not become ruminative. "*Therefore people are more perturbed by their perceived inefficacy to control anxious cognitions than by the cognitions themselves*" (Bandura,p.7(97))(96,97).

Rosenbaum and Palmon (1984) applied this concept to epilepsy (89). They proposed that while individuals responded with fairly uniform levels of depressive mood and state anxiety immediately following a seizure, differences in efficacy, or an analogous concept "learned resourcefulness", mediated the perceived aversiveness of seizures and consequent psychological adjustment. For subjects with low and medium seizure frequencies, high resourceful individuals were less depressed, less anxious and coped better with their disability than low resourceful subjects. Interestingly, for subjects with a high seizure frequency, little difference was found between the high and low resourceful groups, both of whom had significant adjustment problems. Rosenbaum and Palmon suggested (somewhat contentiously as they were unable to provide any supportive evidence) that such difficulties may be largely due to cerebral dysfunction (114).

In conclusion, it has been demonstrated that for many people with epilepsy, active control strategies may be of limited benefit. Alternatively, it may be more adaptive to relinquish behavioural control and assert cognitive control with the aim of reducing the aversiveness of the seizure. It is suggested that this concept may also be applied to the perceived social consequences of epilepsy. However, it is apparent that there are considerable differences in cognitive "efficacy" or "resourecefulness" necessary to attenuate the emotional impact of seizure occurrence or acts of discrimination. Such differences have considerable psychological and social implications.

SUMMARY

It has been demonstrated that perceived control is a central cognitive concept for people with epilepsy, and that the sense of loss of control of the condition may generate to other aspects of voluntary behaviour with deleterious psychosocial consequences.

Research into differences in control based strategies to offset the negative consequences of seizures have highlighted two main strategies; behavioural and cognitive control. Individuals able to predict or control seizures tend to have greater perceived control over other areas of their lives and have better overall adjustment than those whose seizures were unpredictable. However, for many people with epilepsy with limited or no behavioural control, active strategies may increase anxiety. It was suggested that a

more effective approach would be for such individuals to assert "cognitive control" and re-evaluate the aversiveness of the seizure. However, considerable differences were found in the ability to regulate the emotions and cognitions necessary for such a process. Such differences were found to have significant implications for psychological and social adjustment.

Clearly, a major component in perceived control of epilepsy is knowledge: It is obviously impossible for an individual to assert personal control of his/her condition if he/she is ignorant of the causes and potential consequences of the condition. Ignorance and misconceptions may also be a significant causal factor in the development of stigma and fear of epilepsy. This important area will be considered in chapter 4.

CHAPTER 4

PATIENT KNOWLEDGE OF EPILEPSY

INTRODUCTION

The importance of patient knowledge was highlighted by the Commission for the Control of Epilepsy and its Consequences (1978) who stated that "*the understanding that an individual has about any disability is related to the success the individual has in coping with the disability*" (Commission,p.133 (9)).

This is particularly salient for people with epilepsy who have to cope not only with the fear and confusion of seizures, they also have to succumb to complex medical examination, adhere to a lengthy list of medical and social restrictions and be an accurate reporter on the type and frequency of seizures.

It has therefore been suggested that the provision of appropriate information about the individuals' condition may help reduce the emotional impact of both seizures and treatment and help him/her cope with the social and vocational limitations enforced by the seizure disorder (12,35,83). However, it has been well demonstrated in the previous chapters that epilepsy is undoubtedly unique among chronic illnesses in terms of mythology and misinformation. While great advances have been made in the understanding and treatment of epilepsy, patient ignorance appears to remain high. It has, in fact, been suggested by the Commission for the Control of Epilepsy and Its Consequences (1978) that such ignorance may be more disabling than the seizure disorder itself (9).

Clearly, patient knowledge is an area of considerable

importance, not only for psychosocial adjustment but also for effective medical management. Yet this has been given little specific consideration in the literature. Therefore, in this chapter an examination will be made, not only of the relationship between patient knowledge and psychosocial functioning but also of the medical treatment implications of patient knowledge.

It is proposed that the relevant areas of patient knowledge can be subsumed within two broad headings; medical and non-medical. Each of these areas will be reviewed in turn. It will be demonstrated that many people with epilepsy have little knowledge about key areas of their condition. This appears to be a source of considerable dissatisfaction and stress. Therefore consideration will be given to why the information people with epilepsy have about their condition is frequently less than is desirable. Finally, the psychosocial and medical implications of knowledge based programmes will be discussed.

KNOWLEDGE OF MEDICAL ASPECTS OF EPILEPSY

Diagnosis

There is considerable evidence to suggest that the diagnosis of epilepsy is frequently inadequately communicated. Schneider and Conrad (1986) found many of their sample were unaware that they had epilepsy. Thirty four percent initially received a diagnosis other than epilepsy, while others stated they were told that they were "prone to convulsions" or had "a seizure disorder" which was thought to be different to having epilepsy. Nine per cent of this

group eventually diagnosed themselves as having epilepsy (83).

Considerable misconceptions have also been highlighted in the diagnostic procedure. Mittan (1986) found that the E.E.G. machine was thought by many to be able to read patients minds and tell if they were emotionally ill. It was therefore feared and seen as an invasion of personal privacy (34).

Seizures

There appears to be considerable patient ignorance of what happens during a seizure. It was indicated in chapter 2 that many people have considerable fear of seizures. Much of this fear may be due to ignorance and misconceptions. Mittan (1986) found that the majority of his subjects believed it was not only possible but likely that they would die due to a seizure or as a result of an accident precipitated by a seizure and that people with epilepsy frequently die of their seizures. The majority also believed that seizures cause brain damage and were gradually eroding their intelligence. It was also commonly believed that as they had seizures, this necessarily meant that they had a brain tumour. The predominant consequence of such beliefs was heightened anxiety, depression, and avoidance of potentially dangerous situations (34).

Anti Convulsant Medication

Many people with epilepsy appear unsure of the purpose of anti convulsants. Thompson and Oxley (1989) found some

subjects within a group with poorly controlled seizures were waiting for their epilepsy to be cured (10). There are also considerable misconceptions regarding potential side effects of medication. Mittan (1986) found one third of his sample thought anti convulsants were dangerous and addictive and almost one fifth thought side effects would become permanent (34).

While such misconceptions clearly have implications for psychopathology, there are also implications for medical compliance. Errors of ommision are likely to result in increased seizure frequency, while errors of commission are likely to result in drug toxicity which may in turn result in ommissions and increased seizure frequency (9).

The significance of this problem should not be underestimated. The Commision for the Control of Epilepsy and its Consequences (1978) estimated that at least one third of patients are not receiving the preventative benefits of seizure control due to poor compliance (9).

KNOWLEDGE OF NON-MEDICAL ASPECTS OF EPILEPSY

It is suggested that poor understanding of the possible social, vocational and recreational consequences of epilepsy can result in two potential reactions-

1- Fear of possible consequences resulting in overrestrictions and overprotection.

2- The individual is unaware of existing appropriate restrictions with potential physical and psychosocial consequences.

Both types of reactions will be considered in the following sections.

Social Factors

While there are obvious dangers in not taking appropriate precautions in certain high risk situations, there are also considerable costs in overestimating the limitations imposed by seizures. As has already been indicated, many people with epilepsy have significant unfounded fears about seizures. Overconcern and exaggeration of potential hazards may present a severe limitation of activities in all spheres of life (67). Mittan (1986) found that 50% of his subjects were afraid to go out socially and misunderstandings were thought responsible by Craig and Oxley (1988) for restrictions in recreational activities deemed suitable for many with epilepsy (98).

The avoidance of social and recreational activities has been found to result in social isolation and consequently having fewer friends, poorer social skills and higher levels of psychological disturbance (9,10,67).

Erroneous perceptions of limitations have also been thought to contribute to the belief of many people with epilepsy that they are different and inferior to others. For instance, in Mittan's (1986) study, many subjects indicated that they felt that they were "damaged goods" as a result of having epilepsy. It has therefore been proposed that poor knowledge is a strong contributory factor in percieved stigma (10,56,75).

Employment Factors

It has been emphasised frequently that employment is one of the major problem areas for people with epilepsy (9,10,12,35). While numerous factors have been identified as facilitating employment difficulties, there is evidence to suggest that patient ignorance may be a strong contributory factor. For instance, it has been found that participation in social and employment activities is more closely related to perceptions of disability and perceived limitations than to seizure frequency and other more objective measures of epilepsy (56).

It has already been indicated that many people with epilepsy have a fear of seizure related accidents in the workplace and believe that specific conditions in the work environment such as loud noise or flashing lights may cause a seizure (34). Similarly Harding (1986) found there is a general belief that people with epilepsy should avoid working with computers, when this actually only applies to approximately 2% of the population with epilepsy (99). Many of Mittan's (1986) sample would not consider employment involving any mechanical or electrical equipment and were also concerned that job stress would precipitate seizures. While such concerns may, for some, be valid it is suggested such conclusions were reached based on hearsay and hunches rather than objective information on their own condition (34). Conversely, Thompson and Oxley (1989) found some people with epilepsy demonstrated unrealistic vocational goals in areas dangerous and in some cases illegal, such as entering a career which involved driving (10).

Education has been highlighted as an essential component in employment training and rehabilitation for people with epilepsy (98,35). It is important for individuals to know their own strengths and limitations, not only to select an appropriate career, but also for selling themselves to prospective employers and dispelling any misconceptions and biases they may have.

Given the social, emotional and instrumental value in having a knowledgeable patient population. it is perhaps surprising that the information many people with epilepsy have about their condition is so poor. The next section will attempt to provide an explanation of such knowledge deficits.

SUGGESTED REASONS FOR THE LACK OF APPROPRIATE INFORMATION

The main potential source of information for the person with epilepsy is their doctor. As Schneider and Conrad (1986) stated *"Patients rely on their doctor not only for medical and scientific information about epilepsy- What it is as a medical condition or disorder but for an understanding of what their case is like and what having epilepsy means for them as well"* (Schneider and Conrad,p.69(83)).

However. considerable dissatisfaction has been expressed with both the quantity and quality of information provided (83). Scambler and Hopkins (1988) suggest that *"it is paradoxical that physicians charged with treating people with epilepsy are both aware of the problem that epilepsy can cause in families and are generally unwilling*

or reluctant to include discussions of such problems on the agenda for consultation." (Schneider and Conrad,p.174(83)). As a consequence, Scambler (1993) proposed that people with epilepsy and the parents of children with epilepsy have to "*work hard to obtain information from doctors who are all too often evasive*" (Scambler,p.743(63)). For instance, Ley (1982) found little time seems to be spent providing medical information and answering questions to patients' satisfaction during a normal consultation (100). Similarly Waizkin and Stoeckle (1976) found that only about one minute of a twenty minute appointment was spent giving patients information (101). From actual video recordings of doctor-patient consultations, Pendleton (1982) suggested that physicians tend to react less positively to patients dissimilar to themselves and consequently provide the least information to working class patients. It may be supposed that such patients would have been less likely to understand and retain information. However, interestingly, the reverse appeared to be true: The lower the socioeconomic class, the more information that was retained. Possibly as information was such a scarce resource, greater attention was paid (102).

Such problems have been found to be more acute when dealing with specialists such as neurologists who tend to focus much more on the medical and technical details of epilepsy. Morrow (1990) measured the information and support that people with epilepsy attending a neurology clinic were given on initial attendance. The advice or counselling that

subjects had subsequently been given at one year follow up was not found to be significantly greater than the small amount provided on initial attendance (103). Schneider and Conrad (1986) sum up the situation thus "*family doctors are willing to give information but have little; neurologists have information but they give little*" (Schneider and Conrad,p.82(83)). Scambler (1993) contended that as physicians frequently do not meet patients expectations, it is interesting that patients are only ever described as "non-compliant" when this term often may be more applicable to physicians (63).

Information at Diagnosis

As diagnosis is often a protracted and complex process the doctor is limited in the information he is able to relate to the patient, much of which it is thought would be poorly understood, and there is an obvious reticence to relay any diagnostic assumptions he may have (67).

However, it is at this stage information is most sought after as patients need to know what it is that is wrong with them, and just as importantly what it is not. Continuing medical ambiguity is viewed as ominous. For the lay person, problems with the brain tend to be equated with mental illness, tumours or cognitive deterioration. As has indicated in chapter 2, such misconceptions may result in pathological fear (34,63,67).

Even on provision of diagnosis many patients appear unprepared to comprehend and question information. Patients

tend to forget much of what they have been told within hours of consultation (67,100). While this can in part be attributed to the trauma of diagnosis, two other factors appear pertinent.

Firstly, there appears to be certain perceptions by both doctor and patient of what constitutes appropriate patient reactions. The ideal patient is generally viewed as compliant and unquestioning. Patients tend not to express their fears or ask questions of a personal nature, possibly as they do not wish to appear irrational or feel that such questions are inappropriate or a waste of the doctors time. Also, pursuing detailed medical questions is generally avoided as patients do not wish to appear as though they are challenging the doctor's judgement and authority (83).

Secondly, patients' initial poverty of knowledge of epilepsy means that it is difficult to question specifics on how the condition applies to them: in effect many patients would not even know what would be an appropriate question to ask (83,35).

Information Post Diagnosis and Alternative Sources of Information

It has been suggested that routine visits tend to be brief with a focus on medical and physical assessment. Many, if not all of the problems outlined above appear to remain. Despite consistent appeals for the inclusion of the patient as part of the treatment team, based on a mutual sharing of data, this seldom appears to be incorporated into medical consultation (63,67,75,83).

However, there is perhaps an unfair burden placed on the doctor. As Schneider and Conrad (1983) stated "*Illness is something too complex for any single person, no matter how highly trained, to manage*" (Schneider and Conrad, p.229(104)). It should also be noted that at present a variety other disciplines and agencies are involved in the care of people with epilepsy. These include psychology, education, the social services, employment and a growing number of voluntary groups. However, Thompson and Oxley (1993) stated that in the United Kingdom such services remain fragmented and lack coherence (35). Therefore, not only do many people with epilepsy know little about their condition, but they may also not now who to ask to gain information.

RESULTS OF EDUCATION BASED INTERVENTIONS

Results of education based programmes as a means of obtaining better compliance have been encouraging. Gibberd et al (1970) found a significant increase in mean serum concentration levels following a "modified supervision" programme which involved more doctor visits, with doctors giving increased encouragement and attention (104). Similar research by Lund et al (1964) and Dawson (1971) suggested that closer supervision, feedback of information and clear instructions result in more effective patient compliance (105,106). Knowledge based programmes also have positive implications for psychosocial adjustment. Lewis et al. (1990) reported results of a teaching package for children. Significant improvement was found in knowledge about

epilepsy and also improved social competence and greater self confidence (107).

Perhaps the most promising development in this area is the Sepulveda Epilepsy Education program (S.E.E). This group programme was designed to provide psychosocial help and epilepsy related health education for people with epilepsy and their families. In excess of 40 S.E.E. groups are in operation throughout the United States and New Zealand with encouraging results. Helgeson et al (1990) found participants had a significant decrease in overall levels of misinformation and epilepsy related fears and hazardous self management practices and a significant increase in compliance with anti-convulsants. There were also trends towards greater psychosocial adjustment (33).

SUMMARY AND AIMS

It has been demonstrated that knowledge is an essential component for effective adjustment to epilepsy, yet for many people with epilepsy the information they have about their condition is poor. Education based programmes have proved encouraging in terms of better medical compliance, (33,104,105,106) and in reduction of psychosocial problems (33,107).

However, at present there is no commonly accepted measure of patient knowledge, with existing measures tending to give a cursory treatment of knowledge within the broader framework of either psychosocial functioning, such as in the Washington Psychosocial Seizure Inventory (68), or in studies of patient perspectives of epilepsy (81,82). The

development of a short, self administered questionnaire designed to assess patients knowledge, misconceptions and fears about epilepsy could prove to be an invaluable asset in both clinical and non clinical settings for the treatment and care of people with epilepsy.

The development of such a questionnaire designed to assess general knowledge of epilepsy and specific knowledge of own condition; The Epilepsy Knowledge Profile (E.K.P.), will be described in chapters 6 and 7 (Jarvie, Espie and Brodie (108,109)).

CHAPTER 5

A PROPOSED MODEL OF INDIVIDUAL DIFFERENCES IN PATIENT PERCEPTIONS OF EPILEPSY

Page Number

INTRODUCTION

In chapter 1 it was demonstrated that significant numbers of people with epilepsy have psychosocial difficulties. Yet such findings appear to have been of limited benefit for the development of effective treatment programmes for individuals with epilepsy.

It was suggested that the perceptions people with epilepsy have about their condition are powerful mediators of the type and chronicity of psychological and social problems. Therefore, the provision of a detailed model of individual differences of patients' cognitions may provide an extremely valuable insight into why some individuals seem to cope better with their condition than others. Also, such a model may have considerable treatment implications.

Three main areas of investigation were identified as relevant to the development of such a model; the perceived physical and social risks attached to having epilepsy, perceived control over epilepsy and its consequences and the amount and accuracy of information the individual has about his/her condition. Each area was considered in turn in chapters 2,3 and 4. The proposed nature of differences in perception and their effect on psychosocial functioning is summarised in Table 2.

Clearly these areas are not mutually exclusive. For instance, knowledge appears to be intimately related to perceived fear of the physical consequences of having epilepsy. There also appears to be grounds for suggesting that the provision of appropriate knowledge and dispelling

common misconceptions may have a positive effect on the perceived social effects of epilepsy and may lead to

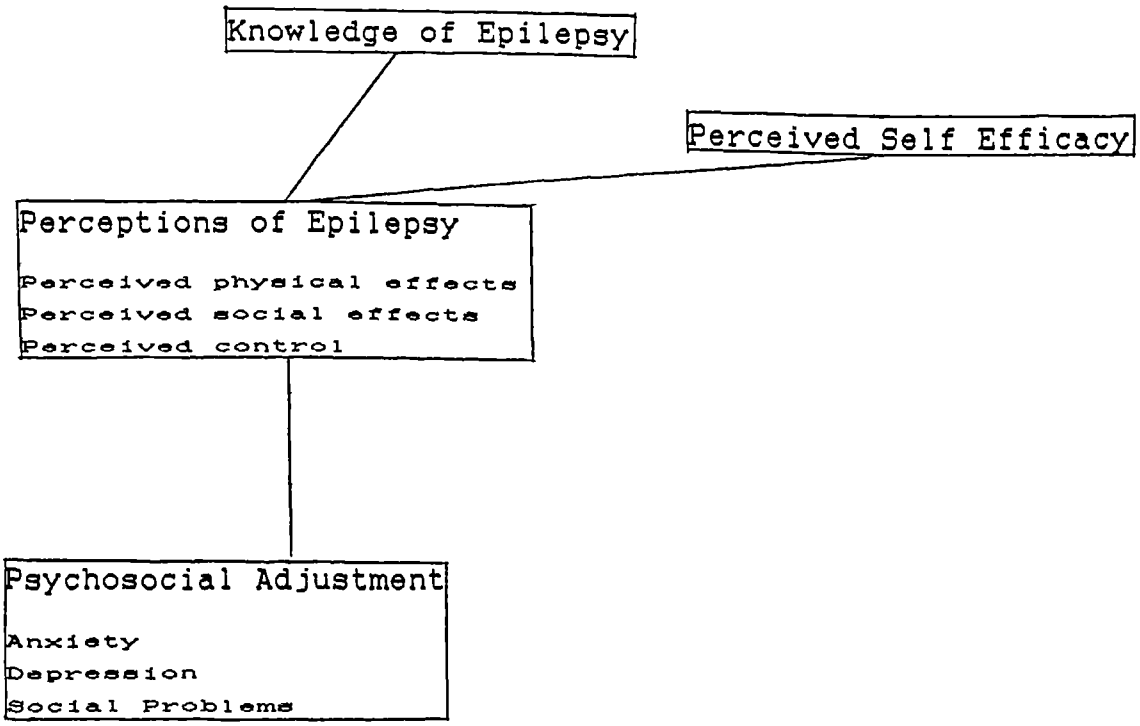
Table 2- Summary of Patients Perceptions and Psychosocial Effects

Patients' Perceptions	Psychosocial Adjustment	
	High	Low
1-Social Effects	Low "felt" stigma, pragmatic concerning disclosure and possible discrimination. Ability to minimise potential impact of epilepsy.	High "felt" stigma, Perceived shame attached to diagnosis and high perceived need to conceal and control potential social ramifications.
2-Physical effects	Low fear of physical consequences of seizures.	High fear of possible death,brain damage or serious accident as a result of epilepsy.
3-Perceived control	1)Perceived internal behavioural control over seizures 2)No perceived behavioural control over seizures but perceived cognitive control over emotional impact of seizures; high "self] efficacy".	No perceived control over seizures or in ability to attenuate emotional impact of seizures; low "self efficacy".
4-Knowledge	Well informed: realistic appraisal of risks and limitations.	Poorly informed; may either take unnecessary precautions or take unnecessary risks.

enhanced perceptions of control. Similarly, the individual who has some predictability or actual control over his/her seizures, or has the cognitive resources to minimise the impact of seizures, may be less likely to see themselves as socially disabled by their condition and may also be less

fearful of seizures. Therefore, it would appear reasonable to hypothesise that all areas may be manifestations of a central cognitive construct; "self perception of epilepsy" (see Fig. 1).

Figure 1- Self Perception of Epilepsy as a Central Cognitive Construct: A Hypothetical Model



It is suggested that most people with epilepsy will lie between the extremes of "adaptive" and "maladaptive" self perception. Key features of this hypothetical model are the knowledge the individual has about his/her condition and his/her perceived efficacy or resourcefulness: "Adaptive perception of epilepsy" is typified by the individual who has a good knowledge of his/her condition, is able to make a realistic appraisal and has the personal resources to cope with the potential risk of both the physical consequences of

the condition and of potential enacted stigma. Such an individual has optimum control of epilepsy through both effective adherence to an anti-convulsant regime (perhaps the major source of personal control for the majority of people with epilepsy) and behavioural self control techniques. However he/she also has the cognitive resources to cope with potential uncontrolled seizures. Conversely, it is suggested that " maladaptive self perception" is typefied by inadequate knowledge of his/her condition and low perceived efficacy. Therefore the individual is not in a position to make a realistic appraisal of risk or effect control over the social or physical properties of epilepsy. Such perceptions correspond to Schneider and Conrads' (1981) "debilitated type" whereby such individuals perceive the condition to have an excessive and overwhelming negative impact on almost all aspects their lives and have developed few or no strategies for managing this impact (110). As has been demonstrated in the previous chapters, such perceptions make the individual vulnerable to a host of psychosocial problems.

AN ADDITION TO THE SELF PERCEPTION MODEL: "UNDERAWARENESS" AS A PSYCHOSOCIAL RISK

Further to the above, results of a brief exploratory study carried out on clients in a residential epilepsy centre may prove useful in the development of a further dimension of this model.

The purpose of this study was to assess the potential efficacy of a self control of seizures programme as an addition to an existing rehabilitation programme. A total of

seven subjects participated in a structured interview (three female, four male) using the Patients' Pre-Behavioural Treatment Questionnaire developed by Balaschak and Mostofsky (1981) (111). This questionnaire is designed to provide a broad assessment of the knowledge and perceptions people with epilepsy have about various aspects of their condition (see Appendix 1).

Intellectual functioning of the sample ranged from mild to borderline learning disabilities (four subjects) to low average intelligence (three subjects). Average seizure frequency ranged from one to eight per month. Six subjects had complex partial seizures, five of whom also had secondary generalised seizures. One subject had tonic and tonic-clonic seizures.

From these interviews three of the subjects indicated that they experienced some degree of seizure predictability with regards to aspects such as time of day, place or body signals. Further, the general perceptions that these subjects had about their condition were broadly in line with the "adaptive" perceptions outlined above. The remaining four subjects did not appear to differ in terms of seizure type or frequency from the other three subjects. However subjects without seizure predictability appeared to have less knowledge of the medical, social and legal implications of having epilepsy, and less information about aspects of their own condition, such as awareness of their current anti-convulsant regime or specific precautions which could be taken to minimise the risk of potential injury.

Such perceptions are similar in nature to those described with respect to "maladaptive self perception". However, subjects differed with respect to the perceived physical and social consequences of having epilepsy; despite having frequent generalised seizures, subjects were neither fearful of seizure occurrence and associated little shame or embarrassment with seizures in public places. Also, subjects stated that they were happy to disclose their diagnosis to others and appeared unaware that this may result in negative evaluation or objective discrimination by others.

Features of such passive perceptions have been described in chronically overprotected people with epilepsy and institutionalised populations (1,38). It is suggested that implicit in the development of such a cognitive model is that the individual is either intellectually unable, or has been deprived of the opportunity, to develop appropriate adaptive responses to his/her condition. While such individuals may cope adequately within the confines of his/her limited environment, there are considerable long term potential deleterious consequences of such passivity, such as poor drug compliance, the inability to discriminate between high and low risk situations or the formation of unrealistic social or vocational expectations (1,33,38). In effect, it is suggested that this small but significant and frequently neglected group, are "understigmatised", "underemotional" and generally under aware of the implications of having active epilepsy.

This, therefore provides an extra dimension to the "self perception" model outlined above (See table 3).

Table 3- Self Perception of Epilepsy: A Hypothetical Model of Individual Differences

Perceptions	Manifestations	Psychosocial Functioning
Maladaptive self perception	Poor knowledge, low self efficacy, high perceived social and physical risk, low of epilepsy.	Potential anxiety, depression, low self esteem, dissatisfaction with social, vocational and recreational activities and possible skills deficits.
Adaptive self perception	Good knowledge, high self efficacy realistic appraisal of risk of potential enacted stigma, optimum control of seizures through medication and behavioural methods and cognitive resources to cope with uncontrolled seizures.	Little or no psychopathology, active involvement in social activities.
Underadaptive perception	Poor knowledge, low self efficacy, low perceived social and physical risk, low perceived control of epilepsy	High dependency on others, passivity, inability to accurately assess risks or plan realistic social or vocational plans. Potential future depression and anxiety through frustration, inability to cope and helplessness.

Such a model has considerable appeal as a framework for understanding the complex nature of patients perceptions. Also, if this model proved to be valid, there are considerable treatment implications: For instance "underadaptive" individuals may benefit from self control and knowledge to encourage him/her to take greater

responsibility for his/her condition. Conversely, individuals with what has been termed "maladaptive perceptions" may benefit from the provision of an accurate assessment of risk and possibly cognitive behavioural therapy for concomitant emotional problems.

AIMS AND HYPOTHESES

As has been indicated, the above model has considerable practical potential for the understanding and treatment of people with epilepsy. However, while this model may make considerable intuitive and theoretical sense as a means of understanding the perceptions of people with epilepsy, it has, at present, little empirical support. Therefore, it is the aim of this study to assess the validity of the "Self perception of epilepsy" model. This will be done firstly by providing detailed assessment of the perceptions and concomitant psychosocial functioning in a selected sample of people with refractory epilepsy. Secondly a series of case studies will be carried out to assess changes in perception and psychosocial functioning before, during and after a brief group epilepsy education programme.

The following specific hypotheses are made-

(1) Measures of perception, namely perceived social and physical effects of epilepsy and perceived control will be significantly related: High perceived social and physical effects will be related to low perceived control.

(2) High subject knowledge and perceived self efficacy will have a significant and positive effect

on subjects' perceptions of control over epilepsy and on the perceived social and physical effects of epilepsy.

(3) Anxiety, depression and social problems will be significantly more prevalent in individuals displaying the manifestations of "maladaptive self perception", than in individuals displaying "adaptive self perception".

(4) In line with previous research, overall levels of anxiety, depression and social problems will be higher than a normal population.

(5) Supplementary to these main hypotheses, examination will be made of the potential existence of the "Underadaptive perception model" which it is proposed will be accompanied by unrealistic and ill informed perceptions of their condition which will result in potential physical and social risk and dependency, rather than psychopathology and perceived social problems.

Clearly, an integral component in such an evaluation of patients' perceptions is the availability of a valid and reliable measurement of the amount and accuracy of information people with epilepsy have about their condition. However, at present there is no commonly accepted questionnaire of knowledge of epilepsy (see chapter 4). Therefore, as a prerequisite to the main study, questionnaires designed to assess general knowledge of epilepsy (E.K.P.- General) and specific knowledge of own condition (E.K.P.-specific) were developed (Jarvie, Espie and Brodie (108,109)). The development of these

questionnaires is described in the following two chapters. Consideration is given to potential other uses of the scales.

CHAPTER 6

STUDY 1

THE DEVELOPMENT OF A QUESTIONNAIRE TO ASSESS KNOWLEDGE OF EPILEPSY: 1- GENERAL KNOWLEDGE OF EPILEPSY

Page Number

INTRODUCTION

It is clear from the review in chapter 4 that the individual's level of knowledge about epilepsy and its effects may play an important role in successful management. However at present there is no commonly accepted measure of patient knowledge. The development of a short, self administered questionnaire designed to assess patient's knowledge, misconceptions and fears about epilepsy could prove invaluable in both clinical and non-clinical settings for the treatment and care of people with epilepsy. This chapter describes the development of such an assessment measure designed to assess general knowledge of epilepsy- the Epilepsy Knowledge Profile - General (E.K.P.-G).

METHOD

The specific aims in the development of the E.K.P.- G were to make it as unambiguous, objective and comprehensive as possible, while remaining accessible to both respondents and administrators.

Three main stages of development were completed:

1- Development of questionnaire format and item pool.

2- External validation and refinement of item pool.

3- Clinical trial of questionnaire.

1- Development of Questionnaire Format and Item Pool

A true/false format was chosen as it is comparatively quick and straightforward, is familiar to individuals of most social and educational backgrounds and as such, was likely to achieve a high return rate (Moser and Kalton 1979(112)).

Items were gathered under two broad headings, namely "medical" knowledge and non-medical or "social" knowledge with the aim of reflecting factual information and common misconceptions. Items were gathered from the main contemporary texts on epilepsy and from existing measures with a knowledge component (Laidlaw et al 1993(113), Chadwick and Usiskin 1987(114), Shorvon 1984(3), Laidlaw and Laidlaw 1984(1), Beran and Read 1980(81), Danesi 1984(82)). No item was included unless the same unambiguous conclusion was reached by more than one source of information. Care was taken to ensure that approximately the same number of true and false items was obtained.

A total of 60 items was obtained with the majority of items (40) falling within the medical section.

2- External Validation of Item Pool

The 60 item draft questionnaire was then sent to a variety of experts in the field of epilepsy. Fourteen replies from a total of sixteen requests for comments were received from backgrounds as diverse as medical sociology and clinical pharmacology.

Those contacted were asked if they felt items were relevant, if they agreed with answers given, if they felt any items were badly worded or ambiguous and if they felt any areas had been over represented or omitted.

Items thought incorrect by any respondent were omitted. Items thought ambiguous were reworded where possible or omitted. Questions were added as requested.

Total items were then reviewed for reading ease using the Flesch formula (115). This places a piece of writing on a scale between 0 (Practically unreadable) to 100 (Easy for any literate person) by calculating average sentence length and average number of syllables per word. This produced a score of 55 which it is suggested is only slightly more difficult to read than a standard magazine article.

Table 4- Revised E.K.P.-G Examples of Item Format

Medical Aspects	No. of Items	Example
Aetiological,Diagnostic	15	"An E.E.G is designed to detect electrical activity from the brain" (T)
Treatment Factors	15	"If epilepsy stops with anti epileptic drugs this means your epilepsy has been cured" (F)
Medical Consequences	4	"Too much alcohol may make seizures more likely" (T)
Social Aspects		
Legal Factors	5	"If you drive you must inform the D.V.L.A about the diagnosis of epilepsy" (T)
Social,Vocational Factors	12	"Most people with epilepsy should avoid working at heights" (T)
Epidemiological	3	"Over half the population with epilepsy will have had their first seizure by the age of 15" (T)

From the above procedure a revised item format was devised (See Table 4 for examples). From the original item pool 29 items in the medical section were included with amendments, with 5 new questions added and 15 items in the social

section were included with amendments, with 6 questions added. This resulted in a total of 55 items- 34 medical and 21 social items.

3- Clinical Trial of the Questionnaire

The main purpose of the trial was to assess the reliability of the scale and also its validity in terms of accessibility and efficacy.

Subjects and Procedure

Subjects were adult outpatients attending the epilepsy clinic at the Western Infirmary, Glasgow. Subjects were approached at 7 consecutive weekly clinics.

Of the 89 forms handed out, a total of 82 completed forms were returned. 77 were returned at the clinic and 5 were returned by post.

The sample consisted of 39 males (47%) and 43 females (53%). Age ranged from 16 to 75 (Mean= 33 years, S.D.=13.5). Age at onset ranged from birth to 65 (Mean= 17 years, S.D.= 13.5). Number of years since onset ranged from less than a year to 33 years (Mean= 14 years, S.D.= 9.39). Seizure frequency at time of completion ranged from less than 1 per month (38%) to greater than 1 per day (2.6%). Seizure diagnosis was as follows: Tonic- clonic 36.7%; myoclonic 5.1%; simple partial 21.8%; atonic 2.5%; absence 5.1%; complex partial 52.6%; secondary generalised 41.8%; other 4.0%. 7.4% of the sample were on no medication, 55.6% were on monotherapy, 37% were on polytherapy.

Results

In terms of accessibility, there is strong evidence that the scale proved to be very "user friendly".

1- Return Rate: This proved extremely high for an unsupervised assessment scale (92%).

2- Frequency of Omissions: No question was omitted by more than 10% of the sample.

78% of the sample answered all questions.

16% had between 1-5 omissions.

Only 6% had greater than 5 omissions.

Omissions did not differ significantly on any of the demographic variables outlined above.

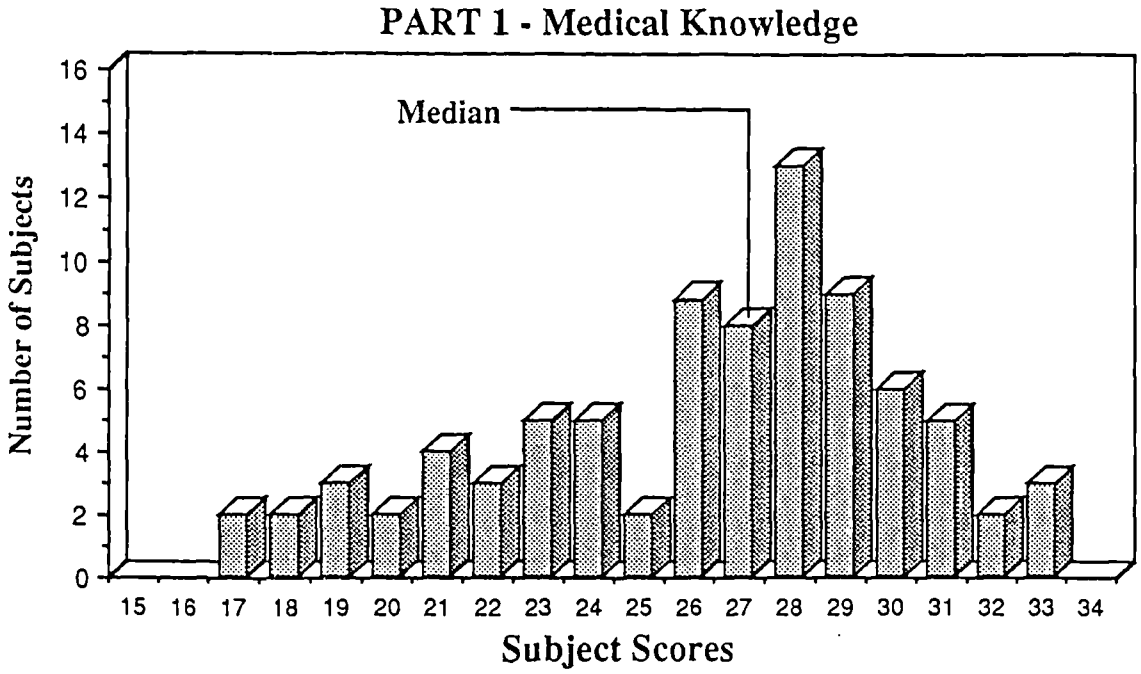
3- Time to completion: The average completion time was 7-8 minutes. It is suggested this is a key factor in the high return rate and low level of omissions. As the scale is comparatively short, boredom or fatigue were infrequent.

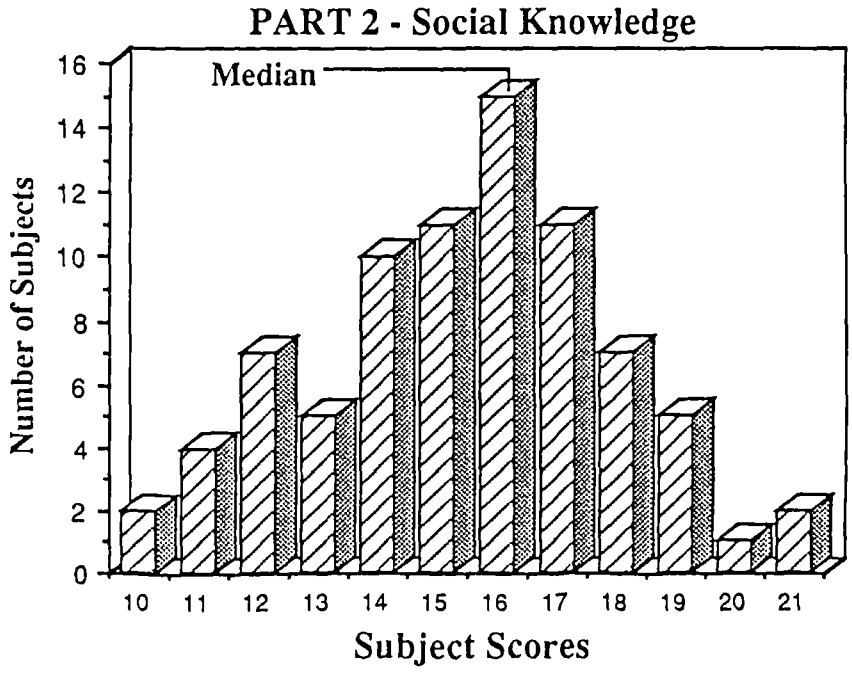
4- Sensitivity: The questionnaire appears sensitive to differences in knowledge as demonstrated by the wide spread of total patient scores. Both scales have a normal distribution with no significant floor or ceiling effects (See Fig.1).

Further assessment of sensitivity was calculated by grading items in terms of ease of response. This was done by calculating the percentage of subjects obtaining the correct answer for each question. On the medical knowledge scale

total correct responses ranged from 98.8% to 23.2% (Median = 82.9%). On the social knowledge scale, scores ranged from 96.6% to 25.6% (Median = 78.0%) (See Appendix 2 for full details).

Figure 2- Total E.K.P.-G Subject Scores





Overall comparison between the scales indicated that subjects found the social knowledge scale slightly more difficult. This may in part be explained by the medical setting in which the questionnaire was completed. For example the most accurately answered question on the medical scale concerns the use of blood samples; a routine procedure in this clinic.

5- Reliability:

a) Internal Consistency

For both the Medical and Social scales a standardised measure of reliability, Cronbach's alpha , was calculated. Item reliability was then assessed by producing an alpha score for each scale with each item consecutively omitted (Alpha if item deleted). As can be seen from Table 5, on both scales no item differed significantly from the total alpha score for each scale. This indicates a reasonably high and uniform level of item consistency (See appendix 3 for full details).

b)Test- Retest Reliability (Total Scores)

Approximately 6 months after initial completion, a total of 21 subjects were selected at random from the original subject pool and were asked to recomplete the questionnaire. 18 completed questionnaires were returned (a 22% sample).

Reliability was assessed by correlating total scores on occasion 1 with total scores on occasion 2. The inter- class correlation procedure was selected as the most sensitive assessment procedure to account for variability within subject scores on both occasions and between subject scores

on each occasion. Given the small number of subjects, results indicate a highly acceptable level of consistency.

Table 5- E.K.P.-G Reliability

1) Alpha Coefficient Scores for Individual E.K.P. Items

1- Medical Knowledge
Total Alpha Coefficient Q1- Q34= 0.6256
Range of scores for individual items-
0.5815 (Q14) - 0.6641 (Q34)

2- Social Knowledge
Total Alpha Coefficient Q1- Q21= 0.4929
Range of scores for individual items-
0.3914 (Q2) - 0.5212 (Q17)

(N=18)

2) Inter-Class Correlations on Total E.K.P.-Specific Scores

Medical Scale	0.875	< 0.001
Social Scale	0.676	< 0.005

(N=18)

c) Test- Retest Reliability (Individual Items)

For individual items there are 4 possible sets of replies:

1- Incorrect occasion 1, incorrect occasion 2 (Response reliably indicating belief in an incorrect answer).

2- Correct occasion 1, correct occasion 2 (Response reliably indicating belief in a correct answer).

3- Correct occasion 1, incorrect occasion 2 (Response unreliable, indicating ignorance of correct answer).

4- Incorrect occasion 1, correct occasion 2 (Response unreliable, indicating ignorance of correct answer).

Analysis of subject responses adds to the information obtained previously on question ease by indicating whether incorrect responses are caused by poverty of knowledge, or through misconceptions.

It was also thought to be of considerable interest to examine whether there was a linear relationship between question ease and question reliability- i.e. were easier questions answered more reliably than difficult questions.

This was done by comparing subjects obtaining the correct answer on occasion 1 with those who obtained the correct answer on occasions 1 and 2 (Category 2). Scores for the 18 subjects in the retest group were broadly consistent with the scores of the 82 subjects in the total group (See Appendices 4,5,6 and 7).

On the medical scale there were no major differences. The biggest discrepancies were on items with a relatively low percentage of correct responses. It is suggested that this reflected uncertainty on the more difficult items.

On the social scale, the same pattern emerged. However as there was a greater number of more "difficult" items it is suggested this accounted for the lower level of reliability, as indicated by the alpha coefficient (See table 5).

Comparison of subjects who were incorrect on both occasions, which indicated strength of belief in an incorrect response (misconception), with total subjects falling into categories 3 and 4- Correct on only one occasion, which indicated poverty of knowledge and guesswork, suggested items with a higher level of unreliability were those which subjects found more difficult, such as question 13 on the medical scale which enquired if lack of oxygen to the brain was a definitive feature of a seizure. Items where subjects tended

to answer incorrectly on a more consistent basis appeared to be those dealing with commonly held misconceptions. such as question 7 which enquired whether it was appropriate to place an object in the mouth of someone who is having a seizure (See Appendices 4,5,6 and 7).

DISCUSSION

Results indicate that the E.K.P.-G, is a valid, and reliable measure of knowledge of epilepsy which is applicable to a wide range of people with epilepsy. It is very quick and easy to administer and produces results which are clinically meaningful. Results can be analysed in terms of total scores or in terms of replies to specific items. To aid interpretation, information has been provided on question ease and also on whether errors are likely to be caused by lack of information or a belief in incorrect information.

The validity studies undertaken in the development of the E.K.P.-G provide strong evidence of the practical applicability of the scale across a wide range of clinical and care settings and of its ability to quantify "knowledge". Furthermore, reliability studies suggest the E.K.P.-G's robustness as a measure which is internally consistent and stable in its measurement across time. There appears, therefore, to be a firm basis at this stage for retaining the 55 item version of the questionnaire. It is suggested that omissions would narrow the scope of enquiry and lessen the discriminative power of the questionnaire. Clearly, further systematic evaluation of the E.K.P.-G's

properties and applications would be welcome. The authors have considered. for example the inclusion of a "Don't Know" column on answer sheets. However, experience indicates subjects tend to have a response bias towards "Don't Know" replies. The forced choice option (True/False), therefore appears preferable.

With regards to practical uses of the E.K.P.-G, it has been recognised that the main potential source of information for the person with epilepsy is his/her doctor. However, despite consistent appeals for the inclusion of the patient as part of the assessment team, based on a mutual sharing of data, this seldom appears to happen in practice (67,75,83). It is suggested that the E.K.P.- G could could act as a basis for cooperation with potentially positive social, psychological and medical treatment implications, since 93% of subjects who completed the scale in this study managed to do so in a hospital outpatient waiting room prior to consultation. It seems therefore that the scale could be easily completed by patients attending hospital epilepsy clinics or general practice surgeries. Furthermore, questionnaires could be scored by either trained or untrained staff and the entire process could be completed in under 10 minutes.

Results from the E.K.P.-G would enable physicians rapidly to assess the overall understanding which patients have about epilepsy and to focus upon areas which are thought to be of specific concern or interest. e.g. poor comprehension of diagnosis, misunderstandings regarding anti-convulsant treatment.

It should also be noted, of course, that communication is a two way process. From the patient's perspective, there is evidence that many feel disadvantaged, and in some respects intimidated, during consultations by their lack of knowledge (83). Completion of the E.K.P.-G, however, may provide patients with a welcome invitation to check their information about epilepsy, to request further information and to engage more fully in the treatment process between appointments.

It has been recognised also that at present a variety of other disciplines and agencies are involved in the care of people with epilepsy. As administration and interpretation of the scale does not require expert medical knowledge, the E.K.P.-G may be applicable in a range of environments for individual or group assessment purposes. One practical application may be in educational programmes where a measure of need or progress is required.

The scale also has considerable research potential. For example, it may prove to be of interest to assess the importance of various medical, social and psychological features as predictors of patient knowledge, to include "knowledge" as an independent matching criterion in outcome trials or to investigate factors relating to compliance with treatment.

In conclusion, while patient knowledge has been highlighted as being of vital importance, and it has been indicated that the E.K.P.-G. is a potentially useful assessment tool, there remains a considerable poverty of

research specifically on this topic. It is therefore hoped the scale may act as a catalyst for future research.

CHAPTER 7

STUDY 2

THE DEVELOPMENT OF A QUESTIONNAIRE TO ASSESS KNOWLEDGE OF EPILEPSY: 2- KNOWLEDGE OF OWN CONDITION

INTRODUCTION

In the previous chapter it was suggested that the E.K.P.-G enabled rapid assessment of knowledge of relevant medical and non medical aspects of epilepsy to be completed.

The development of a scale which provides an assessment profile of what patients know and believe about their own condition would prove to be a useful addition to the E.K.P.-G. A personal knowledge assessment has the potential rapidly to focus upon specific and important deficits in knowledge and upon misconceptions. It would also provide a structure for the patient to express fears and other personal information concerning how epilepsy affects him or her which otherwise he/she may be reticent to disclose during consultation.

This chapter describes the development of a questionnaire to assess knowledge of own condition- The Epilepsy Knowledge Profile- Personal (E.K.P.-P).

METHOD

The specific aims of this study were to produce a comprehensive and accessible assessment tool which provided a profile of knowledge and beliefs which people with epilepsy have about medical and non medical features of their own condition.

As with the E.K.P.-G, three main stages of development were completed:

1- Development of questionnaire format and item pool.

2- External validation and refinement of item pool.

3- Clinical trial of questionnaire.

1- Development of Questionnaire Format and Item Pool

It was decided that the questionnaire should consist of a brief question and answer format. In order to reduce potential confusion and boredom, a "routing" format such as is used in United Kingdom D.S.S. benefit claim forms was adopted.

As with the E.K.P.-G, items were gathered from the main contemporary texts on epilepsy and from existing assessment measures with a knowledge component (1,3,81,82,113,114). Items on knowledge of risks and limitations imposed by seizure disorders, and on awareness of seizure precipitants and self control of seizures were based on items used by Balashak and Mostofsky (1981) in their questionnaire designed to assess potential for psychological control of seizures (111).

A total of 36 questions was obtained.

2- External Validation of Item Pool

The 36 item draft questionnaire was then sent for review to professionals from a variety of disciplines in the field of epilepsy. Fourteen replies from sixteen requests for comments were received covering a wide range of professional interests such as neuropsychiatry and neurophysiology through to rehabilitation staff working in an assessment unit in a residential epilepsy centre. Respondents were asked if they felt any areas were badly worded or ambiguous and whether they felt that any areas had been over

represented or omitted. Questions thought ambiguous or irrelevant were reworded where possible or omitted. Questions were added as requested.

Of the 36 original questions a total of 23 questions was included with amendments. A final open ended question was added asking if respondents felt that they knew enough about their condition. Space was supplied for comments. On completion of the revised item format, questions were reviewed for reading ease using the Flesch formula (115). This places a piece of writing on a scale between 0 (Practically unreadable) and 100 (Easy for any literate person). This produced a score of 95 which indicated that the scale should be readily understood by most people.

3- Clinical Trial of the Questionnaire

The aims of the clinical trial were firstly, to investigate the administrative ease of the E.K.P.-P and to identify any problems in administration; and secondly to assess whether or not the questionnaire could provide a useful profile of patient's knowledge of their condition.

Subjects and Procedure

Seventy-nine Subjects attending the epilepsy clinic at the Western Infirmary, Glasgow, from a sample of 89, completed the E.K.P.-P (See previous chapter for details of the sample).

Results

The high return rate (89%), the short time to completion (8-10 minutes) and the nature of subjects' comments indicated

that the scale was readily completed and viewed by patients as relevant to their situation. In fact subjects actually appeared keen to have an opportunity to assess their knowledge.

Of the 23 questions in the scale, the percentage of subjects completing each question ranged from 84% (Q.3- "Do you know the medical name for your type of seizures?", Q.8- "Do you know what your anti epileptic drugs are supposed to do?"), through to 95% (Q17- Have you lost a job or failed to gain a job because of your epilepsy?"). These figures include 3 subjects who failed to complete any part of the questionnaire.

The E.K.P.-P requires subjects to provide a range of information. It was important therefore, to consider whether information provided was relevant, meaningful and quantifiable. Analysis of responses fell within two logical structures reflecting the content of items: i.e. those with and those without criterion validity. In practice, the former comprised information which could be checked against medical records, such as E.E.G. results or anti-convulsant treatment; the latter, information which represents awareness of condition but which could not be readily checked against medical criteria, such as awareness of seizure precipitants or precautions taken to avoid injury. Results from each of these areas will be considered in turn.

1- Items With Criterion Validity

Responses to Questions 1 to 9 could be checked against the valid criterion measurement of patients' medical notes.

Questions 1 and 2 were concerned with whether subjects believed that they have had seizures and whether they believed that they had epilepsy. These required simple yes or no responses. Questions 3 to 9 required subjects to provide brief decriptive information on assessment and treatment of their epilepsy. Preliminary analysis revealed considerable variability in the accuracy of responses. It was therefore decided to develop an assessment procedure which would quantify the accuracy of subject responses. Such a procedure would ease future interpretation of the questionnaire by providing guidelines for what it is reasonable to expect patients to understand about their condition.

Scoring criteria were developed by means of the following procedure:-

1- Information on treatment and assessment was gathered from each individual's medical notes.

2- All 79 subject responses for E.K.P.-P questions 3 to 9 were gathered.

3- Each subject's responses were evaluated against information gathered from medical notes with regards to the following general scoring procedure-

0- Incorrect/Does not know.
1- Poor description/Poverty of content.
2- Adequate description.

Analysis of comparisons indicated that strict adherence to diagnosis and statements in medical records would be unhelpful in setting criteria since subjects could not be expected to comprehend complex medical and technical details. With this in mind, a more sympathetic, but

nevertheless valid scoring procedure was adopted. This was achieved by developing specific criteria for 0, 1, and 2 point responses to each question through analysis of the content of the pool of subject replies. The most accurate responses were analysed for their chief defining features and were used as examples of 2 point responses. Items clearly incorrect or which demonstrated a marked poverty of knowledge were scored as 0 point responses. Responses which demonstrated some knowledge but did not reach the necessary criterion for a 2 point response were scored as 1 point responses. 1 point responses were then analysed for their chief defining features for the construction of reliable criteria.

These criterion measures were then given to a small number of experts in the field of epilepsy reflecting expertise across the range of questions. i.e. a consultant Physician specialising in epilepsy, a Consultant Clinical Pharmacologist specialising in epilepsy, a Neurophysiologist and a Clinical Psychologist specialising in epilepsy. Disagreements and ambiguities were discussed and from these consultations a revised set of scoring criteria was devised. Participants were then asked to score all subject responses based on the revised scoring criteria. No major differences were found. However when differences of opinion were uncovered, further discussion took place until consensus was reached. Final minor amendments were then made to the criteria (See Appendix 8 for revised scoring criterea and Table 6 for subject responses).

Table 6- Subject Responses- Questions 1 to 9

Question Number	Response			
1- Do subjects have seizures or fits?	No 9.5%	Yes 90.5%		
2- Do subjects accept that they have epilepsy?	No 6.7%	Yes 93.3%		
3- Do subjects know the medical name for their seizures?	No 81.6%	Yes 18.4%		
	No	Poor Desc.	Adequate Desc.	Not Appl.
4- Do subjects know the result of E.E.G. assessment?	71.9%	2.5%	15.8%	9.8%
5- Do subjects know the result of brain scan assessment?	62.2%	1.2%	13.4%	23.2%
6-(a) Are subjects aware they are on anti-convulsant medication?	No 3.9%	Yes 96.1%		
(b) Do subjects know how many drugs they are currently on?	No 1.4%	Yes 98.6%		
(c) Do subjects know the name of some or all of their drugs?	No 2.7%	Yes (For some) 6.8%	Yes (For all) 90.5%	
7-(a) Do subjects know how frequently to take their drugs?	No 2.7%	Yes (For some) 6.8%	Yes (For all) 90.5%	
(b) Do subjects know the correct dose for their drugs?	No 4.2%	Yes (For some) 15.3%	Yes (For all) 80.5%	
8- Do subjects know the purpose of their drugs?	No 27.5%	Poor Description 60.9%	Adequate Description 11.6%	
9- Have any methods other than drugs been used to treat subjects' epilepsy?	No 96.1%	Yes 3.9%		

2- Items Without Criterion Validity

Question 10 was concerned with knowledge of seizure frequency. The remaining questions (Q11-Q23) were concerned with predictability in terms of internal and external precipitants, use of seizure prevention techniques, awareness of seizure related danger and assessment of precautions taken, and assessment of social and vocational limitations imposed by the seizure disorder.

As has been indicated, completion rate for all questions was high. There was no evidence of a trend towards an increase in omissions or a progressive increase in "no" responses in order to avoid providing a description or explanation. Subject responses to each question were gathered for analysis. Replies again varied considerably in content and quality. However all were relevant and were felt to be reflective of the broad range of subjects completing the questionnaire. While many replies were idiosyncratic, a number of recurrent themes developed for each question. These ranged from typical auras such as deja-vu and jamais-vu (Question 11), through to typical desirable jobs which subjects were unable to do due to their epilepsy such as teaching, nursing, the police and fire service (Question 19). Clearly Q10 to Q23 are not open to quantitative analysis but provide important qualitative information information complementary to Q1 to Q9 (For examples of patient responses, see Appendix 9).

DISCUSSION

The aim in the construction of the E.K.P.-P was to provide a comprehensive assessment tool, easy to complete and interpret, and which would provide a meaningful profile of the patient's knowledge and beliefs about his/her own epilepsy.

In order to achieve this, an assiduous approach was adopted at all stages in the development of the scale: Care was taken to ensure that all relevant areas of knowledge were included and that question content was both succinct and accurate by gaining the expert opinion of individuals from a variety of disciplines relevant to epilepsy. Items were also assessed for reading ease. This indicated that the language used was at a level easily understood by most literate people.

From the clinical trial of the questionnaire, results indicate that the scale was successfully completed by a wide variety of people with epilepsy. It is suggested that key factors in the high completion rate were the short time necessary for completion (8-10 minutes), the use of non-technical language, the use of a comparatively straightforward questionnaire format and high subject motivation.

Subject responses were gathered and analysed with the aim of assisting future interpretation of the scale. From this, criteria were constructed which provide an objective means of scoring responses to those items which can be checked against patient's medical notes. For each question specific

criteria for 0,1 and 2 point responses are available with examples. For the remaining items examples of typical patient responses are available which aid the qualitative assessment of replies.

With regards to interpretation of subject responses on items dealing with medical assessment and treatment, it should be stated that the validity of interpretation is dependent on good medical notes. Experience dictates that this is not always the case; for example, individuals who are newly diagnosed, relevant information may not have been gathered, while the notes of individuals with a long history of epilepsy may have sections of notes which have been lost or misplaced over the years, or may contain ambiguous or contradictory information, or it may simply be the case that individuals simply do not have access to all relevant notes. For this reason care was taken to assess the minimum level of non ambiguous information which one could expect to obtain from medical notes. It should also be recognised that clinicians who may use the E.K.P.-P may interpret the scale using their own diagnostic and prognostic opinions which may or may not be well recorded in patient's medical notes.

Many subjects reported pleasure that attention was being paid to their knowledge and understanding, mixed with concern at their own poverty of knowledge. For example, a typical comment was "I am very pleased that a body of people have asked me about my condition in great detail. This is the first time in 20 years that I have been asked, so that

must be good news!" Reaction to the content of the questionnaire was also very positive. For example, one subject commented "This covers all questions you may have about epilepsy, and if you are uncertain about any aspect of it, then you could have the opportunity to ask medical staff about it." Of all subjects questioned only 48% felt happy with their current level of knowledge. This finding is consistent with previous research reports of patient dissatisfaction and further reinforces the need for the development of the current scale.

The practical applications of the E.K.P.-P are considerable. Accurate diagnosis and effective treatment is dependent upon obtaining an accurate history (3). As the E.K.P.-P is self administered and provides information on areas highlighted as important by, amongst others, clinicians, the scale may provide valuable information on the nature and frequency of seizures. Also, as studies indicate that between 10%-20% of cases of epilepsy have been incorrectly diagnosed (3), the scale may aid clinical judgement on whether or not seizures are epileptic in origin.

The E.K.P.-P also highlights deficits in knowledge which may have a detrimental effect on seizure control and general health and safety. For example, a small number of subjects in the present sample was unsure of the purpose of their drugs, while others appeared uncertain of the number of drugs they were on or of how frequently these had to be taken. Also, a number of subjects reported that they had

incurred fairly serious injuries as a result of seizures, yet they did not appear to be taking a commensurate level of precautions to prevent such injuries occurring again. The questionnaire may therefore act as a basis of patient education. In conjunction with the E.K.P.-G, which assess general knowledge of epilepsy, educational programmes could be established and their impact monitored in settings as diverse as schools, workplaces or epilepsy support groups.

The scale also has considerable potential as a research tool and will clearly be of considerable use in the following assessment of patients' perceptions. Interest has also been shown in use of the E.K.P. in a number of other research projects, including its' use as an outcome measure in a psychosocial knowledge based programme, and in a pilot project to assess the ability of a purpose trained practice nurse to provide education and improved self management procedures. Interest has also been shown in the scale as an assessment measure for new patients attending an epilepsy clinic and as a measure of patient knowledge in primary care.

In conclusion, the E.K.P.-P is capable of providing a rapid, yet comprehensive and valid assessment of patients knowledge and beliefs about their own condition. While it was designed to be used in conjunction with the E.K.P.-G to provide an extensive assessment of patient knowledge, it has been demonstrated that it can also be used independently to good effect.

CHAPTER 8

STUDY 3

AN ANALYSIS OF PERCEPTIONS OF EPILEPSY AND PSYCHOSOCIAL FUNCTIONING: SAMPLED GROUP ASSESSMENT

METHODS

Subjects and Procedure

As was indicated in chapter 5, the aim of this study was to provide detailed assessment of the perceptions of epilepsy and associated psychosocial functioning in adults with poorly controlled epilepsy. The following specific inclusion and exclusion criteria were formulated-

Inclusion criteria:

(a) Seizure frequency- Previous studies have varied considerably in definitions of an appropriate criterion for refractory epilepsy. This has ranged from at least 2 per week, to at least 1 per 2 months. The former seems unnecessarily stringent for the present study. A minimum average seizure frequency of at least 1 per 2 months was selected as appropriate.

(b) Duration of Epilepsy- It has been well chronicled that the period following diagnosis is frequently one of considerable distress as individuals attempt to assimilate and accommodate the implications of having epilepsy. Clearly the time taken to develop a stable and enduring set of beliefs will vary considerably between individuals. It has been suggested that this process can take from six months to over a year (46,91). Therefore a conservative figure of illness of at least two years duration with no periods of long term remission was selected.

(c) Age Range - Between 17 and 65 inclusive.

Exclusion Criteria:

(a) Seizure Type- Those suffering from simple absence

seizures alone and those whose seizures were suspected to be non-epileptic in origin were excluded.

(b) Significant Associated Difficulties- Those with a history of mental illness, severe physical disability or suffered from a chronic illness other than epilepsy were excluded.

(c) Cognitive impairment such as to prevent the reliable completion of questionnaires. This was based on available cognitive assessment results or on impressions gained at the clinic. Only those with gross impairments were excluded. Moser and Kalton (1979) suggested that there are three major recurring problems with sampling in research: 1- Using an inaccurate sampling frame, 2- problems in refusal or part of the population impossible to find, 3- biases arising from non random sampling (112).

Such issues have frequently been highlighted as a concern in epilepsy research. In particular it has been argued that it is impossible to obtain a truly representative sample of people with epilepsy as accurate information on the frequency and distribution of epilepsy in the general population is notoriously difficult to obtain. Shorvon (1990) suggested that differences in definition, case ascertainment methods and classification schemes have made it difficult to compare studies (7). Also, in the United Kingdom such problems are further confounded as doctors are not obliged to report patients with epilepsy to local health authorities. Further, it is recognised that many people with epilepsy are not evaluated by medical professionals (2). In an intensive community study, Zielinski (1974) found one

third of those with epilepsy had been in treatment but dropped out, one third had never been in treatment and only one third were currently receiving medical treatment (19).

It has been suggested that under such circumstances where it is impossible to obtain a representative sample of an entire population, efforts should go into defining clearly the group of a given population research is interested in and thereafter attempt to obtain a random representative sample of that group (112,116,117). These were the sampling guidelines for the present study; namely, to provide a representative sample of adults with refractory epilepsy who fitted the inclusion and exclusion criteria outlined above.

Research has consistently indicated that such individuals with a severe seizure disorder are likely to present to specialist medical facilities. For instance, in the Zeilinski (1974) study outlined above, it was found that those currently not under medical care were found to have a less severe seizure disorder (19). Therefore, this was judged to be the most attainable and representative potential source of subjects. Two specific locations were identified:

1- The Epilepsy Centre, Quarriers, Bridge of Weir.

2- The Epilepsy Research Unit, Western Infirmary, Glasgow.

These were selected as they provided a potentially large and heterogeneous sample, not only in terms of epilepsy but also in terms of social and interpersonal factors: Both centres cover a wide geographical area and therefore have clients

from a variety of urban and rural areas and socioeconomic backgrounds. Both centres were also selected as they were able to provide accurate relevant medical and social information from clients medical notes.

The following procedure was adopted to provide a representative sample of desired subjects.

Epilepsy Centre, Quarriers Cohort

The epilepsy centre provides residential care and medical, psychological and social assessment for up to 138 people with epilepsy. All residents were reviewed with respect to the inclusion and exclusion criteria outlined above. A total of 18 residents were found to be suitable. This is obviously a high exclusion rate. As can be seen from table 7, there were a variety of reasons for exclusion. However, as may be expected in such a residential care environment for a neurological disorder, the major reason for exclusion was cognitive impairment (for reasons for exclusion, see Table 7). All potential subjects were approached for participation in the project. Three refused to take part leaving a total subject pool of 15 subjects. Subjects were provided with a brief description of the study and were given instructions on how to complete the assessment measures. Further help was given on request. All forms were returned within five days of receipt. One subject failed to complete the assessment scales, which left a total of 14 completed sets of questionnaires. The sample consisted of 7 males and 7 females, age ranged from 18 to 55 (mean=39.4, S.D.=11.97), current seizure frequency ranged from less than 1 per month

(28.6%) to about 1 per day (14.3%). 7.1% were on no anti-convulsant medication, 7.1% were on monotherapy and 85.8% were on polytherapy. (For full demographic information of the sample, see Appendix 10).

Table 7- Epilepsy Centre, Quarriers Cohort: Reasons for Exclusion

Reason	Frequency
Seizure frequency too low	37 (27.6%)
Significant Cognitive impairment	90 (65.6%)
History of mental illness	6 (4.4%)
Associated physical disability	21 (15.3%)
Age	21 (15.3%)
Other chronic illness	7 (5.1%)
Uncertainty over diagnosis	3 (2.2%)

(Total percentage greater than 100% as majority were excluded on more than 1 criterion.)

Epilepsy Research Unit, Western Infirmary Cohort

The Epilepsy Research Unit provides medical care and assessment for over 1200 people with epilepsy. Constraints on time dictated that it was impossible to review all potential subjects. Therefore, the following procedure was adopted to obtain a random, representative sample of subjects.

The author and a research assistant associated with the clinic attended fourteen consecutive weekly clinics. The medical notes of all available clinic attenders were reviewed prior to medical consultation with respect to the inclusion and exclusion criteria outlined above. Potential subjects were then approached in the waiting room and were asked if they were willing to participate in the study. Only one potential subject indicated at the clinic that he did

not wish to participate; no explanation for refusal was offered. The remaining subjects were provided with a brief description of the study and were given instructions on how to complete the assessment scales. Subjects were provided with a stamped addressed envelope which they were requested to return the questionnaires in within 7 days of receipt. One week after the final clinic visit, a reminder was sent out to all subjects who had failed to return the questionnaires.

It was recognised that in a clinic which caters for an average of fifty clients in just over three hours, it was probable that potential subjects may be missed and this may consequently bias the sample. For this reason it was decided that on two randomly selected clinic visits medical notes would be reviewed, as above, but subjects would not consequently be contacted. This provided an opportunity to assess all medical notes at each clinic, and therefore provide assessment of potential subjects missed during contact time with other subjects. Also, this procedure provided the time to log reasons for exclusion (See Table 8). From this procedure it was found that, on average, 12 subjects were appropriate for inclusion in the study at each clinic. At the 14 clinic visits where potential subjects were contacted, an average of 9.7 subjects were contacted at each clinic. This indicates that only approximately 2 potential subjects were missed at each clinic.

In total, 136 individuals were contacted, from which 97 completed questionnaires were returned (a 71% response). Of

this number further analysis revealed that 2 subjects were found to be inappropriate; 1 due to a chronic illness other than epilepsy, the other was found to be outwith the specified age range. This resulted in a total of 95 completed sets of responses. Comparison of a series of demographic and epilepsy related variables revealed no significant differences between respondents and non-respondents: Respondents consisted of 41 males (56.8%) and 54 females (41.2%). Age ranged from 17 to 65 (mean=34.58). Seizure frequency ranged from less than 1 per month (34.7%) to greater than 1 per day (4.2%). The major reported seizure diagnoses were complex partial (66.3%), secondary generalised (42.1%) and primary tonic-clonic seizures (28.4%). 1.1% were on no anti-convulsants, 53.7% were on monotherapy, 45.2% were on polytherapy (for full demographic details of the sample see Appendix 10).

Non-respondents consisted of 19 males (48.7%) and 20 females (51.3%). Age ranged from 18 to 60 (mean=36.29). The major reported seizure diagnoses were complex partial (60%), secondary generalised (33.3%), simple partial (26.6%) and primary tonic clonic (26.6%). 3.1% were on no medication, 43.75% were on monotherapy, 53.15% were on polytherapy. Figures on current seizure frequency were not available for non-respondents as this was obtained from subject self reports on one of the assessment measures (E.K.P.-P). Medical notes were examined for an estimate of seizure frequency. However, while this proved to be an accurate source as to whether subjects were refractory or seizure

controlled, this did not prove to be a useful source of assessment of current seizure frequency. The higher incidence of simple partial seizures in the non-respondents may be of some significance. For instance it may have been the case that some of these individuals did not perceive their condition serious enough to merit completion of the questionnaires.

Demography of the Combined Sample

As the same rigorous inclusion and exclusion criteria were applied to both the Quarriers and Western groups and between group analysis did not reveal any significant demographic or epilepsy related differences (see above and Appendix 10), subsequent results are based on the combined sample.

Table 8- Epilepsy Unit, Western Cohort: Primary Reasons for Exclusion at Two Randomly Selected Clinic Visits

Reason	Frequency
Seizure frequency to low	4
Significant cognitive impairment	4
History of mental illness	1
Associated physical disability	10
Age	2
Other chronic illness	1
Uncertainty over diagnosis	4
Failed to attend	9
Average total excluded-	35
Average total due to attend clinic-	47
Average total appropriate- for inclusion	12

The total sample consisted of 109 people with intractable epilepsy; 61 females (56%) and 48 males (44%). Age ranged

from 17 to 65 (mean= 35, S.D.=12.3). Number of years since onset ranged from 2 years to 49 years (mean=17, S.D.=12.2). Age at onset ranged from birth to 63 (mean=18, S.D.= 13.4). Seizure frequency at time of completion ranged from about 1 per two months (37%) to greater than 1 per day (3.7%). Seizure diagnoses were as follows: Tonic clonic 29.4%; atonic 0.9%; myoclonic 3.7%; absence 11%; simple partial 17.4%; complex partial 64.2%; secondary generalised 43.1%; other 1.8%. Forty per cent were diagnosed as having only one type of seizure, 47% described 2 recognised seizure types and 13% described 3 seizure types. Seizure diagnoses were obtained from patients medical notes. In only 1.8% of cases was diagnosis made on clinical grounds alone; in 98.2% of cases diagnosis was assisted by results of E.E.G. recording and 90% of diagnoses were assisted by some form of brain scan. 1.8% of the sample were on no medication, 47.7% were on monotherapy; 50.5% were on polytherapy.

Measures

At present, perhaps the most frequently used assessment measure in this area is the Washington Psychosocial Seizure Inventory (W.P.S.I.) (30). This consists of family background, emotional, interpersonal and vocational adjustment, financial status, adjustment to seizures, medical management and overall psychosocial functioning scales.

There has, however, been strong suggestions that the scale has limited practical application (70). Criticisms have highlighted that it has not been validated on a British

population, weightings are based on expert opinion and not on what patients themselves think are important, the lie scale has frequently found to be high, thus invalidating results, and the time taken to administer and score the scale can be prohibitive (69). The scale was also inappropriate for the present study as elements of patient perceptions and psychosocial functioning appeared within each subscale, thus making seperate analysis of each of these areas impossible. Therefore, it was decided to select a series of valid and reliable assessment measures which dealt with the specific aspects of patient perceptions and psychosocial functioning under consideration; namely perceptions of social and physical effects, perceptions of control, knowledge of condition, depression, anxiety and social problems. Where possible assessment measures which have already already proven sensitive to epilepsy populations were selected.

Patient Perceptions

1- Perceived social and physical effects

It was aimed to select measures which provided assessment of the extent to which subjects feel they have been discriminated against as a result of having epilepsy and also of subjects' perceived social and physical limitations as a consequence of having epilepsy.

(1)Perceived Stigma

This was assessed using a 6 item scale developed by Ryan et al (1980)(56). This was designed to assess the extent to which people with epilepsy feel that they are victims of

prejudice; the first 3 items deal with the extent to which respondents feel they are treated differently because of epilepsy, the last 3 deal with perceived inability to change the views of others. Subject responses were measured on a 6 point Likert scale (See Appendix 11).

(2)Perceived effects of epilepsy

Comprehensive analysis of the perceived effects of epilepsy was provided by a version of Linkowsi's (1971) Acceptance of Disability Scale (A.D. Scale) amended for epilepsy (118). The 50 item A.D. scale measures primarily the extent individuals are able to see values other than those in direct conflict with their epilepsy, whether individuals spread the effect of their epilepsy to other aspect of their functioning self and the extent to which the individual compares him/her self to others in terms of areas of limitations and liabilities rather than emphasising assets and abilities. Responses were assessed on a 6 point Likert scale (See appendix 12).

(3)Fear of epilepsy

This was assessed by 5 items identified by Mittan (1986) as central to patients' fears; namely fear of death, brain damage, injury, cognitive impairment and the extent to which patients constantly lived in dread of a seizure (34). In order to minimise potential distress caused by these items they were interspersed within the A.D. scale (See Appendix 12).

2- Knowledge of Epilepsy

General knowledge of epilepsy and specific knowledge of own condition were assessed using the Epilepsy Knowledge Profile (E.K.P.) (See Chapters 6 and 7 and Appendices 13 and 14).

3- Perceived control

(1)Perceived behavioural control over seizures

This was assessed by items from the E.K.P.-P. (See Chapter 7 and Appendix 14).

(2)Perceived control over health

In order to provide assessment of subjects expectancies of control over health related behaviours, the Health Locus of Control (H.L.C.) scale developed by Wallston et al (1976) (120) was used. This consists of 11 items (5 internal, 6 external). Responses were assessed on a 6 point Likert scale (see Appendix 15).

4-Perceived Self Efficacy

The ability to self regulate cognitions, emotions and behaviour was assessed using the Self Efficacy Scale developed by Sherer et al (1982)(119). The scale consists of 23 items (17 General Self Efficacy and 6 Social Self Efficacy items) rated on a 6 point Likert scale (See appendix 16).

Psychosocial Functioning

1- Anxiety and depression

(1)Anxiety

This was measured using the State Trait Anxiety Inventory (S.T.A.I.) developed by Speilberger et al (1970)(121). The

S.T.A.I. Trait scale consists of 20 statements asking people how anxious they generally feel. The S.T.A.I. State scale consists of 20 items requiring subjects to indicate how anxious they feel at time of completion. Agreement with statements was indicated on a 4 point scale (See Appendix 17). This scale has been used frequently as a reliable and valid measure of anxiety in epilepsy populations (62,89).

(2)Depression

This was assessed using the Beck Depression Inventory (B.D.I.) (Beck 1970)(121). This consists of a 21 item self rating scale which provides assessment of overall depressive symptomatology (see Appendix 18). The B.D.I. has also been used frequently in epilepsy populations (33,89).

2-Social difficulties

Subjects completed the Social Problems Questionnaire developed by Corney and Clare (1985) (123). This 34 item questionnaire measures satisfaction with various social aspects of subjects' lives including housing, work, finances, social contacts, relationships, family problems and legal problems. Subjects were required to rate satisfaction on a 4 point scale with ratings of "moderate" or "marked" dissatisfaction consisting a significant problem (see Appendix 19).

Table 9- Measures Used for Assessment of Self Perception of Epilepsy and Psychosocial Functioning

Self Perception	
Social and Physical Effects	Perceived Stigma Questionnaire (Ryan 1980) A.D. Scale (Linkowski 1971) Fear of Seizures (Mittan 1986)
Perceived Control	E.K.P.-P (Jarvie et al (1993) H.L.O.C. (Wallston et al 1976)
Perceived self Efficacy	Self Efficacy Scale (Sherer et al 1982)
Knowledge of Condition	E.K.P. (Jarvie et al 1993)
Psychosocial Functioning	
Anxiety	S.T.A.I. (Spielberger et al 1970)
Depression	B.D.I. (Beck 1970)
Social Difficulties	Social Problems Questionnaire (Corney and Clare 1985)

Intellectual and Demographic Variables

An estimation of current verbal intellectual functioning was obtained using the Mill Hill Vocabulary Scale (Raven 1962)(124) (see Appendix 20). Raw scores were converted into deviation I.Q. scores using Peck's (1970) norms (125). Other demographic variables were obtained from patients medical notes and were recorded on a specially constructed patient data sheet (see Appendix 21).

Assessment of Reliability

As has been indicated, all questionnaires were selected on the basis of previously established reliability. However, as assessment comprised a comparatively large battery of

questionnaires thus providing greater opportunities for error, it was decided to ask a small sample of subjects to recomplete the battery and compare responses. Approximately three months after initial completion, all subjects from one randomly selected clinic visit were contacted and asked to recomplete the questionnaires. A total of 9 subjects were contacted, from which 5 completed replies were received. Comparison of responses to individual items on the E.K.P.-P, the Fear Questionnaire and the Social Problems Questionnaire, and total scores from the remaining assessment measures revealed that subjects completed the scales in a consistent manner. (see appendix 22 for comparison of raw scores).

RESULTS

The structure of the results section will correspond to the hypotheses stated in chapter 5: First of all, analysis will be made of total scores on all measures. Secondly, the relationship between knowledge of epilepsy, self-efficacy and other measures of perceptions of epilepsy will be examined. Next, the hypothesised relationship between these measures and psychosocial functioning will be examined. Finally, the data will be examined for evidence of the hypothesised "underadaptive" perception of epilepsy.

Table 10- Assessment of Psychopathology and Perception of Epilepsy: Means and Standard Deviations of Total Sample

	Mean	Standard Deviation	
Self Perception			
E.K.P.-G (Medical Knowledge)	26.3	3.45	(High score= high knowl.)
E.K.P.-G (Social Scale)	15.2	2.56	(High score= high knowl.)
E.K.P.-P (Medical Knowledge (personal))	7.9	1.92	(High score= high Knowl.)
Self Efficacy Scale	91.0	18.30	(High score= high eff.)
Fear of Seizures	13.1	7.04	(High score= high fear)
Health Locus of Control	40.9	6.94	(High score= ext. cont.)
Acceptance of Disability	223.2	42.36	(High score= high acc.)
Perceived Stigma	17.6	6.48	(High score= high stig.)

Questionnaire			
Behavioural control of seizures (E.K.P.-P)	No	Yes	Failed to Respond
Q.13) Awareness of seizure precipitants.	68.8%	30.3%	0.9%
Q.14) Ability to prevent or abort seizures.	78.0%	21.1%	0.9%

Psychopathology			
S.T.A.I. (State Anxiety)	39.2	11.96	(High score= high anx.)
S.T.A.I (Trait Anxiety)	42.4	11.57	(high score= high anx.)
	Median	**Quartiles**	
B.D.I.	6	Q1=2.2 Q3=14.7	(High score= high depr.)

(N.=109)

1-Psychosocial Functioning and Self Perception: Total Scores

As can be seen in Table 10, E.K.P.-G (Medical) and E.K.P.-G (Social) results are comparable to those of the sample who completed the questionnaire for the development studies of the scale: Mean E.K.P.G (Medical) scores were 26.3 as compared to 26.1 from the scale development sample, Mean

E.K.P.-G (Social) scores were 15.2 for the present sample as compared to 15.3 from the scale development sample (see chapters 6 and 7).

Perceived behavioural control over seizures was assessed by subject responses to question numbers 13 and 14 on the E.K.P.-P. As can be seen from table 11, approximately one third of subjects (30.3%) indicated awareness of seizure precipitants. Typical responses included stress, overwork and sleep deprivation. Approximately one fifth of subjects (21.1%) indicated an ability to prevent or abort seizures. Typical responses included relaxation techniques, muscular tension and occupying the mind with some other mental activity (see Table 10 and Appendix 23 for a full listing of subject responses).

Psychosocial Adjustment

It was hypothesised that in line with previous research, overall levels of anxiety, depression and social problems would be higher than a normal population. Interpretation of results reveals that mean S.T.A.I State and Trait scores are only moderately higher than published norms (121). However State anxiety results are only moderately lower than those of Helgeson et al (1990) of mean pre-treatment State anxiety scores of a comparable population of people with epilepsy attending a medical clinic (mean=42.83) (33).

Analysis of the range of B.D.I. scores indicated that a many subjects did not suffer from significant depressive symptomatology, and in fact the median and quartiles were selected as descriptive tools as subject scores were skewed

towards the low end of the scale (median B.D.I. score= 6, Q1=2.2, Q3=14.7.) Comparison of results with previously published B.D.I. pretreatment scores of epilepsy populations revealed that the above scores were lower than all others (e.g. Helgeson (1990)(33) mean B.D.I.=10.56, Tan and Bruni (1986)(43) mean B.D.I.-(Group1)11.13; (Group2)14.1; (Group3)12.0).

Table 11- Social Problems Questionnaire: Percentage of Sample Reporting Moderate or Severe Dissatisfaction as Compared to Other Reported Samples

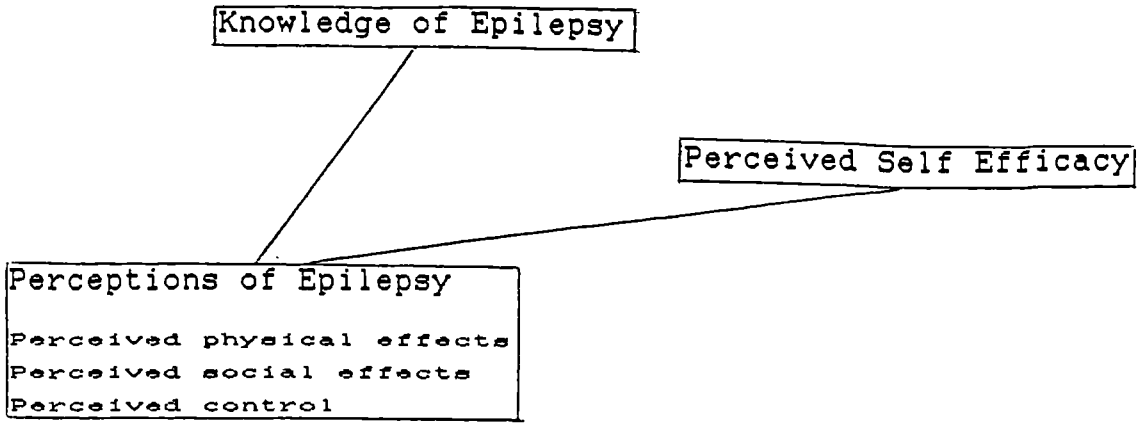
	Problem Area					
	Work	Social Contacts	Marriage/ Relation-ships	Finance	Hous-ing	Rela-tives
Quarriers/ Western sample (N.=109)	21.1%	14.8%	8.3%	19.6%	5.8%	9.2%
Epilepsy assessment centre sample (N.=112)	71%	67%	49%	34%	27%	26%
Epilepsy surgical eval-uation sample (N.32)	34%	22%	28%	22%	6%	16%
Epilepsy out-patients (N.23)	22%	17%	22%	22%	13%	13%
Social Work Referrals (N.=65)	19%	35%	31%	29%	35%	20%
G.P. Atten-ders	12%	21%	19%	26%	17%	11%

(The Social Problems Questionnaire is a 34 item scale designed to measure satisfaction with each of the above areas. Satisfaction was rated on a 4 point Likert scale with ratings of 3 "moderate" or 4 "marked" dissatisfaction consisting a significant problem. Epilepsy assessment centre and surgical evaluation samples reported by Thompson and Oxley (1989)(10). Epilepsy outpatients, social work referrals and G.P. Attenders reported by Corney and Clare (1985) in Thompson and Oxley (1989)(10))

Results from the Social Problems Questionnaire were compared to findings from other groups completing the questionnaire (see table 11). From this procedure, it was found that while the total sample is broadly comparable to the epilepsy outpatient sample, on all areas of assessment the current sample indicated less significant social difficulties. With the exception of work related difficulties, this was also the case when the current sample is compared to other groups (see Table 11).

2- Knowledge, Self Efficacy and Perception: Assessment of Association of Measures

Fig 3- Areas of Hypothetical Model Under Examination



For measures on a continuous scale: namely perceived stigma, acceptance of disability, health locus of control, epilepsy knowledge (general), epilepsy medical knowledge (personal) and self efficacy, initial assessment of association was made by carrying out a series of correlations. As the sample size was comparatively large and distributions of scores

were reasonably normally distributed, a parametric correlation test was selected (The Pearson Product Moment Correlation) (see Table 12).

For assessment of association of nominal data; namely behavioural control items from the E.K.P.-P, and continuous data, the above measures were firstly split at the median to create 2 groups of "high" and "low" scores and compared to behavioural control items using a catagorical assessment of association (Chi-square)(see Table 13). Secondly, in order to provide a more qualitative assessment of trends, subject scores on continuous data were grouped into a larger number of categories (five) of approximately one standard deviation each and crosstabulated w ith the behavioural control items.

Table 12- Knowledge, Self Efficacy and Perception of Epilepsy: Pearson Product Moment Correlation Results

	***			
E.K.P.G. (Social)	+0.537 (p=.000) (Sig.)			
S.Eff.	-0.003 (p=.487)	+0.005 (p=.46)		
	*	*		
H.L.O.C.	-0.164 (p=.050)	-0.171 (p=.045)	+0.050 (p=.309)	
	***		***	***
A.D.	+0.258 (p=.004)	+0.068 (p=.248)	+0.352 (p=.000)	-0.325 (p=.001)
			**	*
Stigma	-0.032 (p=.374)	+0.101 (p=.157)	-0.254 (p=.006)	+0.207 (p=.022)
	*	*	*	***
Fear Scale	-0.166 (p=.048)	-0.205 (p=.020)	-0.216 (p=.015)	+0.325 (p=.001)
	***	***		
E.K.P.-P (Medical)	+0.459 (p=.000)	+0.339 (p=.000)	-0.035 (p=.363)	-0.101 (p=.158)
	E.K.P.-G (Medical)	E.K.P-G (Social)	S.Eff.	H.L.O.C
	***			
Stigma	-0.578 (p=.000)			
	***	***		
Fear Scale	-0.580 (p=.000)	+0.332 (p=.000)		
	*		*	
E.K.P.-P (Medical)	+0.211 (p=.016)	-0.153 (p=.063)	-0.185 (p=.032)	
	A.D.	Stigma Scale	Fear Scale	

*** = p< 0.005

** = p< 0.01

* = p< 0.05

(E.K.P.-G-Epilepsy Knowledge Profile (General); S.Eff.-Self Efficacy Scale; H.L.O.C.-Health Locus of Control; A.D.-Acceptance of Disability Scale; E.K.P.P. (Medical)- Total score, medical knowledge of own condition)

Table 13- Knowledge, Self Efficacy and Perceptions of Epilepsy: Chi-Square Results of Perceived Behavioural Control of Seizures

	Chi-square	
	awareness of seizure precipitants (yes/no)	Perceived ability to prevent or stop seizures (yes/no)
E.K.P.-G (Medical)	31 45 1.45 12 12 (p=.28) (N.Sig.)	39 34 1.27 11 19 (p=.26) (N.Sig.)
E.K.P.-G (Social)	44 29 0.22 15 14 (p=.64) (N.Sig.)	35 46 1.76 13 10 (p=.18) (N.Sig.)
E.K.P.-P (Medical Total)	45 33 0.00 12 11 (p=.96) (N.Sig.)	39 42 1.91 15 20 (p=.16) (N.Sig.)
Self Efficacy Scale	41 31 0.13 15 16 (p=.71) (N.Sig.)	43 31 0.11 16 13 (p=.74) (N.Sig.)
Health Locus of Control	41 31 2.00 12 17 (p=.15) (N.Sig.)	60 28 0.55 23 34 (p=.45) (N.Sig.)
Acceptance of Disability	37 37 2.39 10 20 (p=.12) (N.Sig.)	35 46 1.28 13 10 (p=.27) (N.Sig.)
Stigma Scale	60 30 0.16 22 32 (p=.69) (N.Sig.)	10 69 0.58 10 13 (p=.45) (N.Sig.)
Fear Scale	43 30 0.12 16 13 (p=.73) (N.Sig.)	45 34 0.00 13 10 (p=.97) (N.Sig.)

(All measures (other than behavioural control) split for analysis into "high" and "low" categories by mean.)

1- Perceptions of Condition- Inter-relationship between measures

All measures of perception, namely perceived control over health and perceptions of the social and physical effects of epilepsy related to each other in the manner hypothesised: Results indicated a statistically significant relationship

between external health control, low acceptance, high stigma and low fear of seizures. However, perceived control over seizures was not found to be related to any other measure of perception (see Tables 12 and 13).

2-Knowledge and Perception of Epilepsy

(1) Perceived Control: Results indicate a modest, though statistically significant, negative correlation between both measures of general knowledge of epilepsy and perceived control over health related behaviours ($p<.05$). This is consistent with the hypothesis that increased subject knowledge will be related to greater perceived internal control. However, it is recognised that this is a comparatively weak relationship. While there was evidence of a similar trend with regards to medical knowledge of own condition, this did not reach statistical significance (See Table 12). There was no evidence of a relationship between epilepsy knowledge and perceived behavioural control of seizures (see Table 13).

(2) Perceived Social Effects: It was hypothesised that epilepsy knowledge would be inversely related to perceived social limitations. There were significant positive correlations between measures of medical knowledge, both general and specific, and acceptance of epilepsy (E.K.P.-G (Medical) $p<.005$, E.K.P.-P (Medical) $p<.05$). No noteworthy relationships were evident between general and specific measures of knowledge and stigma (see Table 12).

(3) Perceived Physical Effects: In line with hypotheses, there were significant negative correlations between all

measures of knowledge and fear of seizures. However, it is noted that this relationship was comparatively modest in effect (E.K.P.-G (Medical) $p<.05$, (Social) $p<.05$, E.K.P.-P (Medical) $p<.05$) (see Table 12).

2- Self efficacy and Perception of epilepsy

(1) Perceived Control: Perhaps surprisingly, there is no direct relationship between efficacy beliefs and perceived control over health or perceived ability to predict, control or prevent seizures (see Tables 12 and 13).

(2) Perceived Social Effects: Results are supportive of the hypotheses: There is a strong positive relationship between perceived efficacy and acceptance of the condition and a strong negative relationship between efficacy and perceived stigma (A.D. Scale $p<.005$, Stigma $p<.01$) (see Table 12).

(3) Perceived Physical Effects: Results are modestly supportive of the hypothesis that perceived efficacy beliefs are inversely related to fear of seizures ($p<.05$) (see Table 12).

As a second stage of analysis, for each measure of perception, a series of multiple regression analyses were completed. The purpose of this investigation was twofold: firstly to assess the relative potency of measures of knowledge and efficacy on measures of perception, and secondly to assess the combined predictive value of epilepsy knowledge and efficacy on variance of scores on measures of perception.

3-Regression Analysis: Perception of Epilepsy with Knowledge and Self Efficacy

A series of stepwise multiple regressions was conducted on each assessment measure of patients' perceptions. Measures of epilepsy knowledge, namely the E.K.P.-G (medical and Social) and the E.K.P.-P (medical) and the Self Efficacy Scale were entered on each equation as independent variables. Assessment measures of patient perceptions were entered consecutively in separate equations as the dependent variable (see Table 14). The stepwise procedure was selected as the most appropriate means of concentrating on the variables which accounted for a significant proportion of variance in the dependent variables while discarding non-significant or trivially important variables. Results are congruent with the results of correlational and chi square analysis (see Tables 12 and 13).

(1) Perceived Social Effects: As was hypothesised, perceived efficacy proved to be a strong and significant positive predictor of variance of Acceptance of Disability scores, while E.K.P.-G (Medical) proved to be a considerably less potent, but nevertheless statistically significant predictor variable. As was found with the results of correlation analysis (see Table 12), no relationship was found between knowledge and stigma; perceived efficacy proved to be the only significant positively related variable to perceived stigma (see Table 14).

(2) Perceived Physical Effects: As can be seen from Table 14, the comparatively small correlation between both general and specific medical knowledge and fear of seizures found in Table 12 does not reach significance when other variables are taken into consideration: Only knowledge of the social aspects of epilepsy and, to a moderately lesser extent,

perceived efficacy, reached statistical significance.

Table 14- Significant Multiple Regression Coefficients for Epilepsy Knowledge and Self Efficacy With Perceptions of Epilepsy

	Significant Variables	Standardised Regression Coefficient (Beta)	Level of Significance
Acceptance of Disability	S.Eff.	0.332	.000
Multiple R=0.306 Adj. R Squared=0.074 F=4.85 Sig. F=0.009	E.K.P.-G (Medical)	0.199	.038
Stigma	S.Eff.	-0.242	.018
Multiple R=0.242 Adj. R Squared=0.048 F=5.87 Sig. F=0.018			
Fear Scale	E.K.P.-G (social)	-0.227	.023
Multiple R=0.305 Adj. R Squared=0.074 F=4.85 Sig. F=0.009	S.Eff.	-0.207	.037
Health Locus Control of Control	No significant variables computed at p<.05.		
Awareness of Seizure Precipitants	Nominal data inappropriate as dependent variable		
Perceived Ability to prevent or abort seizures	Nominal data inappropriate as dependent variable		

(Multiple R-Correlation between dependent variable and all significant independent variables; Adj. R Squared-Proportion of variance in the dependent variable associated with variance in the significant independent variables (Adjusted for number of cases); Sig. F- Statistical significance of the regression model)

(3) Perceived Control: The modest relationships between general medical and social knowledge and perceived control over health indicated in Table 12 did not reach an

acceptable level of statistical significance when the effects of other remaining measures of knowledge and perceived efficacy were accounted for (see Table 14).

As can be seen from Table 14, measures of knowledge and efficacy account for a meaningful proportion of variance with regards to the social and physical consequences of epilepsy. However it is clear that other unaccounted factors also play a significant part in the variance of scores (see R squared scores, Table 14). This is particularly true with regards to perceived control where both epilepsy knowledge and efficacy failed to produce a significant effect.

Therefore, investigation was made of the effect of other potentially relevant variables on patients' perceptions of their condition: A comprehensive list of social, demographic, intellectual and epilepsy related variables was examined using correlation and chi-squared analysis (see Appendix 21 for a full listing of recorded variables and Table 15 for results of significant variables).

Table 15- Significant Results of Pearson Correlation and Chi-Square Analysis of Perception of Epilepsy With Medical, Demographic and Intellectual Variables

	Significant Variables	Level of Significance	
Acceptance of disability	Verbal I.Q.	C.=+0.421	p=0.000
	Seizure Type 1- Tonic Clonic	C.S.=6.36	p=0.012
	Duration of Epilepsy	C.=-0.175	p=0.038
	Age at Onset	C.=+0.165	p=0.048

(Contd. overleaf)

(Table 15 contd.)

	Significant Variables	Level of Significance	
Perceived Stigma	Verbal I.Q.	C.=-0.265	p=0.004
	Age at Onset	C.=-0.263	p=0.004
	Duration of Epilepsy	C.=+0.240	p=0.008
Fear Scale	Verbal I.Q.	C.=-0.259	p=0.005
H.L.O.C	Verbal I.Q.	C.=-0.222	p=0.015
	Seizure Frequency	C.S.=5.01	p=0.025
	Age	C.=+0.169	p=0.046
Awareness of Seizure Precipitants	Seizure Type		
	2- Complex Partial	C.S.=6.85	p=0.009
	1- Tonic Clonic	C.S.=5.90	p=0.015
Perceived Ability to Prevent Seizures	No significant variables at p< .05		
E.K.P.-G (Medical)	Verbal I.Q.	C.=+0.487	p=0.000
	Duration of epilepsy	C.=-0.263	p=0.003
	Age	C.=-0.219	p=0.012
E.K.P.-G (Social)	Verbal I.Q.	C.=+0.328	p=0.000
Self Efficacy	Age at Onset	C.=+0.346	p=0.000
	Age	C.=+0.248	p=0.006
	Verbal I.Q.	C.=+0.254	p=0.006

(C.-Pearson Correlation Coefficient. C.S.- Chi Square. H.L.O.C-Health Locus of Control)

(1) Perceived social effects: Results indicate individuals who suffered from primary tonic-clonic seizures appeared to enjoy greater acceptance of their condition than individuals with other seizure types. It was also observed that there was a strong (though statistically non-significant) trend for individuals with complex partial seizures to have poor acceptance of their condition (see Table 16). Results also indicate that a shorter duration of epilepsy is significantly correlated to greater acceptance and reduced stigma. Verbal intelligence also had a strong and significant positive effect on the perceived social effects of epilepsy (see Table 15).

Table 16- Chi Squared Analysis of Acceptance of Epilepsy by Seizure Type

		Tonic-Clonic			Complex Partial	
		No	Yes		No	Yes
Acceptance	Low	41	7	Low	12	36
	High	35	22	High	24	33
Chi Square=6.36		p=0.012		Chi Square=3.38		p=0.066

(Acceptance scores split at mean into "high" and "low" groups)

(2) Perceived physical effects: No direct relationship was found between fear and any epilepsy related variables. However, fear was inversely related to verbal intelligence (see Table 15).

(3) Perceived control: Results indicate that seizure frequency was related to perceived control over health: Subjects who suffered from fewer seizures had a greater

level of perceived internal control. Results of Chi-squared analysis on the behavioural control of seizures items revealed that people with generalised epilepsy reported more potential triggers to their seizures than individuals with complex partial seizures (see Table 15). No other areas of significance were uncovered by this analysis.

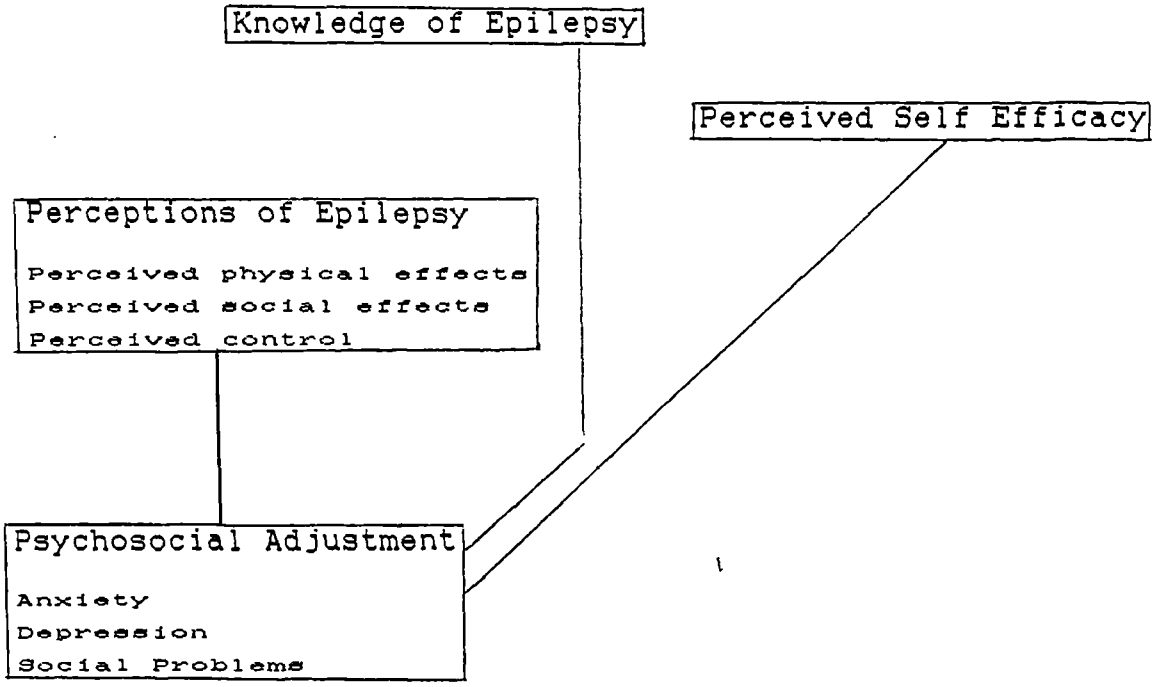
(4) Epilepsy knowledge: there was a significant relationship between duration of epilepsy and medical knowledge. No other significantly related epilepsy variables were uncovered by this analysis. The variable with by far the strongest relationship with knowledge was verbal I.Q. (see Table 15).

(4) Perceived efficacy: No significant findings were uncovered between epilepsy related variables and efficacy. However there were moderate trends suggesting that individuals with less complex epilepsy (low seizure frequency, monotherapy) possessed greater efficacy beliefs. Efficacy was positively correlated with age, verbal I.Q. and age at onset (see Table 15).

In summary, of all predictor variables, clearly verbal intelligence was most strongly related to positive perceptions of epilepsy. Results also consistently highlight that negative perceptions were related to longer duration of epilepsy and diagnosis at an early age (see Table 15).

4-Knowledge, Self Efficacy and Perception of Epilepsy: Assessment of Association With Psychosocial Functioning

Figure 4- Areas of Hypothetical Model Under Examination



Once again, as a first stage of assessment of association between measures, a series of parametric correlations (Pearsons Product Moment Correlation) was conducted on continuous data. As it was noted that the distribution of scores on the B.D.I. was skewed, it was decided that a non parametric correlation test was most appropriate (Spearman Rank Correlation Coefficient) (see Table 17).

For comparison of nominal data a series of crosstabulations was performed. Statistical significance was assessed by means of the Chi-Square test. For comparison of association between nominal and continuous data, the latter was once again split into "high" and "low" groups at the mean, or in the case of the B.D.I., the median (see Table 17).

Table 17- Assessment of Association of Perception of Epilepsy With Psychosocial Functioning: Correlation Coefficients and Chi Square Results

S.T.A.I.[1] (State)	-0.142 (p=.073)	-0.0174 (p=.429)	-0.469*** (p=.000)	+0.146 (p=.442)	-0.508*** (p=.000)
S.T.A.I.[1] (Trait)	-0.013 (p=.448)	-0.018 (p=.426)	-0.638*** (p=000)	+0.0518 (p=.304)	-0.494*** (p=.000)
B.D.I[2]	-0.112 (p=.126)	+0.032 (p=.371)	-0.523*** (p=.000)	+0.073 (p=.233)	-0.616*** (p=.000)

	E.K.P.-G (Medical)	E.K.P.-G (Social)	S.Eff	H.L.O.C.	A.D.
S.T.A.I.[1] (State)	+0.390*** (p=.000)	+0.401*** (p=.000)	-0.226** (p=.010)	33 32 31 13 C.S.=3.09 (p=.54)	41 28 27 12 C.S.=1.57 (p=.81)
S.T.A.I.[1] (Trait)	+0.438*** (p=.000)	+0.415*** (p=.000)	-0.026 (p=.395)	37 27 33 10 C.S.=4.34 (p=.36)	37 31 31 09 C.S.=4.27 (p=.37)
B.D.I.[2]	+0.404*** (p=.000)	+0.308*** (p=.001)	+0.067 (p=.247)	30 32 19 24 C.S.=1.71 (p=.78)	31 35 20 20 C.S.=1.24 (p=.87)

	Stigma Scale	Fear Scale	E.K.P.-P (Medical)	Awareness of seizure precipitants (yes/no)	Ability to prevent or stop seizures (yes/no)

*** - p< 0.005

** - p< 0.01

* - p< 0.05

(1-Pearson Correlation; 2-Spearman Correlation; E.K.P.-G. -Epilepsy Knowledge Profile (General); S.Eff.-Self Efficacy Scale; H.L.O.C.-Health Locus of Control; A.D.- Acceptance of Disability Scale; S.T.A.I. (State)- State anxiety; S.T.A.I. (Trait)- Trait Anxiety; B.D.I.- Beck Depression Inventory; E.K.P.-P (Medical)-Total score, medical knowledge of own condition; C.S.-Chi Square)

Table 18- Assessment of Association Between Perception of Epilepsy, Knowledge and Self Efficacy With the Social Problems Questionnaire: Chi Square Results

	Housing Problems (yes/no)	Work Problem 1 (yes/no)	Work Problem 2 (yes/no)	Financial Problems (yes/no)
E.K.P.G (Soc)	C.S.=0.00 (p=.993)	C.S.=0.00 (p=.961)	* 18 09 07 14 C.S.=5.26 (p=.022)	C.S.=2.10 (p=.147)
E.K.P.G (Med.)	C.S.=1.25 (p=.263)	C.S.=1.41 (p.=235)	C.S.=1.52 (p=.217)	C.S.=0.24 (p=.621)
E.K.P.P (Med.)	C.S.=0.89 (p=.340)	C.S.=2.06 (p=.150)	* 20 11 06 14 C.S.=4,87 (p=.027)	C.S.=0.36 (p=.550)
S.Eff.	C.S.=N/A (p=N/A)	C.S.=N/A (p=N/A)	C.S.=1.02 (p=.311)	C.S.=N/A (p=N/A)
Behav. Cont.1	C.S.=0.77 (p=.378)	C.S.=0.23 (p=.628)	C.S.=0.12 (p=.723)	C.S.=0.02 (p=.887)
Behav. Cont.2	C.S.=2.16 (p=.141)	C.S.=2.06 (p=.150)	C.S.=0.57 (p=.449)	C.S.=1.05 (p=.306)
H.L. O.C.	C.S.=N/A (p=N/A)	C.S.=0.95 (p=.331)	C.S.=2.10 (p=.147)	C.S.=0.28 (p=.592)
A.D.	C.S.=1.55 (p=.213)	C.S.=0.51 (p=.473)	C.S.=0.38 (p=.563)	31 49 * 14 06 C.S.=5.11 (p=.024)
Fear Scale	C.S.=1.91 (p=.166)	C.S.=0.01 (p=.923)	C.S.=0.09 (p=.767)	C.S.=0.46 (p=.497)
Stigma	C.S.= N/A (p=N/A)	C.S.=2.10 (p=.147)	C.S.=1.62 (p=.203)	C.S.=0.50 (p=.048)

*** - p< 0.005
** - p< 0.01
* - p< 0.05

N/A- Not Applicable as cells with expected frequency< 5 were greater than 20%

(C.S.-Chi Square; Housing problems- Satisfaction with present accommodation; Work problem 1- Satisfaction with present job; Work problem 2- For those not working, satisfaction with this situation; Financial Problems- satisfaction with current financial position; E.K.P.G (Soc)- E.K.P.- General (Social); E.K.P.G (Med.)- E.K.P.-General (Medical); E.K.P.P (Med.)- E.K.P.-P (Total score, medical knowledge of own condition; S.Eff.- Self Efficacy; Behav. Cont.1- Awareness of seizure precipitants; Behav. Cont.2- Perceived ability to control seizures; H.L.O.C.- Health Locus of Control; A.D. Scale- Acceptance of Disability Scale)

(Contd. overleaf)

(Table 18 contd.)

E.K.P.G (Soc.)	C.S.=3.22 (p=.073)	C.S.=1.00 (p=.315)	C.S.=2.36 (p=.124)
E.K.P.G (Med.)	C.S.=3.22 (p=.073)	C.S.=0.31 (p=.578)	C.S.=0.35 (p=.553)
E.K.P.P (Med.)	C.S.=1.18 (p=.673)	C.S.=2.51 (p=.113)	C.S.=0.02 (p=.991)
S.Eff.	*** 41 47 / 14 01 C.S.=9.45 (p=.002)	*** 34 13 / 21 35 C.S.=11.10 (p=.001)	C.S.=0.13 (p=.715)
Behav. Cont.1	C.S.=0.39 (p=.531)	C.S.=1.86 (p=.405)	C.S.=0.00 (p=.928)
Behav. Cont.2	C.S.=0.90 (p=.342)	C.S.=1.99 (p=.368)	C.S.=1.80 (p=.179)
H.L. O.C.	C.S.=0.04 (p=.840)	C.S.=0.04 (p=.848)	C.S.=N/A (p=N/A)
A.D.	*** 35 55 / 12 02 C.S.=10.72 (p=.001)	C.S.=N/A (p=N/A)	C.S.=0.16 (p=.684)
Fear Scale	C.S.=1.49 (p=.221)	C.S.=0.17 (p=.677)	C.S.=1.16 (p=.691)
Stigma Scale	* 46 42 / 02 12 C.S.=5.55 (p=.018)	* 17 31 / 3 1 23 C.S.=4.08 (p=.043)	C.S.=1.70 (p=.191)
	Social Problem 1	Social Problem 2	Misc. Other Problems

*** - p< 0.005
** - p< 0.01
* - p< 0.05

N/A- Not Applicable as cells with expected frequency< 5 were greater than 20%

(C.S.-Chi Square; Social Problem 1-Satisfaction with time out; Social Problem 2- Number of friends (none, a few or many); Misc. Other Problems- Any other social problems; E.K.P.G (Soc)- E.K.P.- General (Social); E.K.P.G (Med.)- E.K.P.-General (Medical); E.K.P.P (Med.)- E.K.P.-P (Total score, medical knowledge of own condition; S.Eff.- Self Efficacy; Behav. Cont.1- Awareness of seizure precipitants; Behav. Cont.2- Perceived ability to control seizures; H.L.O.C.- Health Locus of Control; A.D. Scale- Acceptance of Disability Scale)

1- Perception of Epilepsy and Psychopathology

(1) Perceived Control: It was hypothesised that perceived control would be inversely related to psychosocial functioning. However, as can be seen from Table 17, no significant relationship between health locus of control and any measure of psychopathology was present. Also, H.L.O.C. scores and items from the Social Problems Questionnaire failed to reveal any notable trends (See Table 18). Perceived control over seizures, also did not appear related to any of the measures of psychopathology or social problems (see Tables 17,18).

(2) Perceived Social Effects: Both acceptance and stigma are correlated to all three measures of psychopathology in the direction predicted by the hypotheses; low stigma and high acceptance appear related to low psychopathology. There was also evidence of a relationship between stigma and acceptance and responses to the Social Problems Questionnaire. For instance stigma was significantly related to satisfaction with the amount of time subjects were able to get out and the number of friends subjects had while acceptance appeared positively related to satisfaction with finances and social time (see Table 18).

(3) Perceived Physical Effects: As was hypothesised, results suggest a strong and significant positive relationship between fear of seizures and psychopathology. No noteworthy trends were observed between the perceived physical effects of epilepsy and social problems (see Tables 17 and 18).

2- Knowledge of Epilepsy and Psychosocial Functioning

It was hypothesised that knowledge would have a significant inverse relationship with psychosocial functioning. However no direct relationship was evident between anxiety and depression, and general measures of knowledge. although specific medical knowledge of own condition was significantly inversely correlated with state anxiety. Significant relationships were found between measures of knowledge and social problems; general social knowledge and specific medical knowledge were significantly related to dissatisfaction with unemployment (see Tables 17 and 18).

3-Self Efficacy and Psychosocial Problems

Results indicate a strong and significant negative correlation between self efficacy and measures of psychopathology. There were also significant areas of association between efficacy and the Social Problems Questionnaire. For example, low efficacy appeared related to greater dissatisfaction with social contacts and number of friends (see Tables 17, 18).

As a second stage of analysis, for each measure of psychopathology, examination was made of the effect of each measure of perception, controlling for the effects of all other measures through a series of multiple regression analyses.

5-Regression Analysis: Perception of Epilepsy, Self Efficacy and Epilepsy Knowledge With Psychopathology

Analysis was was made of the relative significance of measures of all stages in the hypothetical patient

perception model (perceptions of social and physical consequences of condition, perceived control, epilepsy knowledge, perceived efficacy) with measures of psychopathology (see Fig. 4).

A series of stepwise multiple regressions was conducted consecutively on each measure of psychopathology; namely state and trait anxiety and depression, with all measures of patient perceptions (see Fig.5). Each measure of psychopathology was entered as the dependent variable. Measures of perception were entered as independent variables.

1-Regression Analysis: Perception of Epilepsy, Self Efficacy and Epilepsy Knowledge With Psychopathology

Figure 5- Areas of the Hypothetical Model Under Consideration

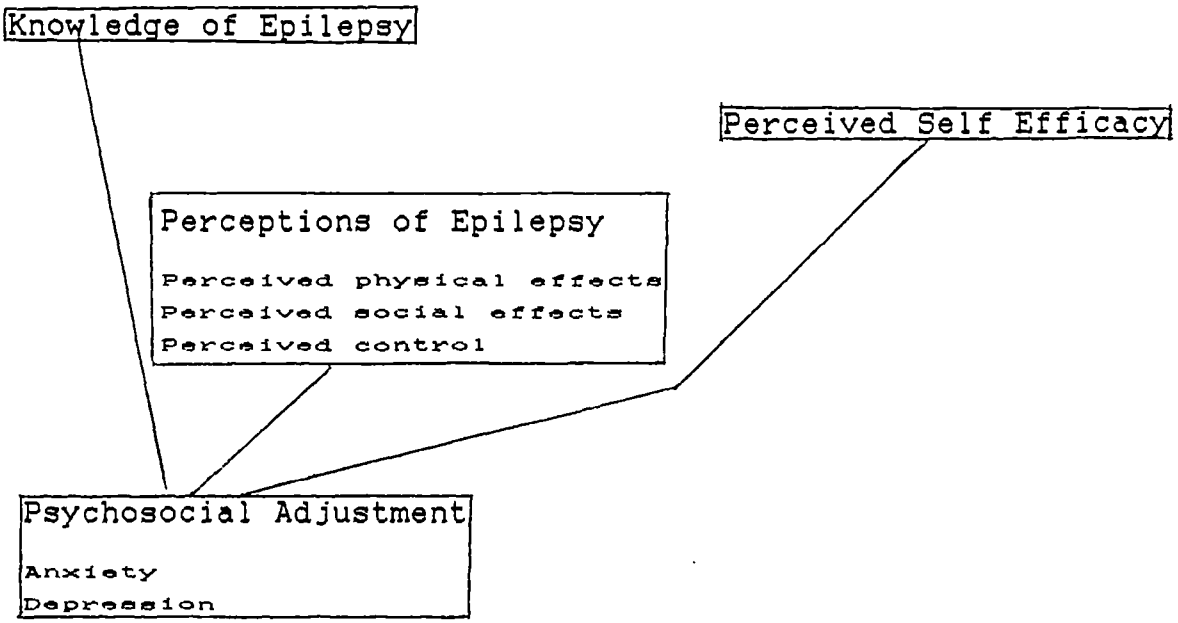


Table 19- Significant Multiple Regression Coefficients: Perceptions of Epilepsy, Self Efficacy and Epilepsy Knowledge With Psychopathology

	Significant Variables	Standardised Regression Coefficient (Beta)	Level of Significance
S.T.A.I. (State) Multiple R=0.639 Adj. R Squared=0.386 F=18.65 Sig. F=0.000	Acceptance of Disability	-0.396	.0000
	Self Efficacy	-0.341	.0003
	E.K.P.-P (Medical)	-0.181	.0416
S.T.A.I. (Trait) Multiple R=0.718 Adj. R Squared=0.497 F=28.04 Sig. F=0.000	Self Efficacy	-0.476	.0000
	Acceptance of Disability	-0.397	.0000
	Awareness of seizure preciptants	+0.169	.0347
B.D.I. Multiple R=0.718 Adj. R Squared=0.504 F=43.68 Sig. F=0.000	Acceptance of Disability	-0.559	.0000
	Self Efficacy	-0.314	.0002

(Multiple R-Correlation between dependent variable and all significant independent variables; Adj. R Squared-Proportion of variance in the dependent variable associated with variance in the significant independent variables (Adjusted for number of cases); Sig. F- Statistical significance of the regression model)

The above results indicate that measures comprising the "perception of Epilepsy" model predict a strong and statistically significant proportion of variance of psychopathology scores. Table 19 also indicates that by far the most significant variables in this model are acceptance of condition and perceived self efficacy. These are most influenced by verbal intelligence, seizure type, duration of epilepsy, age at onset and age at time of completion (see

Table 15).

It is also of interest to note that a measure of perceived control (awareness of seizure precipitants) was once again related to increased psychopathology (see Table 19).

6- "Underadaptive" Perceptions of Epilepsy

While results provide supportive evidence for the main hypotheses concerning "adaptive" and "maladaptive" perceptions, there was little supportive evidence for the supplementary hypotheses concerning "underadaptive" perceptions of epilepsy: It was suggested in chapter 5 that a key feature of this model was that extreme low epilepsy knowledge and perceived self efficacy would result in unrealistic and passive perceptions of epilepsy. However, analysis of a series of scatterplots of measures of knowledge and efficacy, with measures of perception failed to reveal any distinctive trends in this direction. Also, detailed anaysis was made of the profiles of the lowest scoring 10% of subjects on scales of general knowledge and efficacy. However, once again, this failed to reveal any distinctive trend (see Table 20 for summary results).

Table 20- "Underadaptive" Perceptions of Epilepsy: Summary Profile of the Lowest Scoring Subjects (Bottom 10%) on Epilepsy Knowledge and Self Efficacy Scales

	E.K.P.-G (Medical)	E.K.P.-G (Social)	Self Efficacy Scale	Total Sample
Health Locus of Control	M=40 R=28-54	M=40 R=32-58	M=38 R=32-63	Mn=40 R=28-63
Acceptance of Disability	M=224 R=117-270	M=227 R=137-283	M=182 R=157-283	Mn=223 R=117-289
Perceived Stigma	M=18 R=10-24	M=18 R=7-28	M=19 R=7-25	Mn=17 R=6-32
Fear of Seizures	M=16 R=8-30	M=18 R=2-28	M=15 R=5-30	Mn=15 R=5-31
S.T.A.I. (State)	M=42 R=29-54	M=39 R=24-67	M=44 R=35-64	Mn=39 R=20-69
S.T.A.I. (Trait)	M=44 R=25-64	M=39 R=25-64	M=54 R=40-64	Mn=42 R=21-68
B.D.I.	M=7 R=0-54	M=3.5 R=0-30	M=13 R=3-30	M=6 R=0-31
Verbal I.Q.	M=92 R=77-106	M=89 R=74-105	M=97 R=86-121	Mn=101 R=74-130

(M-Median, Mn- Mean, R-Range)

SUMMARY

(1) In Chapter 5 it was hypothesised that in the present study of 109 subjects with intractable epilepsy, overall levels of anxiety, depression and social problems would be higher than a normal population. However, anxiety and depression were found to be only moderately higher than published norms and social problems were found to be less than a comparable epilepsy population.

(2) It was hypothesised that there would be a significant relationship between measures of the perceived social and physical effects of epilepsy and perceived control of

epilepsy. Results provided significant support for this hypothesis.

(3) It was hypothesised that increased knowledge and self efficacy would be positively related to increased perceptions of control over epilepsy and reduced perceived social and physical effects of epilepsy. Results produced significant supportive evidence for this proposition. However, it was recognised that epilepsy knowledge and perceived efficacy had only modest predictive power over measures of perception. Therefore analysis was made of the relationship between a series of social. demographic, intellectual and epilepsy related variables and measures of perception. A number of areas were found to be of significance.

(4) It was hypothesised that anxiety, depression and social problems would be significantly more prevalent in subjects displaying "maladaptive" perceptions than those displaying "adaptive" perceptions. Overall results supported this hypothesis.

(5) Results failed to provide notable supportive evidence for the "underadaptive" model of perception.

Full discussion of these results will be provided in chapter 10. In the following chapter the practical applicability of this model will be assessed through the analysis of a short series of clinical case studies.

CHAPTER 9

STUDY 4

AN ANALYSIS OF PERCEPTIONS OF EPILEPSY AND PSYCHOSOCIAL FUNCTIONING: CASE STUDIES

Page Number

INTRODUCTION

It was hypothesised that measures of perception would vary in a manner consistent with the "perception of epilepsy" model and that such perceptions would relate to psychosocial functioning (see Chapter 5). In the previous chapter, results from a sample of people with intractable epilepsy provided supportive evidence for this model. However, it has already been recognised that a group profile is representative of everyone and no one. Therefore in this chapter, an assessment of the practical applicability of the "perception of epilepsy" model for individuals with epilepsy is made through analysis of a series of case studies.

It was highlighted in chapter 4 that information programmes for people with epilepsy have been found to result in reduced psychopathology and improved medical compliance. Therefore, it was decided an appropriate format for analysis was to provide detailed examination of subjects perceptions of his/her condition before, during and after a brief, intensive epilepsy education programme.

METHODS

Subjects

A total of 5 subjects from the Quarriers cohort were asked if they would be willing to participate. All agreed. While it is not suggested that subjects are totally representative of all people with refractory epilepsy, efforts were made to provide as varied a subject pool as possible.

Measures

Subjects were asked to recomplete measures of self perception used in the previous study (see Table 9, p.133). Psychopathology was assessed as state anxiety and depression using the S.T.A.I. (state)(121) and the B.D.I. (122).

Design

The structure of the study was a series of controlled single subject designs with one reversal phase (ABAB) (126).

Subjects were asked to complete assessment forms on a total of 6 occasions: One baseline measures was obtained from subjects two days prior to the commencement of the group. The duration of the programme was one week. Two treatment measures were obtained. Subjects completed all measures after the first and last group meeting. Measures at the return to baseline were obtained at the middle of the week following the programme. The final set of results were gathered after the single "booster" session during the following week. Comparison was also made between initial baseline assessment (Ass. 2) and subject's results from assessment in the main study (Ass. 3) which were obtained some three months previously (see Chapter 8) (see Table 21).

Table 21- Design of Case Studies

Ass.1	Ass.2	Ass.3 Grp.1	Grp.2	Ass.4 Grp.3	Ass.5	Ass.6 Grp.4
A		B			A	B
Baseline (3 months)		Epilepsy Education group sessions (1 week)			Return to baseline (1 week)	Single "booster" session

(Ass.-Assessment number; Grp.- Group session number)

Groups consisted of three one and a half hour sessions on the Monday, Wednesday and Friday of one week. All subjects attended each group. The structure of each group was informal and subjects were encouraged to contribute their own experiences and raise questions during sessions. Time was set aside at the end of each session for open discussion. The aim of the sessions was firstly, to provide subjects with a general understanding of relevant aspects of epilepsy and secondly, to provide information about the subjects own condition.

Session 1: This consisted of the provision of general information concerning the definition and treatment of epilepsy. Care was taken to ensure that information was provided at a level which would be readily understood by group members. For this reason, existing teaching aids were used whenever possible: Subjects were shown a short instruction video made by the National Society for Epilepsy and provided with factsheets developed by the Epilepsy Association of Scotland.

Session 2: This consisted of a brief resume of the assessment and treatment issues raised in the first session. The main content of the session was concerned with the social and legal ramifications of having epilepsy. Once again, factsheets were provided from the Epilepsy Association of Scotland.

Session 3: This session was devoted to discussion of the extent to which areas covered in the previous two sessions

affected subjects. Areas discussed included potential precautions which could be taken in social, domestic and vocational situations to minimise the impact of subjects' condition, information concerning anti-convulsant medication and subjects' perceived ability to predict or prevent seizures. Subjects appeared to obtain the greatest enjoyment from this session and perhaps appeared to learn more from the experiences of other subjects than from formal teaching materials.

Session 4: This session consisted of a discussion of areas covered in all previous sessions.

RESULTS

Subjects will be considered in turn. For each subject, a brief background history will be provided. Next, analysis will be made of subjects' perceptions of his/her condition and level of psychopathology. Finally a brief discussion will be made of any potential care and treatment implications arising as a result of this analysis.

Case Study 1

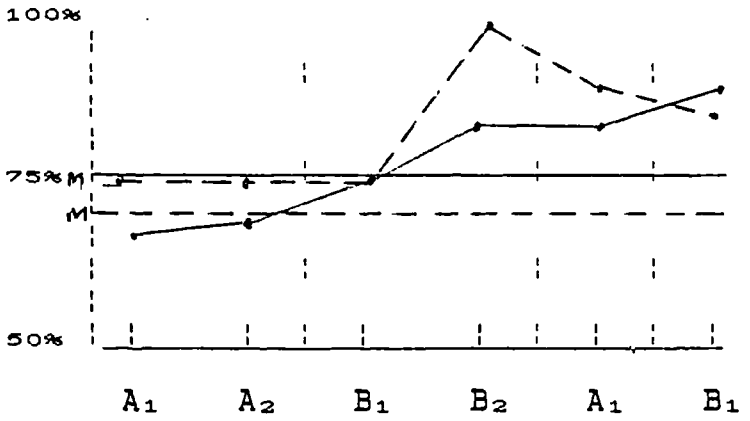
Subject A was forty three year old man whose epilepsy began at age thirteen. Seizures were primary tonic-clonic. Seizure frequency at time of assessment was between 1 and 2 seizures per month.

The subject attended normal schooling. However, on leaving school he has had only limited work experience. At time of admittance to the Epilepsy Centre for medical assessment, Subject A resided in the family home.

Results of psychological assessment produced a full scale WAIS-R score of 108. No areas of significant organic dysfunction were noted.

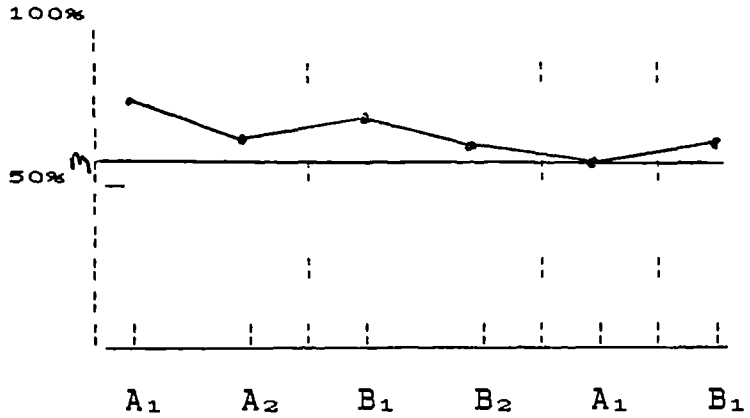
Figure 6- Case Study 1: Results of Assessment of Perception of Epilepsy and Psychopathology

(1) Knowledge of Epilepsy



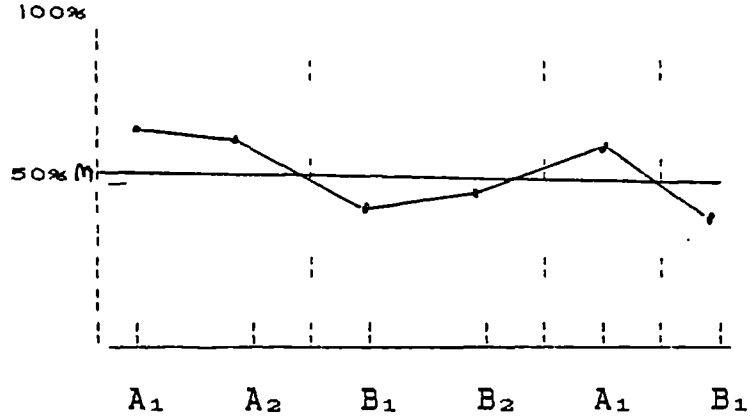
E.K.P.-G (Medical)= ——— M= Mean score of total
E.K.P.-G (Social)= — — — subjects in main study
(N=109)

(2) Perceived Self Efficacy



M=Mean score,total subjects

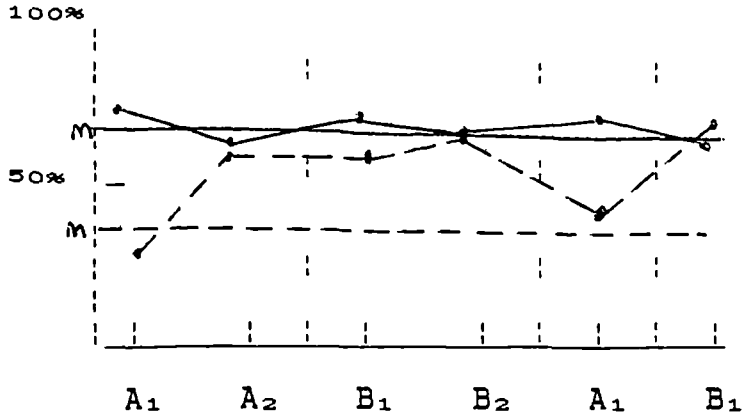
(3) Health Locus of Control



High score=external control, M=Mean score,total subjects

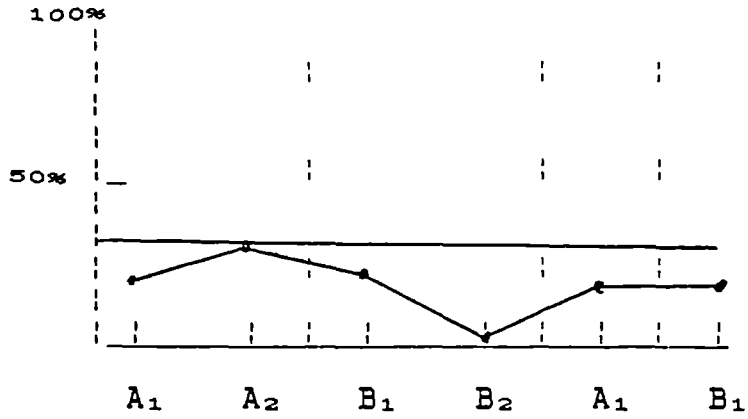
(Fig.6 contd.)

(4) Perceived Social Effects



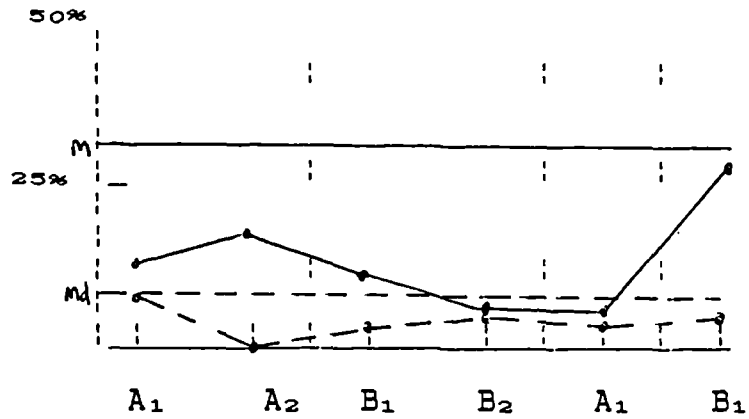
A.D. Scale= ——— M=Mean score,total subjects
Stigma Scale= —·—

(5) Fear of Seizures



M=Mean score,total subjects

(6) State Anxiety and Depression



M=mean score, total subjects, Anx = ———
Md=median score,total subjects Dep. = — —

Table 22- Case Study 1: E.K.P.-P. Results

	A_1	A_2	B_1	B_2	A_1	B_1
Awareness of seizure precipitants.	No	No	No	Yes	No	Yes
Perceived ability to stop seizures.	No	No	No	No	No	No
Knowledge of own seizure type.	Yes	Yes	Yes	Yes	Yes	Yes
Knowledge of E.E.G. assessment.	Yes	Yes	Yes	Yes	Yes	Yes
Knowledge of C.T. assessment.	No	No	No	No	No	No
Any recognisable aura.	No	No	No	No	No	No
Any awareness during a seizure.	No	No	No	No	No	No
Incurred injury or been at risk due to a seizure.	Yes	Yes	Yes	Yes	Yes	Yes
Job loss due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Desirable jobs unable to do due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Activities/hobbies unable to do due to epilepsy.	No	No	No	No	No	No
Precautions taken in home due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Precautions taken outwith home due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Happy with current knowledge of condition.	No	No	No	No	No	No

In line with the hypothetical model of patient perceptions, Subject A's initial profile indicated a broadly "adaptive" perception of his condition: As compared to means of the

total 109 subjects in the main assessment group, the subject had average knowledge of his epilepsy and good awareness of aspects of his own condition, slightly higher acceptance and slightly lower perceived control. The subject did not indicate any perceived behavioural control over his condition. However, as the subject's seizures are primary generalised, this is perhaps not surprising. There was no evidence of significant psychopathology (see Fig.6 and Table 22).

The subject's profile immediately prior to the group treatment phase had become moderately more maladaptive: Perceived efficacy and acceptance declined while perceived stigma and fear increased. This was accompanied by a moderate increase in anxiety (see Fig.6 and Table 22).

During the group treatment phase, as was expected general knowledge of epilepsy increased. It can also be seen that following the final group session, the subject indicated an awareness of potential seizure precipitants which he had previously been unaware of (during sleep and following strenuous work).

The most notable effects of group sessions on perceptions of his condition concerned perceived control over health which became markedly more internal. Also, fear of seizures was reduced. However, stigma remained high and in fact moderately increased during the treatment phase. Results from the reversal phase reinforced the effect of group treatment on these areas (see Table 22).

Discussion

Given the background information concerning Subject A, it is suggested that he possessed an acceptable "adaptive" perception of his condition with no areas of major concern. The overall effects of group treatment did not result in major changes; perceived control was more internal, the subject was made aware of potential seizure precipitants and fear of seizures was marginally reduced. However, this appeared to be at the cost of slightly higher perceived stigma and anxiety.

In conclusion, it is suggested that Subject A appeared to have both adequate knowledge and cognitive resources to cope with not only the medical treatment aspects of his condition, but also the social implications of his epilepsy.

Case Study 2

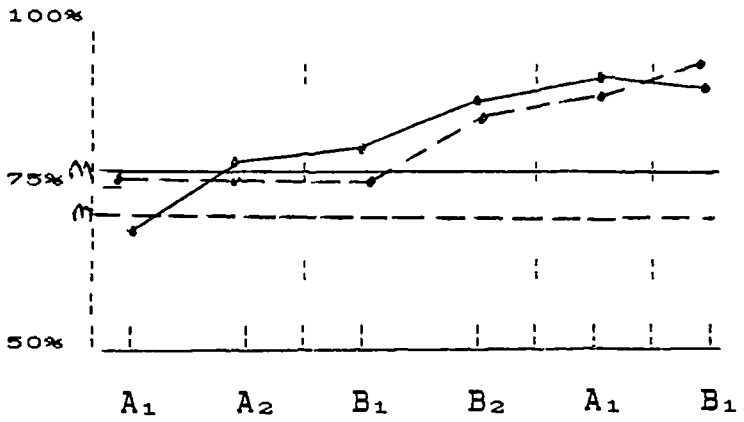
Subject B was an eighteen year old woman who has had epilepsy since the age of three. Seizures were generalised absence and tonic-clonic. At time of assessment, seizure frequency was less than 1 per month.

Subject B attended mainstream schooling, where she attained six standard grades and one "O" grade. However, she has been reported as having great difficulties making friends and has frequently been described as disruptive and socially immature. This has resulted in previous involvement of paediatric and psychological services.

The subject has also been reported as suffering from low self esteem and depression. It has also been noted that her parents have had major difficulty accepting the diagnosis of epilepsy and that family relationships have been severely strained for some considerable time.

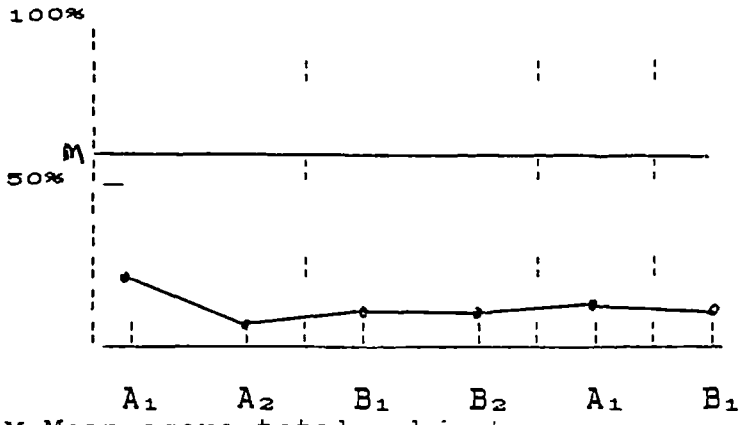
Figure 7- Case Study 2: Results of Assessment of Perception of Epilepsy and Psychopathology

(1) Knowledge of Epilepsy



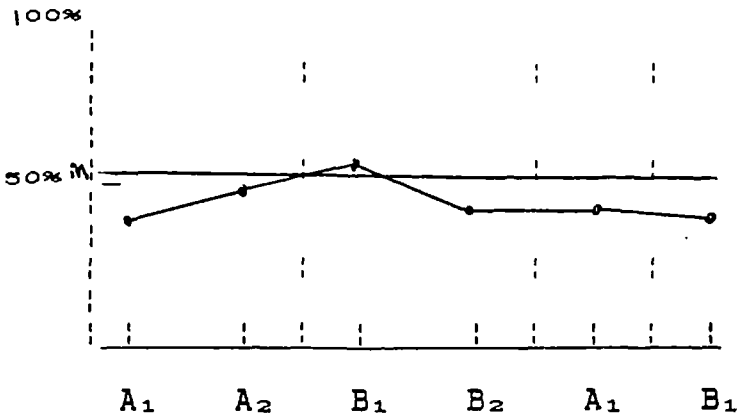
E.K.P.-G (Medical)= ———— M= Mean score of total
E.K.P.-G (Social)= — — — subjects in main study
(N=109)

(2) Perceived Self Efficacy



M=Mean score,total subjects

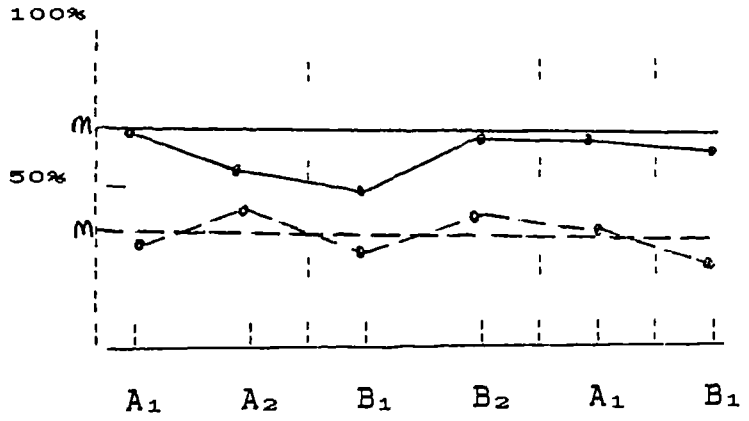
(3) Health Locus of Control



High score=external control, M=Mean score,total subjects

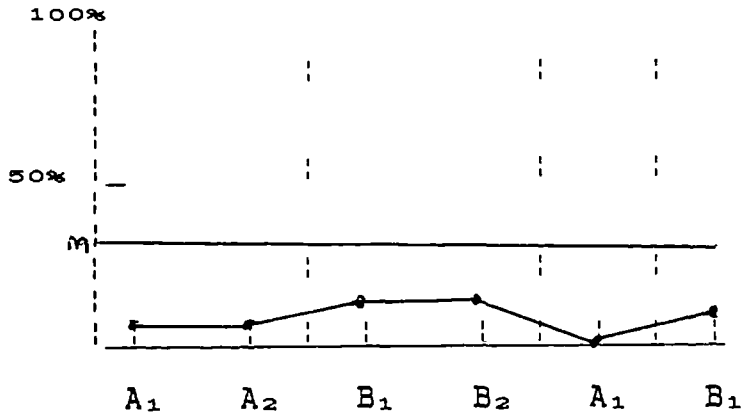
(Fig.7 contd.)

(4) Perceived Social Effects



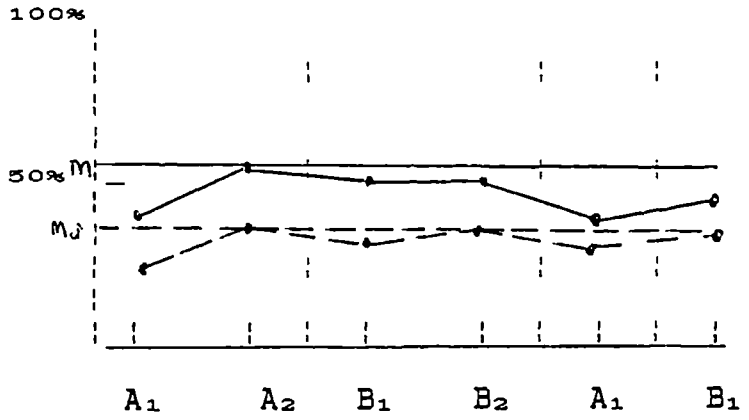
A.D. Scale= ——— M=Mean score,total subjects
Stigma Scale= — — —

(5) Fear of Seizures



M=Mean score,total subjects

(6) State Anxiety and Depression



M=Mean score,total subjects, Md=Median score,total subjects
Anx = ——— Dep. = — —

Table 23- Case Study 2: E.K.P.-P. Results

	A_1	A_2	B_1	B_2	A_1	B_1
Awareness of seizure precipitants.	No	No	No	No	No	No
Perceived ability to stop seizures.	No	No	No	No	No	No
Knowledge of own seizure type.	No	No	No	No	No	No
Knowledge of E.E.G. assessment.	Yes	No	No	No	No	No
Knowledge of C.T. assessment.	No	No	No	No	Yes	Yes
Any recognisable aura.	No	No	No	No	No	No
Any awareness during a seizure.	No	No	No	No	No	No
Incurred injury or been at risk due to a seizure.	Yes	Yes	Yes	Yes	Yes	Yes
Job loss due to epilepsy.	No	No	No	No	No	No
Desirable jobs unable to do due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Activities/hobbies unable to do due to epilepsy.	No	Yes	Yes	Yes	Yes	Yes
Precautions taken in home due to epilepsy.	No	No	No	No	No	No
Precautions taken outwith home due to epilepsy.	No	No	No	No	No	No
Happy with current knowledge of condition.	Yes	Yes	Yes	Yes	Yes	Yes

Initial assessment produced a profile of perceptions of epilepsy broadly consistent with "adaptive" perceptions of

epilepsy: Knowledge of condition, health locus of control, acceptance of condition, and perceived stigma were within the average range and fear of seizures was low. However, perceived self efficacy was extremely low and levels of anxiety and depression were significantly high. By the second baseline assessment, the subject's perceptions of her condition had become notably more maladaptive, with the exception of fear of seizures which remained stable (possibly as the subject had not had a seizure in the interim period).

During the treatment phase, as expected, knowledge increased. However perceived efficacy remained consistently low. Overall, the group knowledge programme had a marginally positive effect on perceptions and psychopathology. However, while measures of perception of condition remained within the average range, perceived self efficacy and psychopathology remained areas of concern.

Discussion

The above results suggest that while the group knowledge programme had a moderately positive effect on Subject B's perceptions of her condition, this did little to ameliorate high levels of anxiety and depression.

Given the subject's background and the stable condition of her epilepsy at time of assessment, it is appears evident that her problems were not directly related to current perceptions of her condition. There were, however, suggestions of overprotection and possibly rejection due to

epilepsy over a prolonged period through her childhood. For example, the subject indicated that she had been prevented from participating in all sports as a child. This clearly may have an inhibitory effect on the development of efficacy beliefs and therefore may have contributed to social anxiety and possibly the development of learned helplessness (see Chapter 3).

While such speculations must remain somewhat tentative given the limited contact made with the subject, it is suggested that while a project designed to influence perceptions of condition may have some effect on how the individual perceived epilepsy, there is considerably less likelihood of it having a significant influence on a long term learning experience of anxiety and depression.

Clearly, any future interventions bases at behavioural control of seizures would be inappropriate as the medical components of epilepsy did not appear to be the major problem for this subject. Also, there appears little benefit in pursuing further the subject's perceptions of her condition. Rather, it is suggested that a treatment programme specifically for psychopathology, such as cognitive-behaviour therapy may be of benefit.

Case Study 3

Subject C was a forty four year old man who had epilepsy since birth. Seizures were complex partial with occasional secondary generalisation. Seizure frequency at time of assessment was on average between 1 and 2 per day.

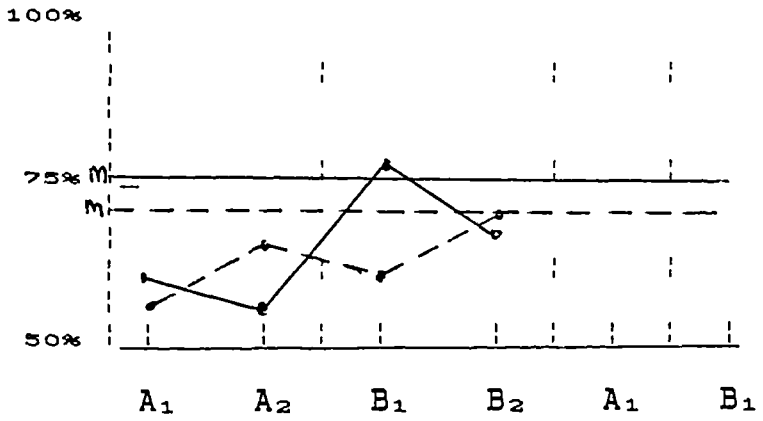
Subject C had been resident in the epilepsy centre for nine years. He had also previously lived for some time in another epilepsy centre in England. He was admitted to the centre as his elderly parents were finding it increasingly difficult to manage his epilepsy.

Psychological assessment approximately a year before the current assessment provided a WAIS-R full scale I.Q. score of 80.

Subject C had a relatively high degree of independence: He was self medicating and able to cook, shop and travel by himself and has attended a number of employment training courses.

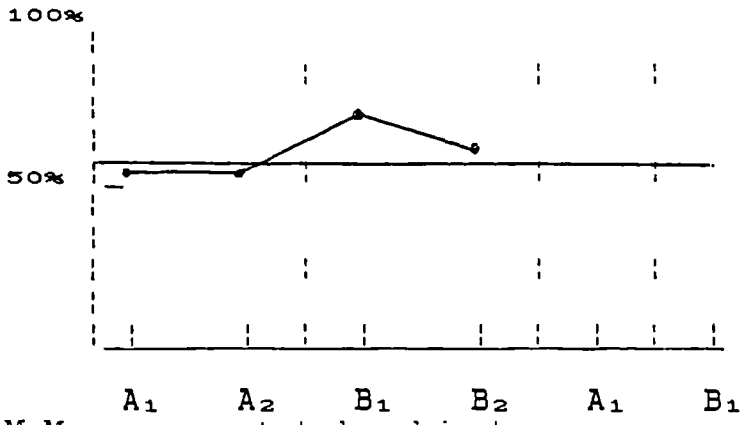
Figure 8- Case Study 3: Results of Assessment of Perception of Epilepsy and Psychopathology

(1) Knowledge of Epilepsy



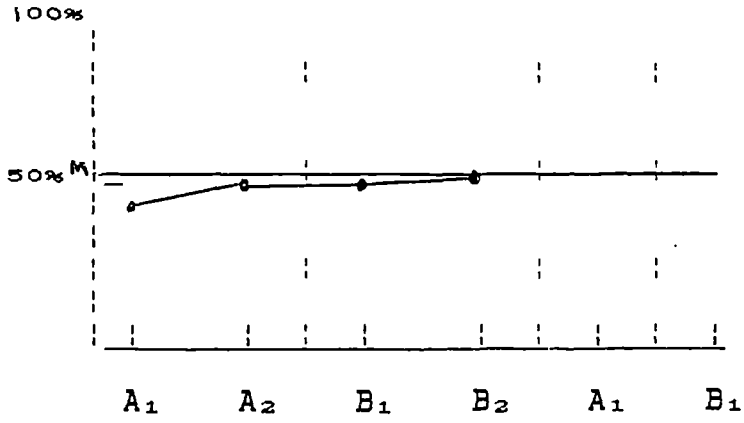
E.K.P.-G (Medical)= ——— M= Mean score of total
E.K.P.-G (Social)= — — subjects in main study
(N=109)

(2) Perceived Self Efficacy



M=Mean score,total subjects

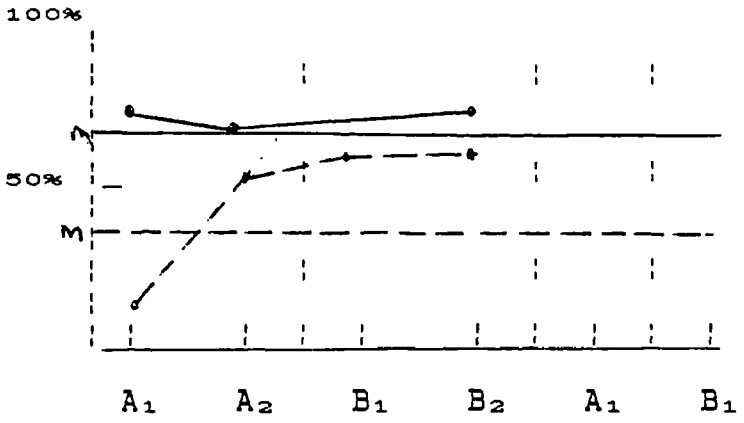
(3) Health Locus of Control



High score=external control, M=Mean score,total subjects

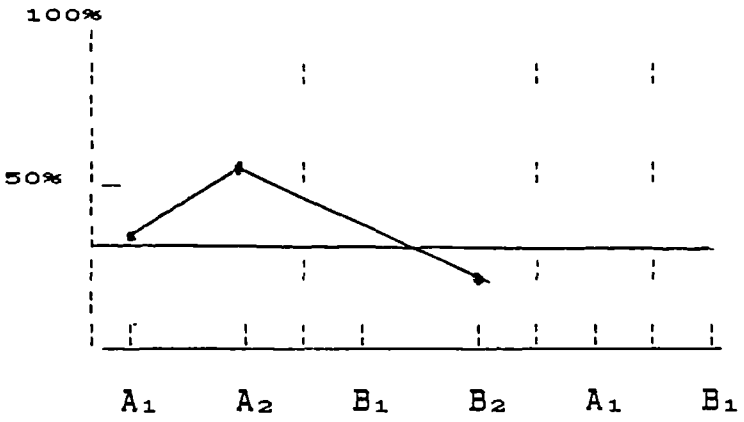
(Fig.8 contd.)

(4) Perceived Social Effects



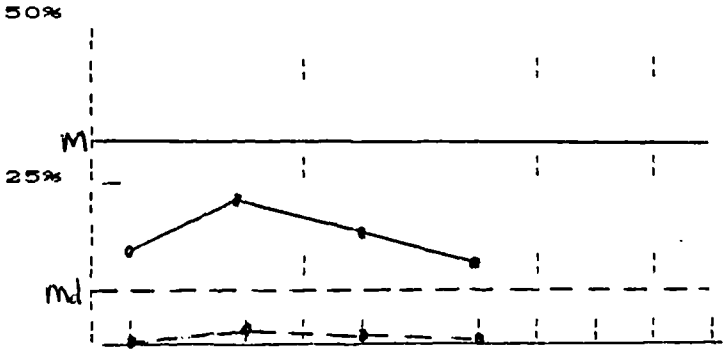
A.D. Scale= —— M=Mean score,total subjects
Stigma Scale= — —

(5) Fear of Seizures



M=Mean score,total subjects

(6) State Anxiety and Depression



M=Mean score,total subjects Anx = ——
Md=Median scores total subjects Dep. = — — —

Table 24- Case Study 3: E.K.P.-P. Results

	A_1	A_2	B_1	B_2	A_1	B_1
Awareness of seizure precipitants.	No	No	No	Yes	-	-
Perceived ability to stop seizures.	No	No	No	Yes	-	-
Knowledge of own seizure type.	Yes	Yes	Yes	Yes	-	-
Knowledge of E.E.G. assessment.	No	No	No	No	-	-
Knowledge of C.T. assessment.	No	No	No	No	-	-
Any recognisable aura.	No	No	No	Yes	-	-
Any awareness during a seizure.	Yes	No	Yes	Yes	-	-
Incurred injury or been at risk due to a seizure.	Yes	Yes	Yes	Yes	-	-
Job loss due to epilepsy.	Yes	Yes	Yes	Yes	-	-
Desirable jobs unable to do due to epilepsy.	No	No	No	No	-	-
Activities/hobbies unable to do due to epilepsy.	Yes	No	No	No	-	-
Precautions taken in home due to epilepsy.	Yes	Yes	Yes	Yes	-	-
Precautions taken outwith home due to epilepsy.	Yes	Yes	Yes	Yes	-	-
Happy with current knowledge of condition.	No	No	No	No	-	-

As can be seen from Figure 8 and Table 24, unfortunately Subject C failed to complete the final two sets of questionnaires. Therefore, analysis of data is limited to an

A-B design.

Initial assessment indicated a series of broadly adaptive perceptions: The subject had a comparatively poor general knowledge of epilepsy. However he did have an adequate level of awareness concerning his condition. Fear of seizures was moderately high. However, given the subject's high seizure frequency, this was of little surprise. At the second baseline assessment, the subjects perceptions had changed slightly for the worse, most notably with regards to stigma and fear of seizures. This was perhaps due in part to greater moves towards independent living made in the interim period. Also, the subject suffered a minor head injury as a result of a seizure shortly before completing the questionnaires (see Table 24 and Fig. 8).

The overall effect of the group was extremely positive: Knowledge and efficacy both improved. While general control remained fairly static, as a result of discussions in the final session, the subject found that he was able to predict and in certain situations control seizures. As a consequence, subjects fear of seizures was considerably reduced. While acceptance increased slightly, perceived stigma remained high, and in fact moderately increased during group sessions.

Discussion

Overall results suggested that the subject obtained considerable benefit from the group sessions: Not only was the subject made aware of potential seizure inhibition techniques, but he also became considerably more aware of

his condition. For instance, responses to the E.K.P.-P indicated greater awareness of potential precautions which could be taken to minimise danger.

While the subject's acceptance of epilepsy score was high, perceived stigma also remained high. It is perhaps worth referring back to chapter 8, where it can be seen that the perceived stigma questionnaire referred to the perceived behaviour and attitudes of others and the ability to change others minds, while the acceptance scale referred to the extent to which individuals see themselves as different and less worthy as a result of having epilepsy. Given the subject's high seizure frequency, it is perhaps a realistic appraisal that he is treated differently by others. However, the high acceptance score is an encouraging indication that the subject's self image remains positive.

In conclusion. as significant progress appeared to have been made during this group and given the limited effect of anti-convulsants and as surgery has already been ruled out as an option, it is suggested that further knowledge and self control methods may prove to be an extremely useful intervention for this man. However, as an experiment, this case is limited due to the design being incomplete.

Case Study 4

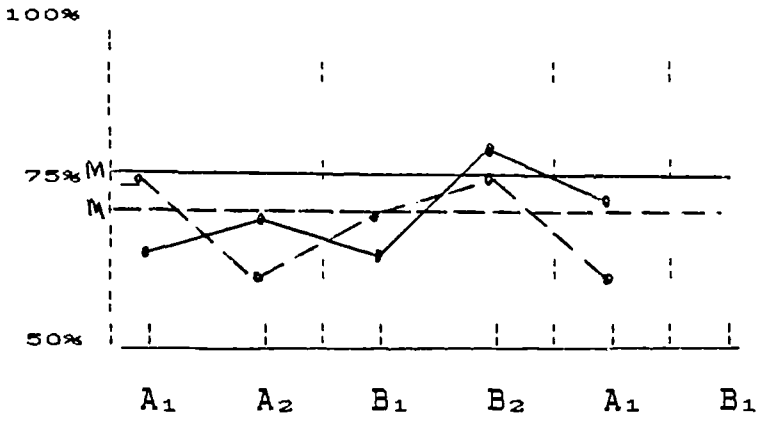
Subject D was a fifty one year old woman whose epilepsy began at age three following a head injury. Seizures were complex partial with occasional secondary generalisation. At time of assessment, seizure frequency was, on average, greater than one seizure per day.

Subject D attended normal schooling and worked as a clerk for a short period in a family business. However, following a significant increase in her seizures she was forced to give up work. Her husband was also forced to give up work to look after his wife. This was reported as having put a considerable strain on her marriage. The subject was prone to bouts of depression and anxiety which appear to have exacerbated seizure frequency. The subject has attended a clinical psychologist for this.

Admission to the epilepsy centre was for medical assessment. An estimate of verbal I.Q. using the Mill Hill Vocabulary Scale produced a score of 86.

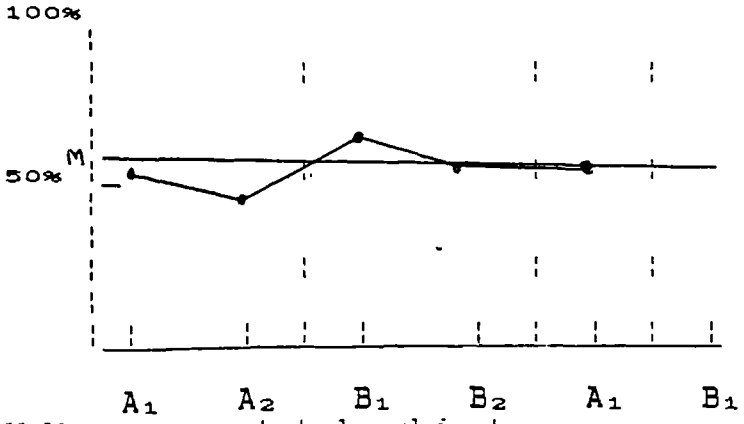
Figure 9- Case Study 4: Results of Assessment of Perception of Epilepsy and Psychopathology

(1) Knowledge of Epilepsy



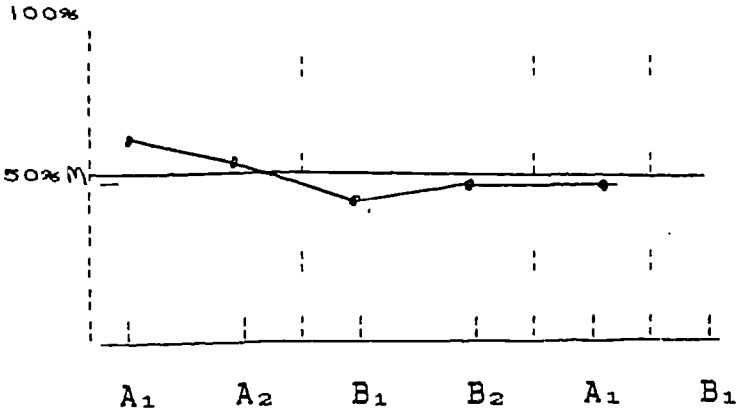
E.K.P.-G (Medical)= ———— M= Mean score of total
E.K.P.-G (Social)= — — — subjects in main study
(N=109)

(2) Perceived Self Efficacy



M=Mean score,total subjects

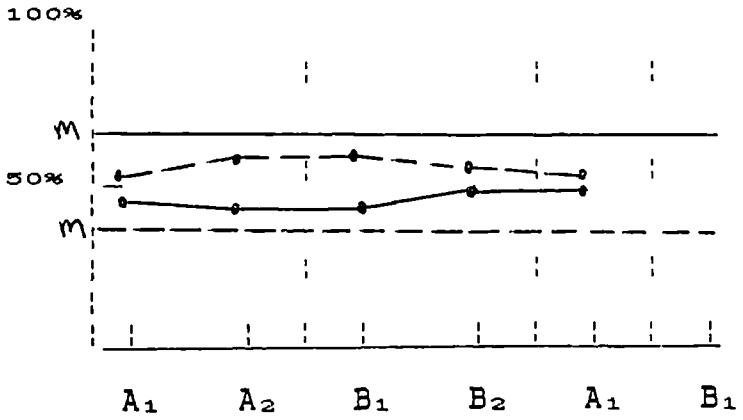
(3) Health Locus of Control



High score=external control, M=Mean score,total subjects

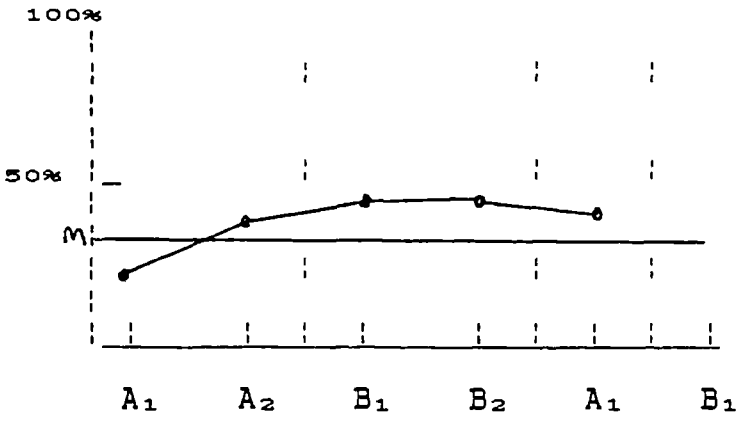
(Fig.9 contd.)

(4) Perceived Social Effects



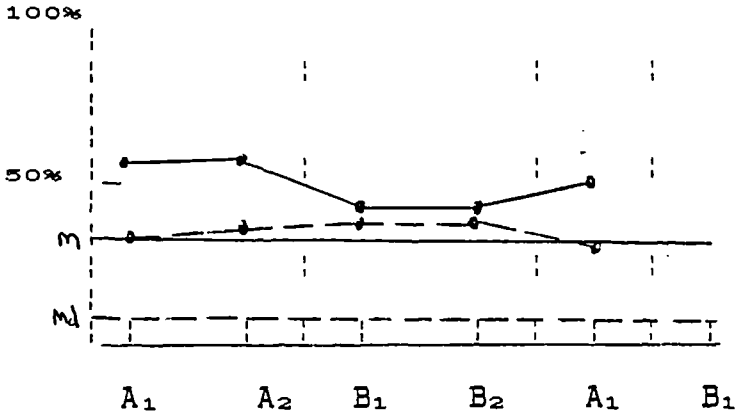
A.D. Scale=——— M=Mean score,total subjects
Stigma Scale=— —

(5) Fear of Seizures



M=Mean score,total subjects

(6) State Anxiety and Depression



M=Mean score,total subjects
Md = Median
Anx.= ———
Dep.= — — —

Table 25 - Case Study 4: E.K.P.-P. Results

	A_1	A_2	B_1	B_2	A_1	B_1
Awareness of seizure precipitants.	No	No	No	Yes	Yes	-
Perceived ability to stop seizures.	No	Yes	Yes	Yes	Yes	-
Knowledge of own seizure type.	No	No	No	No	No	-
Knowledge of E.E.G. assessment.	No	No	No	No	No	-
Knowledge of C.T. assessment.	No	No	No	No	No	-
Any recognisable aura.	Yes	Yes	Yes	Yes	Yes	-
Any awareness during a seizure.	No	No	No	No	No	-
Incurred injury or been at risk due to a seizure.	Yes	Yes	Yes	Yes	Yes	-
Job loss due to epilepsy.	Yes	Yes	Yes	Yes	Yes	-
Desirable jobs unable to do due to epilepsy.	Yes	No	No	No	No	-
Activities/hobbies unable to do due to epilepsy.	Yes	Yes	Yes	Yes	Yes	-
Precautions taken in home due to epilepsy.	Yes	Yes	Yes	Yes	Yes	-
Precautions taken outwith home due to epilepsy.	Yes	Yes	Yes	Yes	Yes	-
Happy with current knowledge of condition.	No	Yes	No	Yes	Yes	-

As can be seen from figure 9 and Table 25, unfortunately, the subject failed to complete the final set of questionnaires. Therefore, results are limited to an ABA

design.

Initial assessment indicated a moderately "maladaptive" set of perceptions which became markedly more maladaptive at the second baseline assessment. The major identified problem area concerned both measures of the perceived social effects of epilepsy. The overall effect of the group was positive with regards to knowledge, efficacy, perceived control over health and behavioural control over seizures. However this was at the cost of a small increase in fear of seizures, perhaps as a consequence of greater awareness of her condition (see Fig.9 and Table 25).

Discussion

The above results indicated that this brief knowledge based programme had a positive effect on the subject's maladaptive perceptions of her condition. A more detailed psycho-educational programme which explored the subjects potential behavioural control over seizures, while also tackling the subject's acceptance and stigma difficulties at a cognitive level may prove to be of considerable benefit.

Once again, it is recognised that interpretation is limited due to the design being incomplete. The subject indicated that the reason she failed to complete the final assessment forms was that she felt her answers would be no different than on previous occasions. However it was strongly suspected that "assessment fatigue" may have taken place!

Case Study 5

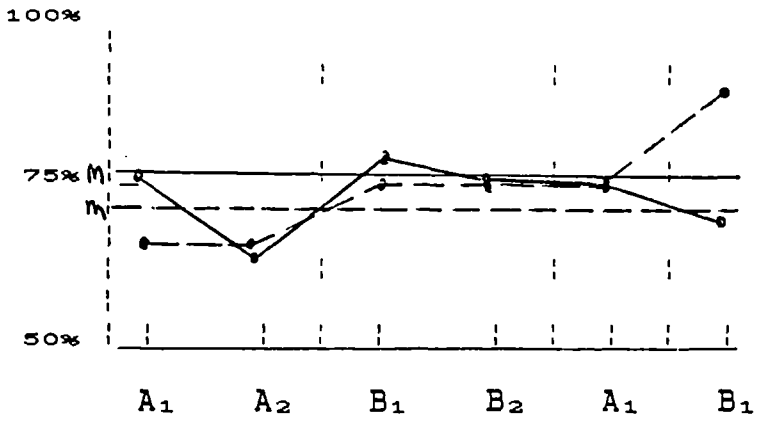
Subject E was a twenty two year old woman who developed epilepsy at the age of thirteen. Seizures were tonic-clonic and appeared to be preceded by myoclonic jerks.

Onset of epilepsy was accompanied by rapid cognitive deterioration which was described as problems with basic conceptualisation, poor motivation and memory and visual planning difficulties. Schooling was erratic and work has been limited to sheltered employment.

Since admission to the epilepsy centre, the subjects medication was considerably reduced and Lamotrigine was introduced to fairly dramatic effect: From a seizure frequency of approximately 1 every 3 to 4 days, the subject had been seizure free for almost 2 months at time of assessment. Also, there was a dramatic improvement in cognitive state: Shortly after admission the subject obtained a WAIS Verbal I.Q. score of 75; at time of assessment an estimation of verbal intellectual functioning using the Mill-Hill Vocabulary Scale Provided a Verbal I.Q. of 104. The subject had become active in a wide range of social activities, was attending college and was preparing for full independent living.

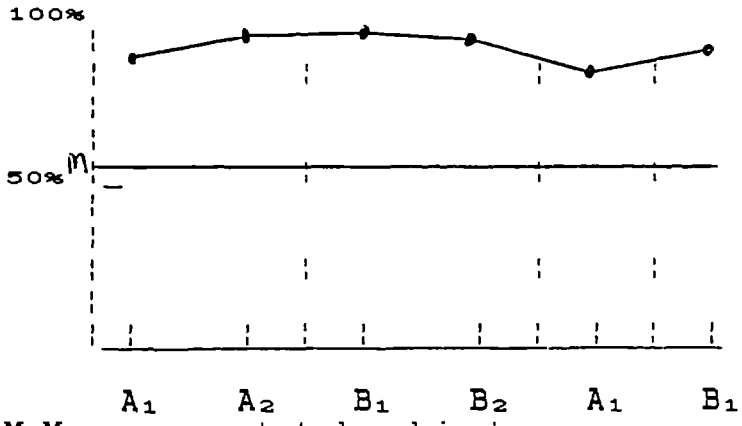
Figure 10- Case Study 5: Results of Assessment of Perception of Epilepsy and Psychopathology

(1) Knowledge of Epilepsy



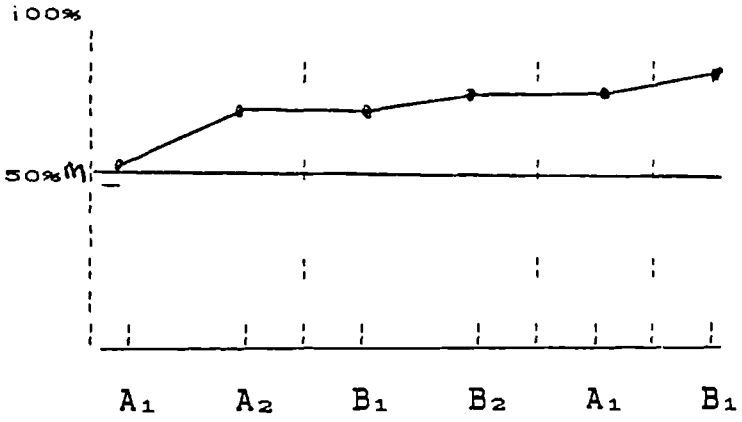
E.K.P.-G (Medical)= ———— M= Mean score of total
E.K.P.-G (Social)= — — — subjects in main study
(N=109)

(2) Perceived Self Efficacy



M=Mean score,total subjects

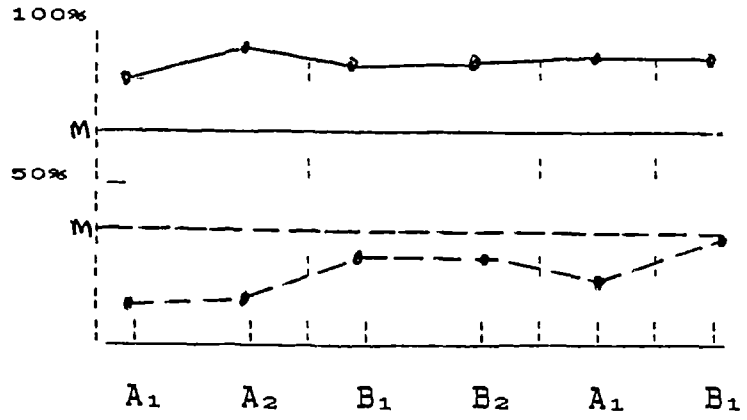
(3) Health Locus of Control



High score=external control, M=Mean score,total subjects

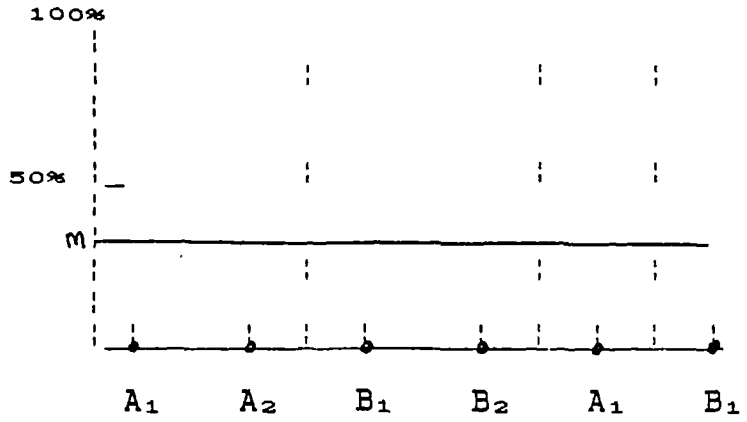
(Fig.10 contd.)

(4) Perceived Social Effects



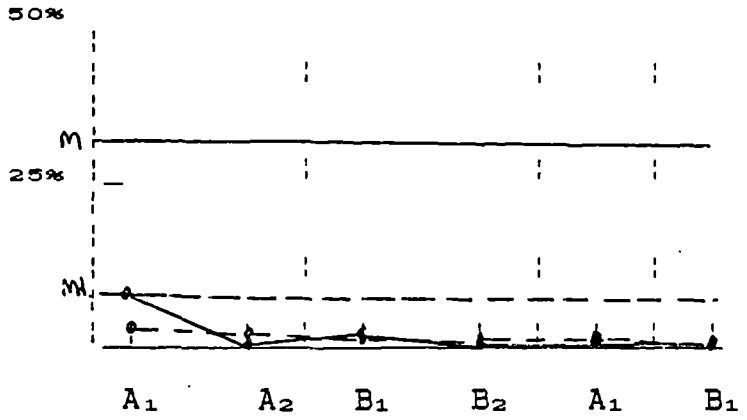
A.D. Scale= ——— M=Mean score,total subjects
Stigma Scale= — —

(5) Fear of Seizures



M=Mean score,total subjects

(6) State Anxiety and Depression



M=Mean score,total subjects, Md=Median score,total subjects
Anx= ——— Dep. = — — —

Table 26- Case Study 5: E.K.P.-P. Results

	A_1	A_2	B_1	B_2	A_1	B_1
Awareness of seizure precipitants.	No	No	No	No	No	No
Perceived ability to stop seizures.	No	No	No	No	No	No
Knowledge of own seizure type.	Yes	Yes	Yes	Yes	Yes	Yes
Knowledge of E.E.G. assessment.	Yes	Yes	Yes	Yes	Yes	Yes
Knowledge of C.T. assessment.	No	No	No	No	No	No
Any recognisable aura.	Yes	Yes	Yes	Yes	Yes	Yes
Any awareness during a seizure.	No	No	No	No	No	No
Incurred injury or been at risk due to a seizure.	Yes	Yes	Yes	Yes	Yes	Yes
Job loss due to epilepsy.	No	No	No	No	No	No
Desirable jobs unable to do due to epilepsy.	Yes	Yes	Yes	Yes	Yes	Yes
Activities/hobbies unable to do due to epilepsy.	No	No	No	No	No	No
Precautions taken in home due to epilepsy.	No	No	No	No	No	No
Precautions taken outwith home due to epilepsy.	No	No	No	No	No	No
Happy with current knowledge of condition.	Yes	Yes	Yes	Yes	Yes	Yes

Discussion

The above results highlight a profile of highly "adaptive" perceptions of epilepsy: The subject had an adequate knowledge and the cognitive resources to cope with, by then infrequent, seizures. However, it is interesting to note that the subject had comparatively strong external beliefs of control of health. This will be given full consideration in the following chapter. It is also interesting to note that acceptance decreased and stigma increased during the group sessions. Perhaps, as the subject had been seizure free for some time prior to the group sessions, she had spent little time thinking of the social implications of having epilepsy. Therefore, having this brought to her attention may, in fact have had a moderately detrimental effect. With regards to future treatment and care, the results indicate that perhaps the subject is best left alone and allowed to enjoy the dramatic improvements in both seizure control and cognitive state!

SUMMARY

In order to assess the practical applicability of the "perception of epilepsy" model, a series of five case studies was investigated before, during and after a brief knowledge programme.

While the results were broadly consistent with the adaptive/underadaptive model, each individual exhibited specific strengths and weaknesses within these perceptions. The nature of these differences was discussed with reference

to the subjects social and medical history.

Results indicated that this model proved to be a meaningful framework for understanding the nature of individual differences in the perceptions of people with epilepsy, and that it has considerable care and treatment implications.

CHAPTER 10

DISCUSSION AND CONCLUSIONS

INTRODUCTION

In Chapters 8 and 9, the results of an examination of the "perception of epilepsy" model were presented (studies 3 and 4). In chapter 5 it was proposed that for individuals with intractable epilepsy, perceptions would vary between "adaptive" (high epilepsy knowledge, high perceived efficacy, high perceived control of condition, low perceived social and physical risk) and "maladaptive" perceptions (low knowledge, low efficacy, low perceived control of condition, high perceived social and physical risk) of his/her condition.

Results from the detailed assessment of 109 subjects with intractable epilepsy provided strong support for this model: Firstly, subjects perceptions of control, social stigma, acceptance of the limitations caused by epilepsy and fear of seizures all appeared intimately related. Results also highlighted the importance of subjects' knowledge of epilepsy and perceived efficacy beliefs for the development and maintenance of these perceptions. Secondly, subjects perceptions strongly predicted levels of anxiety and depression and provided a valuable insight into social problems suffered by subjects.

Supplementary to the above, examination was made of the potential existence of "underadaptive" perceptions (low epilepsy knowledge, low perceived efficacy, low perceived control, low perceived social and physical effects of epilepsy). However results failed to provide any supportive

evidence for this model.

To the author's knowledge, this is the first detailed examination of the inter-relationships within areas of patients' perceptions, and between patients' perceptions and psychopathology. It is suggested that the potential assessment and treatment implications of this model are considerable. The structure of this discussion chapter will be as follows: Firstly, a full discussion of results in Chapters 8 and 9 (studies 3 and 4) will be provided (A full discussion of studies 1 and 2 which were concerned with the development of the Epilepsy Knowledge Profile (E.K.P.) is provided at the end of chapters 6 and 7). Secondly, consideration will be given to the potential practical applications of the model. Finally, some thought will be given to potential future developments of this model.

SELF PERCEPTION AND PSYCHOSOCIAL FUNCTIONING IN SUBJECTS WITH INTRACTABLE EPILEPSY: DISCUSSION OF RESULTS

As has been indicated, overall results supported the hypothesis that identified areas of patients' perceptions would be related, and that perceptions would prove to be a potent predictor of psychopathology. However, as expected, not all areas of perception were found to have a uniform relationship. In the following section full consideration will be given to each area of patients' perceptions. Consideration will also be given to any other areas of interest uncovered during analysis.

1- Perceived Control

Perceived control proved to be perhaps the most enigmatic of measures of self perception. Control over health related

behaviours was positively related to acceptance of epilepsy and stigma, and inversely related to fear of seizures, as hypothesised: This suggests that the more subjects believed that they were able to assert personal control over their health, the more they felt that they were able to control the social implications of their condition and the less fearful they were of seizures. However, contrary to the hypothesis and previous research (88,89), no relationship was apparent between perceived ability to control seizures and any of the measures of patient perceptions. Therefore, there was no indication that individuals who were able to either control or predict seizures were less fearful of seizures or felt their condition was less of a social handicap than subjects without any perceived control over seizures. However, there was some supportive evidence for this hypothesis in the case studies. For instance, in case studies 1 and 3, the development of an awareness of either seizure precipitants or seizure abatement techniques was accompanied, most notably, by a reduction in fear of seizures and a moderately greater acceptance of epilepsy.

Comparison of measures of perceived control with epilepsy knowledge and self efficacy revealed an expected positive relationship between knowledge and subjects perceived ability to effect control over their health. Clearly greater knowledge is conducive to greater control over a diverse range of health related behaviours, from appropriate care with medication through to eating and exercise. This was well illustrated in case studies 1 and 4. For these

subjects, the information based treatment programme resulted in greater epilepsy knowledge and also appeared to result in an increased awareness of areas of their lives where they could assert personal control over their condition, as demonstrated by greater H.L.O.C. scores and responses to items on the E.K.P.-P.

Similarly, it was interesting to note that intellectual functioning was related to perceived health control; subjects with lower verbal I.Q. scores perceived themselves as having less control over their health. However, it was recognised that the relationship between health locus of control and epilepsy knowledge was comparatively modest.

Two possible factors are suggested as possible sources of weakness in this relationship. Firstly, it must be recognised that the H.L.O.C. scale was not epilepsy specific and items may apply equally to having epilepsy as to, for example, catching a cold (e.g. Item 7- "There are so many strange diseases around that you can never know how or when you might pick one up, Item 9- "People who never get ill are just plain lucky")(see Appendix 15). Secondly, the scale fails to distinguish between external factors such as chance or fate and powerful others, such as doctors or the control of health with medication. It has been recognised that people with epilepsy may realistically attribute control over their health to the latter. For example, Arnston et al (1986) found that 93% of his sample indicated that taking medication regularly was the most important thing they could do to control their seizures (45). This was most saliently

demonstrated by case study 5. Despite having had an adequate knowledge of epilepsy, and having displayed an overall "adaptive" perception of her condition, this subject's H.L.O.C. scores remained stubbornly external. However, as was indicated in chapter 9, until some two months prior to assessment, the subject was not only suffering from poor seizure control, but was also suffering from significant cognitive impairment. At this time, fundamental changes were made to the subject's anti-convulsant medication with dramatic positive effects. Therefore, it was not surprising that this subject may attribute health control to external factors (the medical skill of the physician and the dramatic effects of the new anti-convulsants) and maintain a positive outlook about her condition. In retrospect, for a more revealing assessment of health control, it may have proven useful to have used the more recently developed Multi-dimensional Health Locus of Control Scale (124) (see also Methodological Issues).

No relationship was found between efficacy and health control. This is perhaps surprising as perceived efficacy beliefs have frequently been related to perceived control of health (96,97,118). It is suggested that the questionnaire weaknesses identified above may have been a contributory factor. However it is also suggested that a major reason that there is no significant relationship between self efficacy and perceived control over health, is that epilepsy may be unique among chronic illnesses in that perceived behavioural control may not necessarily be the most adaptive response to the condition: High perceived efficacy may, for

some subjects, be directed towards controlling and adapting various aspects of behaviour and the environment in an attempt to control the effects of epilepsy. However, for others, high efficacy beliefs may be directed more effectively towards controlling the cognitive and emotional reactions to what may realistically be perceived as an unavoidable aversive event (see chapter 3).

Results also indicated that greater health control was related to fewer seizures. There can be a number of possible explanations for this finding. For instance, it may be the case that subjects with more internal beliefs have fewer seizures through better medical compliance and by adopting a healthy lifestyle, or alternatively, subjects with fewer seizures may perceive health control efforts as more rewarding than subjects with poor seizure control. However it is also speculatively suggested that for subjects with a higher seizure frequency, perhaps the most efficacious tactic was to learn how to endure seizures. This last point can be illustrated with reference to case study 3. Despite having a high seizure frequency, this man maintained an average series of scores on the self efficacy scale, and in fact, as a result of the knowledge programme, efficacy beliefs increased and fear of seizures decreased. However, perceived control over health became moderately more external. It is suggested that this subject may have realised the limited nature of behavioural control over his condition and had begun to concentrate more on cognitive aspects of coping.

With regard to perceived behavioural control over seizures, once again, no relationship was apparent with either knowledge or self efficacy. However, from case studies 1,3 and 4 there was moderate supportive evidence to suggest that the development of seizure prevention techniques or awareness of seizure precipitants was related to increased knowledge and self efficacy.

Finally, no relationship was found with measures of psychosocial functioning and perceived control. However, once again there was some evidence of such a relationship in case studies 3 and 4.

Total results of the group sample suggest the ability to predict or control seizures made no discernible impact on how subjects perceived their condition, or on consequent levels of psychopathology or social problems. While the ability to assert control over broader aspect of health appeared more pertinent to how individuals saw their epilepsy, this too did not appear to be significantly related to anxiety, depression and social problems. However, results from the series of case studies highlighted above suggest that treatment interventions resulting in the development of perceived behavioural control may have a positive effect.

Such findings are of considerable importance given the emphasis that is currently placed on self control of seizure programmes, and more significantly, the limited evidence available on the psychosocial outcomes of these.

Results suggest that cognitive control, or self efficacy beliefs, appear to be more intimately related to a subject's perceptions of his/her condition and consequent psychosocial functioning than perceived behavioural control over epilepsy. Perhaps, the limited supportive evidence indicating improved psychosocial functioning following such programmes is due, in part, to potential response biases by subjects who feel obliged to report favourable outcomes of treatment. However, alternatively, it is suggested perceived improvements may be due to the provision of mastery experiences and improvements in subjective perceived coping skills, which have been implicated as vital components in the development of efficacy beliefs (96,97), rather than improved quality of life as a direct consequence of having fewer seizures. To this end, Gillham (1990) suggested that the provision of perceived coping skills may be the most effective feature of all forms of psychological treatment for people with epilepsy (62). This would suggest that irrespective of the form of psychological intervention, it would appear to be reasonable to expect at least some improvement in maladaptive perceptions and associated psychopathology. However, it is proposed that the most effective patient interventions will be achieved by selecting an appropriate treatment based on an individual's perception of his/her condition. This will be discussed in greater detail shortly.

Previous research has also indicated that feelings of loss of control and helplessness in people with epilepsy appears

to reside in the individual's social situations as much as his/her seizure activity. The perceived social effects will be considered next.

2- Perceived Social Effects

Two conceptually different areas of the perceived social effects of epilepsy were assessed. Firstly, the Acceptance of Disability scale was used to measure the extent to which individuals saw their condition as having a pervasive negative impact on their lives and the extent to which they saw themselves as different from others and less worthy as a result of having epilepsy (117). Secondly, the Stigma Scale was used as a measure of the perceived negative attitudes and behaviour of others and difficulties in changing minds.

As predicted, these measures inter-correlated strongly and correlated with other measures of perception. Results from the series of case studies were congruent with these findings. However it is worth making a brief reference to case study 3 as a meaningful example of how acceptance and stigma may be divergent. It was suggested that as the subject had a high seizure frequency, the subject's high stigma score may have represented a realistic appraisal of how he was treated by others, while it was proposed that the high acceptance score was an indication that, despite such potential negative evaluation by others, the subject managed to maintain a positive self image and was realistic about the potential limitations imposed by his condition. Such findings highlight that a pragmatic approach is essential in determining whether an individuals perceptions are truly

maladaptive, or simply represent a realistic appraisal of his/her condition. This will be discussed in more detail shortly.

The relationship between measures in the total sample was particularly strong between acceptance of epilepsy and other measures of perception: Subjects with poorer acceptance of the limitations imposed by their condition were more likely to feel victims of discrimination (or at least felt they would be if others were aware of their condition), they were more likely to perceive health as outwith their control and fear seizures.

It was of interest to observe that their was only a modest link between the perceived social effects and knowledge of epilepsy, while there appeared to be a strong relationship between efficacy beliefs and social effects. This would appear to suggest that while knowledge may contribute to lower stigma and higher acceptance, the group profile suggests that this is secondary to subjects' belief in their cognitive resources to cope with social limitations and the potentially negative reactions of others, as and when they arise.

Analysis of potential causal factors in low acceptance and high stigma revealed a number of interesting trends. Firstly duration of epilepsy was inversely related to acceptance and directly related to stigma. As the sample was selected from a group of individuals with a history of poorly controlled epilepsy with no noteworthy periods of remission, results

would appear to suggest that rather than learning to adapt to their condition, a greater duration of uncontrollable seizures tended to result in more negative perceptions of the social effects of epilepsy. With reference to the treatment implications of such findings, it seems reasonable to infer that any form of intervention based on helping an individual cope with the social limitations of his/her condition would be most effectively implemented as early as possible following diagnosis as the magnitude of problems appears, for many, to increase over time. Therefore, for such an individual with a long history of poor seizure control, there appears to be an inherent danger that not only may the medical condition be refractory to treatment, but there is a potential risk that the associated negative, maladaptive perceptions of his/her condition may have become so deeply ingrained that they too may be refractory to therapy. Such findings further demonstrate that there is a need for physicians (whether General Practitioners or hospital based Consultants) to routinely monitor not only the medical aspects of epilepsy, but also how patients feel about having epilepsy.

Perhaps the most interesting background feature concerned seizure type: Subjects with primary generalised seizures tended to have a better acceptance of their condition than subjects with partial seizures, and in particular complex partial seizures.

There are a number of possible explanations for this relationship. Firstly it is possible that subjects with

complex partial seizures may have had more complicated epilepsy (e.g. poorer seizure control, multiple seizure types, polytherapy). This may be particularly pertinent as the majority of these subjects also suffered from secondary generalised seizures. However, it should be noted that no other epilepsy related variables were significantly related to acceptance. Secondly, it is highly possible that subjects with complex partial seizures may have had greater structural brain damage than subjects with primary tonic-clonic seizures, which may have contributed to poorer acceptance. However, unfortunately no detailed information was obtained on patients' neuropsychological status other than the measure of verbal intelligence which failed to reveal any notable difference between seizure types. A final possible contributory factor may simply be that complex partial seizures were seen as more intrusive, bizarre and socially embarrassing than tonic-clonic seizures.

Clearly this is an important issue with considerable treatment implications. For instance, if social embarrassment proved to be the major difference between seizure groups, as there is a delicate balance in the pharmacological treatment of epilepsy between seizure reduction and side effects, patients with complex partial seizures may benefit more from treatment which erred on the side of seizure reduction while subjects with primary generalised seizures may benefit more from treatments with minimum side effects and a marginally higher seizure frequency. However, if poor acceptance was related to medical side effects for individuals with more complicated

partial and secondary generalised seizures, the converse may be true.

Such issues cannot be answered from the present data. Future research in this area should firstly establish whether such a difference in perceptions between seizure groups is replicable. If this proved to be so it is suggested that investigations into the potential causes of such differences would necessitate a detailed assessment of neurological status and cognitive functioning. Also, a measure dealing with more detailed assessment of specific problems in the acceptance of epilepsy such as social intrusiveness or embarrassment should be developed (see also Methodological Issues).

The perceived social effects appeared intimately related to psychosocial functioning and in fact, of all measures within the perception model, acceptance appears to have the strongest relationship with measures of state anxiety and depression and also appears strongly related to stable trait like properties of anxiety. This should not come as a surprise as the A.D. scale was with little doubt, the least ambiguous of all measures of perception used and dealt with a central feature of patients' cognitions about epilepsy; how they saw themselves as an individual as a result of having epilepsy. Those who perceived themselves to be less worthy than others as a result of having epilepsy were much more likely to incur psychological and social difficulties than individuals who did not perceive themselves to be significantly impaired as a result of having epilepsy.

With reference to social difficulties, given the comparatively low level of social problems expressed by this sample, it was recognised that it may have proven difficult to provide significant inferential statistical findings between patient perceptions and social problems. However, it was observed (with interest) that social problems encountered by subjects tended to be significantly attributed to perceived social limitations imposed by their epilepsy. For instance, subjects with low acceptance and high perceived stigma were more likely to have fewer friends and be more dissatisfied with the time they were able to go out. This again emphasises that the perceptions people with intractable epilepsy have about themselves with respect to their epilepsy can have a pervasive effect on their lives. In turn, the limited social contacts many people with epilepsy have may further reinforce the perceived social undesirability of having epilepsy.

3-Perceived Physical Effects

As has already been indicated, with the exception of behavioural control over seizures, there was a strong relationship between perceived physical effects or fear of seizures and measures of perception. These findings were consistent with the hypothesis and with previous research. For instance Arangio (1980) proposed a hypothetical model whereby fear of seizures, either by the person with epilepsy or his family or carers, resulted in overprotection and consequent failure to develop peer interactions with consequent social problems (67).

The most strongly expressed fears concerned the belief that seizures may cause a loss in the ability to think clearly and that seizures may result in injury. Subjects were least fearful that they would die as the result of a seizure.

There was a moderate, although statistically significant relationship between knowledge, perceived efficacy and fear of seizures: Greater knowledge tended to be related to low fear of seizures. Perhaps the reason that the relationship between these variables was not stronger was due to the fact that for many subjects fears may be a realistic appraisal of danger, based on a sound knowledge of his/her condition (e.g. fear of cognitive impairment as a result of either seizures or anti- convulsant medication). This was well demonstrated by case study 3. This subject had a comparatively high fear of seizures. However it was observed that the subject also suffered from a high frequency of physically damaging seizures. As the subject's fears focused primarily on fear of injury it was felt that these fears were entirely appropriate. Conversely, some individuals' lack of knowledge may result in a lack of awareness of realistic potential dangers. However, overall it should be stressed that patient fears tended to be related to poor knowledge of epilepsy. As Collings (1990) stated "*Without information, the person is not in a position to make a realistic adjustment to their lifestyle that is necessitated by having epilepsy and therefore is more likely to fall victim to myths and other inaccurate information*" (Collings,p.425 (57)).

With regard to the relationship between the perceived physical effects or fear of seizures and self efficacy. there was a modest relationship between high efficacy and low fear. This was consistent with the hypothesis and previous research. While it may be expected that seizure occurrence would be regarded by most subjects as an unpleasant experience, subjects who perceived they possessed the cognitive resources to cope with the emotional impact of seizures tended to have less fear of the potential physical effects of seizures.

As hypothesised, there was a strong relationship between the perceived physical effects and levels of anxiety and depression: Higher fear was related to higher levels of psychopathology. Analysis of potential background factors related to fear of seizures indicated only a positive relationship between fear and verbal intellectual functioning. Similar results were found in Mittan's (1986) study (34). It is of some relevance to observe that no epilepsy related variables, such as seizure type or frequency, were related to levels of fear. Such findings would appear to reinforce the need to emphasise the central role of patients perceptions of their condition, rather than concentrating purely on medical aspects. Alternatively it should be recognised that this may also raise some doubts about the accuracy and reliability of information obtained from medical notes which was frequently collated from a variety of sources (see Methodological Issues).

4- Epilepsy Knowledge and Self Efficacy

As has already been indicated, both measures clearly had a significant, positive effect on subjects' perceptions of their condition and consequent levels of anxiety and depression. However, perceived self efficacy was considerably the more influential of these measures. Such results are consistent with self efficacy theory developed by Bandura and his colleagues. According to this theory, two types of expectancies exert powerful influences on cognition and behaviour. Firstly outcome expectancies which refer to the belief that certain behaviours will lead to certain outcomes (in this situation, the knowledge that subjects have about their condition) and secondly self efficacy expectancies; the belief that one can successfully perform the behaviour in question. According to Bandura (1977,1989) self efficacy expectancies are most important as they determine the initial decision to perform a behaviour, the effort expended and, perhaps most importantly with regards to epilepsy, persistence in the face of adversity (96,97,118). This emphasises that sufficient knowledge is not enough; people with epilepsy must believe they have the resources to act appropriately on relevant information.

It was also observed that self efficacy was positively related to age at onset. It is worth recalling that for all individuals, efficacy beliefs are believed to develop through experiences with success and failure. As has been suggested, such beliefs appear intimately related to psychological adjustment (96,97). It would appear reasonable

to suggest that, to varying degrees, epilepsy presents a set of negative. helpless life experiences which are likely to have a detrimental effect on efficacy beliefs. However. if an individual has developed a series of positive efficacy beliefs prior to the onset of epilepsy, then he/she is clearly in a strong position to attenuate the emotional impact of the condition. Therefore, it is not unexpected to find that the younger subjects were at onset, the less chance they had to develop effective efficacy beliefs. This was well demonstrated in case study 2. This girl who was diagnosed as having epilepsy at an early age was not only subject to unpredictable seizures but also appeared to have had considerable social limitations imposed as a result of her epilepsy. Clearly, as a result. this girl had limited opportunities for success and achievement through her own efforts. At time of assessment, despite the cessation of seizures, she presented with very low efficacy beliefs with associated anxiety and depression.

Returning to knowledge, duration and age were significantly related to epilepsy knowledge: The longer the duration of epilepsy and the older the subject, the less they tended to know about their condition. This at first appears counter intuitive. There are a number of potential explanations for this. It is possible that as subjects remained refractory irrespective of the number assessments and treatments they have had to endure, subjects may feel that it makes little difference what they know about their condition as there is little that can be done anyway. Alternatively, subjects with a low knowledge of their condition may well be less

compliant with medication and have remained refractory for longer. There are a wide variety of alternative explanations as to why this should be the case. for instance patients may simply have been provided with less information in the past than they are now or they may simply have forgotten. However the clinical significance is that this once again emphasises that individuals with longer duration are more problematic and perhaps may be made something of a priority for treatment.

However, unfortunately the most intensive treatment interventions for people with epilepsy appear to be during the early course of the condition. Thereafter patients tend to present only at routine clinical visits which may occur as rarely as once or twice a year, or when significant medical problems occur. It may therefore be of some benefit to routinely provide patients with information about their condition, such as the constantly updated factsheets developed by the Epilepsy Association of Scotland.

It may also be useful to have patients routinely complete a very brief postal questionnaire which provided them with the opportunity to highlight any major epilepsy related medical, social or psychological problems they are currently experiencing. Difficulties arising may thereafter be dealt with at the clinic if necessary. However, it may be the case that problems can be countered by a brief letter or telephone call providing appropriate guidance (see also Potential Applications of the Self Perception Model).

5- "Underadaptive" Perceptions

Supplementary to the above hypotheses, it was proposed that subjects with extreme low knowledge and low perceived efficacy would demonstrate an under awareness of potential social and physical limitations imposed by their condition, and low psychopathology which would result in passivity and dependency. However, results failed to provide significant supportive evidence for this hypothesis. In fact it was observed that of all background measures assessed, verbal intelligence was most strongly related to measures of perception and psychopathology; maladaptive perceptions and high anxiety and depression were associated with low intelligence. Dodrill (1980) found broadly similar results using the W.P.S.I. He suggested that an individual with greater cognitive and neuropsychological impairment had fewer "adjustive resources" to cope with his/her condition (128). This is a concept which sounds strikingly similar to efficacy beliefs. As has been demonstrated above, clearly the ability to cognitively evaluate risks and limitations and have the intellectual and emotional resources to cope with such difficulties are essential features in adjustment and psychosocial functioning. Also, as has been indicated, the belief that certain behaviours will lead to certain outcomes has been found to exert powerful influences on cognition and behaviour (96,97).

It is suggested that the more intellectually limited individual may frequently fail to make such a connection: Not only may his/her own body reactions appear totally

unpredictable, but also the reaction of others may appear unpredictable irrespective of his/her behaviour. As was indicated in chapters 2 to 4 such perceptions may result in feelings of helplessness and fear of the social and physical consequences of his/her condition.

It should, however, be recognised that verbal I.Q. scales such as the one used in the present assessment have a strong academic component (see Methodological Issues). It must also be recognised that subjects with more problematic epilepsy and/or who were overprotected may have had limited academic experience. Also individuals who have a poor self perception may academically underachieve through low self image, perceived helplessness, anxiety or depression. However, irrespective of the potential causes, the clear treatment implications of such findings are that the individual with limited intellect may require more time not only to fully assess his/her perceptions of his/her condition but also to help begin to recognise these and begin to effect positive change.

Returning to "underadaptive" perceptions, it is suggested that rather than dismissing this hypothesis, perhaps a "not proven" verdict may be a more meaningful interpretation of results: As there was evidence of a "floor" effect on verbal I.Q. scores, it was strongly suspected that individuals displaying such perceptions would be those who were either intellectually unable, or were deprived of the opportunity to develop appropriate adaptive responses, subject displaying such perceptions may have been excluded from the study as they would have been unable to complete the

questionnaire battery.

This raises a broader issue concerning the assessment of people with learning disabilities and epilepsy. While epilepsy is significantly more prevalent in people with learning disabilities than the general population, with a few notable exeptions (e.g. Montgomery et al 1988 (124), Espie et al 1989 (125)) psychological and social assessment of this group has largely been ignored. Perhaps a major reason for this is that, as has been found in the present study, many standardised scales are inappropriate for people with learning disablilies.

It is therefore suggested that analysis of the "underadaptive" model may best be carried out through the use of scales standardised on a learning disabilities population, or alternatively through the use of a semi-structured interview such as was described in Chapter 5 using the Patients Pre-Behavioural Treatment Questionnaire (109). If the "underadaptive" model proved valid in future research, it would be extremely valuable to assess the critical point at which "maladaptive" perceptions switch to "underadaptive" perceptions.

Summary of Results

In summary, it has been demonstrated that the perceptions of a person with epilepsy's perceptions concerning his/her condition has a central role in his/her psychosocial, and potentially medical adjustment and consequently, an evaluation of such perceptions is an essential component for

the treatment and care of people with epilepsy.

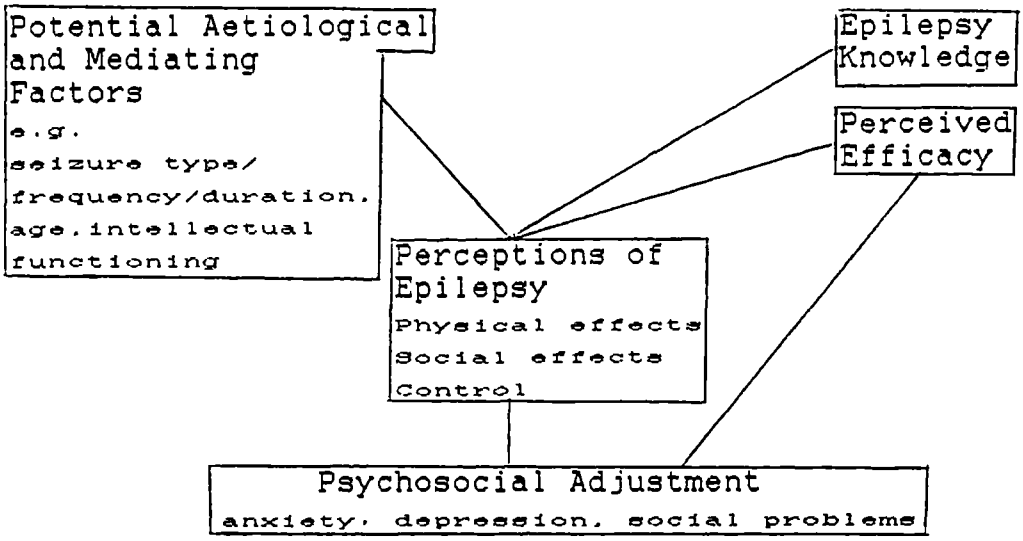
While much previous research has focused on specific areas of perceptions, such as stigma or fear of seizures, it has been clearly demonstrated that there is a need to provide a broader evaluation of the inter-relationship between such areas. However as Mathews and Barabas (1986) stated "*without a conceptual basis, contributions to the literature provide little more than an evergrowing checklist to the possible problem areas*" (Mathews and Barabas, p.165 (90)). This study has endeavoured to provide an analysis of the relationship between key areas of patient perceptions (see Fig. 11).

It is proposed that while the features of the self perception model may vary in intensity between people with intractable epilepsy, these features tend to covary in a manner consistent with the "adaptive" and "underadaptive" conceptual models of self perception. Such perceptions appear strongly related to the chronicity of associated psychosocial adjustment.

It is further suggested that inconsistencies in patient perceptions may be understood if reference is made to the context within which such perceptions develop. For instance, as has been discussed above, case study 3 appeared to have a broadly adaptive perception of his condition. Yet, perceived stigma and fear of the physical effects of epilepsy presented as moderately high. However, as the subject had a high frequency of potentially physically damaging and socially intrusive seizures, these perceptions appeared to

represent a realistic, adaptive apraisal of his condition. This highlights that an understanding of an individual's social and medical history is essential for the effective interpretation of the beliefs people with epilepsy have about their condition.

Figure 11- Self Perception in People With Epilepsy: A Proposed Model



Clearly, an understanding of potential aetiological and mediating factors is important for two reasons. First, as has been highlighted above, such information may provide a more complete and qualitative assessment of an individuals current perceptions. Secondly, identification of potential risk factors such as low intellectual functioning, early onset, or the presence of partial seizures, may lead to early interventions to prevent or limit future adjustment difficulties.

Obviously, the aetiological and mediating factors identified in this study are by no means an exhaustive list. For instance it may prove useful to examine the beliefs and

attitudes about epilepsy of significant others, such as family members, friends and work colleagues. It is hoped that future research may provide a more comprehensive understanding of this important area.

METHODOLOGICAL ISSUES

1- Assessment Measures

It has been recognised in the previous section that a number of the questionnaires used in the study were not ideal. For instance, it was suggested that the Health Locus of Control Scale yielded only limited information and that it may have proven to more effective to use the Multi-Dimensional Health Locus of Control (127). However, it is suggested that future research in this important area would benefit from the development of an epilepsy specific health locus of control scale which may usefully incorporate areas such as beliefs about self control of seizures, the effects of anti-convulsant drugs, the role of physicians in controlling epilepsy and the extent to which seizures are perceived as unpredictable and uncontrollable.

The need for the development of epilepsy specific questionnaires for other areas of patient perceptions was also apparent. For instance, while the amended version of the Acceptance of Disability scale proved to be an extremely valuable assessment tool, it should be recognised that, as the scale was designed primarily for people with physical disabilities, many of the questions were not appropriate for people with epilepsy (e.g. "If a person is not entirely physically able, he/she is that much less of a person").

Clearly, the development of measures designed specifically for people with epilepsy will produce more meaningful results.

It also became apparent during the course of the study that a more detailed assessment of cognitive functioning would have been highly beneficial. Perhaps the present study would have benefitted from the use of a non-verbal measurement such as Raven's Progressive Matrices which was designed to be used as a complementary measure with the Mill Hill Vocabulary Scale (124).

2- Sampling and Procedural Issues

While efforts were made to provide as representative a sample of subjects fitting the inclusion and exclusion criteria from the two locations as possible (see chapter 8, Methods section), a number of potential methodological weaknesses must be acknowledged.

Firstly, subjects were requested to complete questionnaires at home and return them by post. This was felt to be a highly effective procedure which it was strongly suspected yielded a much higher return rate than if subjects were asked to attend the hospital to complete the scales. However, by adopting this procedure it must be recognised that potentially valuable information was lost. For instance there is no information on whether subjects found any of the questionnaires particularly difficult or whether specific areas were of particular relevance or were of little or no consequence. Also, as the battery consisted of a

comparatively high number of questionnaires, there is no evidence of whether subjects succumbed to fatigue towards the end of completion and began to answer questions in a less reliable manner. However, overall subject motivation and compliance appeared high: Not only was there a high return rate but the completion rate for each questionnaire was also high. Perhaps there is no evidence of fatigue on any particular questionnaire as subjects were not asked to complete measures in any particular order and in fact the order of presentation of the questionnaires within the battery varied during the period of assessment. However, informal discussion with subjects indicated that the topics covered by the assessment were perceived as important by subjects and many indicated a willingness to be as accurate and honest as possible.

It should also be recognised that as subjects were not observed during the completion of the questionnaires, it is not known whether the subjects completed the measures alone or with the assistance of others such as friends and family. Therefore, responses may not necessarily represent the perceptions of the subject, but rather the perceptions of a number of individuals. However,it is strongly suspected that subjects would be unlikely to provide answers which were highly inconsistent with their own beliefs. In future similar research projects it may prove beneficial to include a short form asking if subjects encountered any difficulties and if they managed to complete the scales without help.

It must also be recognised that, as the battery was fairly

long and time consuming, this may have resulted in a moderate sampling bias towards well motivated subjects with spare time to complete the measures. Therefore, it may be possible that, for instance, apathetic depressed people with epilepsy or busy working parents may be under-represented. However, it should be stressed that a broad range of subjects, with regard to demographic, intellectual and epilepsy related variables manged to successfully complete the measures.

It was also observed in the previous section that the information obtained from hospital notes may frequently have been unreliable. This has been a consistent problem in epilepsy research and unfortunately does not appear to be one which is easily resolved. However, it is suggested that the medical information at both subject sources was maintained to a high standard: In both the Western Infirmary and Epilepsy Centre settings patient information was monitored, recorded and frequently updated by the highly experienced Consultants based in these care settings.

3- Case Studies

Once again, it is important to emphasise that, while efforts were made to provide as broad a range of people with epilepsy in the case studies, it cannot be claimed that subjects were totally representative of a population of people with refractory epilepsy. Therefore, it is suggested that while the ABAB single case design method was a robust and valid methodological procedure which yielded valuable illustrative information, as with all single case

experimental designs, clearly, there are limitations as to how much these result can be generalised (see also chapter 9, Methods section).

Also, as the author was responsible for the administration and collation of the research measures and was also responsible for running the epilepsy education sessions, it must be recognised that subjects may have been biased to produce what they perceived as favourable results. This may, in part, explain the trend towards more adaptive perceptions as a result of the education programme. However, it was emphasised to subjects prior to each completion of the battery that there were no right or wrong answers (with the exeption of the E.K.P.-G) and that they should answer as honestly as possible. Clearly in future such research it would be beneficial if the treatment programme and the assessment of perceptions were run by separate individuals, and that subjects were informed that individual responses would not be fed back to the person who ran the group.

It must also be recognised that it was asking a lot of subjects to complete a lengthy battery of questionnaires a total of six times. It was apparent from informal discussions with subjects that "questionnaire fatigue" was the major reason for the failure of some of the subjects to complete all of the measures. This clearly placed limitations on the meaning which could be drawn from results. It must also be recognised that for those subjects who did complete the scales some degree of fatigue may also have set in; towards the end of the study subjects may well

have been paying less attention to individual questionnaires in their haste to be finished. It may also have been possible that subjects were remembering previous responses to questions rather than reconsidering their replies. However. given the length of the battery, this seems unlikely. In future research it may well pay off to have fewer questionnaires which may may well yield a greater number of more reliable responses. This highlights the need for the development of a shorter, but nevertheless valid. means of assessing patient perceptions (see Potential Developments of the Perception of Epilepsy Model).

4- Analysis of Results

Much of the results are based on correlational and chi-squared analysis. Therefore, it must be acknowledged that these procedures do not indicate causality. Consequently, while it is suggested that, for instance, maladaptive patient perceptions result in high psychopathology, it may equally be inferred that high levels of psychopathology cause maladaptive perceptions. However, it should be emphasised that further analysis (stepwise multiple regression) which does make inferences about causality was used as means of assessing the predictive power of each stage of the model. This also produced results consistent with both correlational analyses and the hypotheses. However, it is proposed that this important issue may be further clarified by both longitudinal studies examining the development and course of perceptions and associated psychopathology, and through assessment of the effectiveness of treatment programmes designed to treat maladaptive

perceptions.

Finally, it should also be stated that great weight is placed on the results of inferential statistical models in social science research, not, it should be added, with out considerable justification. However, as Scambler (1990) recognised, there is a temptation to see formulae which develop from such models as scientific, or as deriving authority from science. However, a model such as the "perception of epilepsy" model necessarily involves judgements of value which cannot be determined by science. Yet, there are a number of assessment scales and formulae in epilepsy research which are presented as scientific. As Scambler (1990) states, the danger is that "*people may cease to debate or contest them ..and even when their true status is understood (they) become reified and institutionalised*" (Scambler p.64 (128)). For this reason emphasis has been placed on the clinical relevance and applicability of the perception model.

POTENTIAL APPLICATIONS OF THE SELF PERCEPTION MODEL

It has already been recognised that a variety of disciplines are involved in the care and treatment of people with refractory epilepsy. Clearly recognition of individuals' perspective on their condition may be extremely beneficial in all such settings. Ideally, the perceptions of individuals with poorly controlled epilepsy could best be explored and acted upon through specialist clinics offering a multi-disciplinary service such as those available for, for instance diabetes or cancer. However, despite consistent appeals for the widespread provision of specialized epilepsy clinics, at present such services are few and far between. Chadwick (1990) suggested that such poor quality of services for people with epilepsy may, in part, be attributed to the "*certain stigma that still attaches to epilepsy and that this penetrates to professionals as much as it is prevalent in the community as a whole*" (Chadwick, p.4 (69)).

However, in the absence of such multi-disciplinary facilities, it is proposed that there are two main domains where the self perception model may be of practical use. The first of these concerns the medical treatment environment. The second concerns psychological based treatment interventions. Each of these areas will be considered in turn.

1- Self Perception and Medical Consultation

It has been argued that consideration of how a person views his/her condition should be a vital component of medical consultation since self perception may have considerable

psychosocial and medical treatment implications. Therefore, such considerations may result in a more qualitative medical judgement, rather than one based predominantly on seizure counting. Also, by involving a patient as an active participant in treatment, this is likely to improve knowledge and efficacy beliefs and may also result in an overall more adaptive perception of his/her condition. A consequence of this may be better medical compliance and the adoption of a healthier lifestyle which ultimately may prove to be a cost effective procedure resulting in fewer medical consultations.

It is recognised that both General Practitioners and hospital based physicians have considerable time constraints and it will often prove impossible to examine patient perceptions in the depth that that has been carried out in this study. However, if this model is to be usefully applied, it will most frequently be medics who would be most able to carry out initial and routine screening of patient perceptions, and may also be best placed to combat maladaptive perceptions. It is suggested that a significantly large amount of valuable information can be gathered in a comparatively short space of time. For instance, it has already been suggested that the E.K.P. can be filled in prior to consultation. This alone provides considerable qualitative information on a patient's perceptions and may also form the basis for future dialogue. Alternatively, physicians may wish follow a short structured interview or checklist covering areas of relevance from components of the self perception model (For an example of a patient

perceptions checklist, see following section and Table 27).

It is suggested that many of the problems uncovered during such an assessment may be dealt with rapidly in the clinic. There may be a variety of potential aetiological and maintaining factors which may be of considerable relevance when planning an appropriate intervention. However, in many cases such perceptions may simply have arisen through knowledge deficits, misconceptions or irrational fears which may be quickly corrected during consultation. Also feelings of perceived helplessness may be combatted through the process of making the patient a co-participant in the care of his/her condition, or it may be the case that a key feature of a patient's maladaptive perceptions may be the perceived social effects. In such cases the physician may be in a position to provide the patient with a realistic appraisal of the social limitations imposed in his/her condition or possibly make the patient aware of support groups for people with epilepsy such as the Epilepsy Association. Such interventions may be completed rapidly and may make an enormous impact on a patient's life. Yet they do not appear to be part of routine clinical practice (see following section and Table 27).

2- A Guide for the Assessment and Treatment of Patient Perceptions of Epilepsy During Medical Consultations

(To be used in conjunction with Table 27)

1- Self Image Discrepancy (see box 1)

Is there a significant discrepency between the patient's current perceived self, and how they believe they would be if they did not have epilepsy?

(1) *Do you feel that your life would be a lot better if you did not have epilepsy?* (If yes, go on to 2)

2- Perceived Social Effects (see box 2)

Does the patient feel that he/she is significantly socially disadvantaged as a result of having epilepsy?

(1) (a) Do you feel that you are treated differently by others because of your epilepsy?

(b) (If yes) In what way?

(c) On a scale of 1 to 10, how much would you say that this bothered you? (See box 4)

(2) (a) Do you feel that your epilepsy stops you from doing things which you either used to enjoy or feel you may enjoy? (i.e., forms of employment, sport and leisure activities or activities involving social interaction)

(b) (If yes to any of the above) Why do you feel that you are not able to do this?

(c) On a scale of 1 to 10, how much does this bother you?

3- Perceived Physical Effects (see box 3)

Is the patient afraid of the potential physical consequences of seizures?

(1)(a) Do you worry that something may happen to you as a

result of a seizure? (i.e. Loss of ability to think clearly, physical injury, brain damage or death)

(b) On a scale of 1 to 10, how much do you worry about this?

4-Reality of Perceptions (see box 4)

Based on the above information and on clinical impressions gained from an understanding of the patient's medical history, are these perceptions based on a realistic appraisal of social and physical risk (e.g. Does the patient have a high frequency of physically damaging or potentially embarrassing seizures)?

(If yes, go onto 5, if no, go onto 6 and 7)

5- Ability to cope with perceptions of risk (see box 5)

Based on the above information, does the patient appear to be having difficulty coping with these perceptions? (If yes, go onto 6 and 7, if no, no further action is necessary, but continue to routinely monitor perceptions)

6- Investigate options for control of seizures (see box 6)

Alongside standard medical control techniques, behavioural control techniques may be considered. It may be helpful to ask the following-

(1)(a) Are you able to stop any of your seizures?

(b) (If yes) How?

(2)(a) Are there certain times when you almost always have a seizure?

(b) Are there certain times when you almost never have a seizure?

It may be possible to construct a brief behavioural programme during the clinic. However, if this is not viable. but behavioural control would appear to have positive implications for this patient. referal to an appropriate clinical psychologist or psychiatrist is recommended.

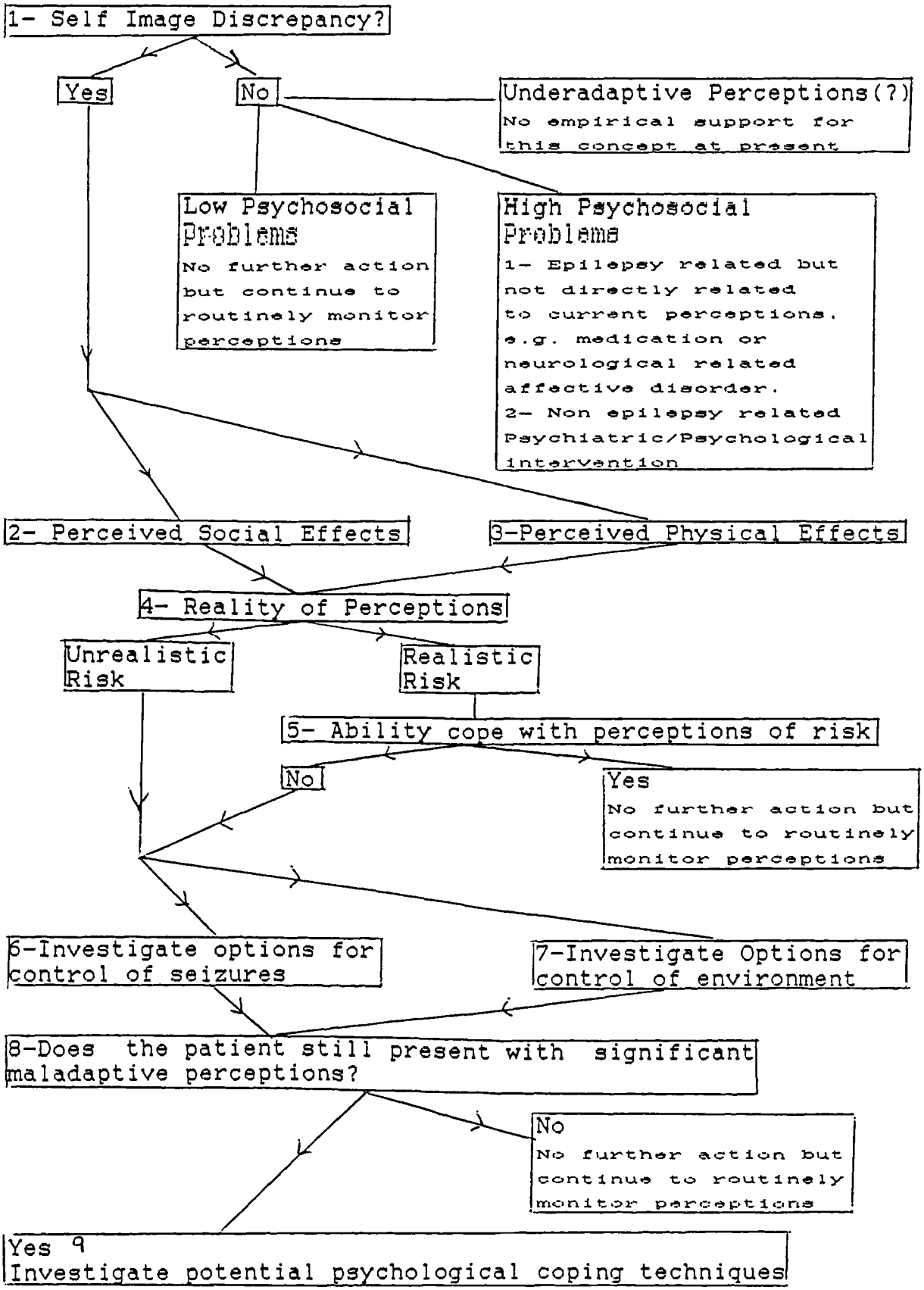
7- Investigate Options for Control of Environment (See box 7)

If the patient's concerns are based on a realistic appraisal of risk it may be helpful to highlight further potential safety precautions or make the patient aware of other potential sources of information and support such as a local epilepsy association. If patient's perceptions are based on an unrealistic appraisal of risk, it may be helpful to dispel misconceptions and help create a realistic perception of potential limitations.

8- Re-assessment of Perceptions (see box 8)

Does the patient still present with maladaptive perceptions? If yes, refer onto clinical psychology or psychiatry (see box 9 and following section).

Table 27- A Guide for the Assessment and Treatment of Patient Perceptions of Epilepsy During Medical Consultations



3- Self Perception and Psychological Consultation

It appears obvious that detailed assessment of how people with refractory epilepsy perceive their condition should be an essential component of any psychological treatment. A primary aim of treatment should be to make such perceptions more adaptive. Yet, as has been demonstrated, this does not appear to be routine clinical practice.

It has been argued that current interventions are primarily control based and that a distinction can be drawn between behavioural control based interventions, which are geared towards self control of seizures and cognitive based techniques which are geared towards coping with the emotional consequences of both having seizures and having a diagnosis of epilepsy, or in other words, being "epileptic".

As has been demonstrated, behavioural control may be a valid option for many and may well result in more adaptive self perceptions. However, it has also been argued that for many, maladaptive perceptions are not directly related to objective features of the seizure disorder such as seizure frequency, but rather are based on subjective components such as the perceived unpredictability of seizures, or the perceived shame of having epilepsy. Therefore it is argued that cognitive based coping techniques must form, at the very least, a component of treatment of people with refractory epilepsy and associated psychological difficulties. It has been argued that for many it may be most adaptive to relinquish constant attempts at controlling

epilepsy, as this may well be a source of some considerable distress. and work on re-interpreting the meaning of the seizure experience and also what it means to have a diagnosis of epilepsy. For instance Betts (1989) has proposed that it may frequently be be useful to show a patient a video recording of his/her seizure. or as fear of seizures in public places is common. carefully tailored graded exposure programmes have also been found to be effective (46). It may also prove effective to examine and treat the maladaptive cognitions through cognitive therapy. Clark (1989), for instance. described a series of questions designed to treat faulty cognitions in anxiety, such as "Am I over estimating how much control I have over how things work out?" or "What if it happens? What would be so bad about that?" which may be applicable for challanging maladaptive thoughts about epilepsy (129).

Clearly, the most effective treatment will be one based specifically on an individuals experiences. Therefore a key component in the formulation of treatment is how realistic the patient's perceptions of his/her condition are. This raises the question of whether the reactions of many people with refractory epilepsy are truly pathological or are normal reactions to abnormal situations (see Table 27, box 4). As has been demonstrated, fears and anxieties may be based on a realistic appraisal of risk and may therefore be functional. Therefore, it should be emphasised that anyone dealing with the psychological difficulties associated with refractory epilepsy must have a sound knowledge of epilepsy.

2- A Guide for the Assessment and Treatment of Patient Perceptions of Epilepsy During Psychological Consultations

1- Assess Current Content of Maladapive Perceptions

(See Table 27)

2-Investigate current modulating and maintaining factors

Interpersonal- attitudes of significant others such as friends, family and colleagues.

Situational- Are certain situations perceived as a source of high or low social or physical threat?

Behavioural- e.g. avoidance of specific feared situations.

Affective and Physiological- Is the patient frequently self monitoring for somatic indications of a seizure? e.g. physical symptoms of anxiety perceived as the onset to a seizure.

Cognitive-e.g. "Having a seizure is the worst thing that could possibly happen","people will always avoid me if they know I have epilepsy".

3-Treatment based on reinterpreting meaning of having seizures

For instance:

- Show patient video recording of his/her seizures.
- Provide information about what happens during a seizure.
- Cognitive therapy based on challenging maladaptive cognitions of seizure related social or physical risk.
- Graded exposure to feared situations.

3-Treatment based on reinterpreting meaning of having epilepsy

For instance:

- Provision of appropriate information about epilepsy, e.g. it is not related to mental illness, most people with

epilepsy are of average intelligence and are capable of full time employment.

- Support from other people with epilepsy such as is provided by the Epilepsy Association of Scotland.

- Hypotheses testing; Encourage patient to find out whether attitudes of others are as negative as he/she perceives them to be.

- Emphasise non-epilepsy positive life events and help plan future positive non epilepsy life events.

FUTURE DEVELOPMENTS OF THE "PERCEPTION OF EPILEPSY" MODEL

It has been demonstrated that there is considerable scope for the development of this model: It has already been recognised that routine clinical interventions are time limited and it would obviously not be practical to routinely complete all assessment measures used in this study. Therefore, at present, the application of this model must necessarily rely on subjective clinical judgement.

Clearly, the next logical step in the development of this model is the construction of a short standardized scale which will provide a means of assessing rapidly patients' perceptions of their condition in a clinical setting. It is suggested that this could be developed in a manner similar to the development of the E.K.P.-P (see chapter 7). An open ended questionnaire on clinically relevant areas of patient perceptions (see Table 27) may provide a heuristic model of assessment and treatment which is meaningful to both clinician and patient.

It must also be recognised that the potential treatment recommendations outlined in Table 27 are hypothetical. Clearly future research must provide an empirical evaluation of the efficacy of these measures. It is suggested that the development of such a measure of patient perceptions is an essential prerequisite to such research.

There are a number of other areas of potential development of this model. For instance. as the model has been applied to individuals with a comparatively high seizure frequency, it is recognised that this covers a relatively small range

of the entire population of people with epilepsy. It has frequently been indicated that individuals with a relatively low seizure frequency may also have considerable difficulties coping with their condition (69). It is suggested that analysis of the perceptions of such individuals may prove useful in the development of more effective treatment. Also, it has been indicated that individuals take some time to come to terms with a diagnosis of epilepsy. The perception model may prove to be an extremely valuable framework for assessing adjustment in newly diagnosed people with epilepsy and may also provide valuable information on the processes which facilitate or inhibit the development of adaptive perceptions of epilepsy.

As was indicated above, the present study failed to provide evidence of the "underperception" model. It is hoped that further analysis of this, and further projects examining the perceptions of people with epilepsy and learning disabilities will be forthecoming.

It is also suggested that further aspects of patients' perceptions may usefully be added to the model. For instance, during the course of assessment it became apparent that it may be useful to provide analysis of patients' attitudes to taking anti-convulsant medication. It may also be of considerable value to develop a locus of control scale specifically for epilepsy. Also, the scope of psychosocial problems examined was fairly limited. Perhaps future developments may usefully include areas such as sexual difficulties or phobic disorders for a more complete

understanding of the relationship between self perception and psychosocial functioning.

SUMMARY AND CONCLUSIONS

Clearly epilepsy is an extremely complex disorder. Not only can it have multiple causes and manifest in many forms, but as has been demonstrated in the previous chapters, there is enormous variation in the potential social, psychological and behavioural effects. Such complexities have resulted in great problems in developing a commonly accepted framework for the effective treatment of such problems. However the present research is based an a very simple premise- Regardless of the objective features of an individuals condition such as seizure type or frequency, if he/she perceives his/her epilepsy to be a problem, then it is a problem.

With this in mind a conceptual framework of assessment based on patients' perceptions of their condition was developed. From results of assessment of a wide range of people with epilepsy and through the analysis of a series of case studies, it has been demonstrated that this model has considerable practical potential.

In conclusion, it is hoped that this research contributes to recent developments in the process of viewing people with epilepsy as individuals with unique medical, social and psychological needs, rather than merely a sum of his or her symptoms.

APPENDIX 1

THE PATIENTS' PRE-BEHAVIOURAL TREATMENT QUESTIONNAIRE

-1-

Name:_____

Date:_____

Age:_____

1. Why do you come here to the hospital?

2. What is the name of your problem?(For subsequent questions, use the patient's own term for seizures, tics, or other symptoms. If he has no particular term use the word which you fell best describes his problem).

3. In your own words tell me what a (seizure,tic, etc.) is.

4. How long have you had (seizure, tics, etc.)? How old were you when they first started?

5. Do you remember the very first (seizure, tic, etc.) you ever had?

6. How often do you have (seizures, tics, etc.)? How many do you usually have in a week?

7. Can you tell when you are going to have a(seizure, tic, etc)?(If yes) How?

8. Are there certain times or situations when you <u>almost always</u> have a (seizure, tic, etc.)? Describe them.

9. Are there certain times or situations when you <u>almost never</u> have a (seizure, tic, etc.)? Describe them.

10. Tell me all about your symptom. What happens and what does it feel like?

FIGURE 2
Patient's Pre-Behavioral-Treatment Questionnaire.

-2-

11. Have you or anyone else ever prevented one of your (seizures, tics, etc.) from happening? (If yes) How?

12. Have you or anyone else stopped one of your(seizures, tics, etc.) once it had started? (If yes) How?

13. What else helps you prevent or stop your (seizure, tic, etc)?

14. (a) Do you take medicine?

(b) What kind of medicine do you take, how much, and how often?

(c) How does it make you feel to have to take medicine?

(d) What do you think that the medicine does for you?

15. (a) What do your family members(parents, husband, wife, etc.) do when you have a (seizure, tic, etc.)?

(b) How does that make you feel?

16. (a) What do other people do when you have a (seizure, tic, etc)? Your friends? Your teachers (or co-workers)?

(b) Tell me how that makes you feel.

17. (a) What is the worst thing about having your symptoms?

(b) Are you aware of when your symptom is occurring?

(c) Do you ever feel embarrassed by your symptom?

(d) Do other people notice your symptom?

FIGURE 2
(continued)

-3-

(a) How has your symptom affected or changed your life?

18. What is the best thing about having (seizures, tics, etc.)

19. (a) If you could choose, would you like to have more (seizures, tics, etc.) or less or just the same number you have now?

(b) How many (seizures, tics, etc.) would you like to have every week?

(c) When, where and with whom would you prefer to have them?

20. What methods have you tried to reduce your symptom?

21. Is there anything else that you would like to tell me about your symptom?

NOTES:

FIGURE 2
(continued)

APPENDIX 2

E.K.P.-G - QUESTION EASE- MEDICAL SCALE

Rank	Question Number	Percentage Correct	Question
1	22	98.8%	Blood samples can be used to measure the concentration of anti-epileptic drugs in the system.
2	8	97.6%	An E.E.G is designed to detect electrical activity from the brain.
2	19	97.6%	In order for anti-epileptic drugs to be successful, they must be taken regularly.
4	6	95.1%	An E.E.G can be used to help detect epilepsy.
5	32	93.9%	Too much alcohol may make seizures more likely.
5	34	93.9%	Stress may cause some seizures.
7	11	92.7%	Some Seizures may last for a matter of seconds and not be noticed by others.
7	15	92.7%	For most people, doctors can effectively treat epilepsy with drugs.
7	26	92.7%	If seizures stop with anti-epileptic drugs, this means your epilepsy has been cured.
10	5	91.5%	Almost anyone can have a seizure given the appropriate circumstances.
10	21	91.5%	Some people get a warning or feeling shortly before a seizure.
10	25	91.5%	It is always helpful to take extra doses of anti-epileptic drugs when not feeling well.
13	3	89.0%	Epilepsy is a symptom of mental illness.
14	2	87.8%	Epilepsy is not infectious.
15	18	85.4%	An epileptic seizure can be described as an abnormality of the function of nerve cells in the brain.

Rank	Question Number	Percentage Correct	
16	24	82.9%	Most peoples seizures are well controlled soon after starting regular drug treatment.
16	29	82.9%	There is no need to continue taking anti-epileptic drugs if your seizures stop.
18	12	79.3%	All seizures affect both sides of the brain.
19	1	78.0%	Epilepsy is always caused by brain damage.
19	33	78.0%	Most seizures result in brain damage.
21	4	75.6%	All people with epilepsy have similar symptoms.
21	16	75.6%	All those who start drugs for their epilepsy have to take them for life.
23	9	74.4%	All people with epilepsy lose consciousness during seizures.
24	7	69.5%	If an E.E.G is abnormal. this is a definite sign of epilepsy.
25	17	68.3%	Increasing the dose of anti-epileptic drugs increases the chances of side effects.
26	27	65.9%	Few people with a diagnosis of epilepsy are on anti-epileptic drugs.
27	14	64.6%	A normal E.E.G means that you do not have epilepsy.
28	23	63.4%	People taking a combination of anti-epileptic drugs are more likely to have side effects than those on only one.
29	31	57.3%	Most mothers on anti-epileptic drugs are able to breastfeed.
30	30	51.2%	Brain surgery is still used as a method of preventing seizures.
31	28	45.1%	Some people have been taught to control their seizures by psychological methods.

Rank	Question Number	Percentage Correct	
32	10	41.5%	An epileptic seizure can be described as a temporary lack of oxygen to the brain.
33	13	34.1%	Too much alcohol may make seizures more likely.
34	20	23.2%	If you forget to take anti-epileptic drugs for a day, it is usualy O.K to take 2 doses together.

(Total number of subjects=82. Missing Values included as incorrect)

E.K.G.-P QUESTION EASE- SOCIAL SCALE

Rank	Question Number	Percentage Correct	Question
1	1	97.6%	If you drive you must inform the Driving and Vehicle Licensing Centre (D.V.L.C) about the diagnosis of epilepsy.
1	6	97.6%	Most children with epilepsy can attend normal schools.
3	10	96.3%	Most people with epilepsy are of low intelligence.
4	12	93.9%	Most people with epilepsy are capable of full-time employment.
5	13	91.5%	Most people with epilepsy are able to go swimming as long as someone is with them.
6	8	89.0%	If a person with epilepsy has a simple uncomplicated seizure. there is no need to call a doctor or ambulance.
6	15	89.0%	Most people with epilepsy should avoid taking an active part in most sports.
8	17	82.9%	Most people with epilepsy should avoid working at heights.
9	9	81.7%	People with epilesy are more prone to violent anti-social behaviour than those without epilepsy.

Rank	Question Number	Percentage Correct	
10	20	79.3%	In medical terms. epilepsy is a fairly recent phenomenon.
11	16	78.0%	Most people with epilepsy should avoid working with open machinery.
12	7	75.6%	If a person with epilepsy has a seizure. you should put a hard object such as a spoon or pen in his/her mouth.
13	4	73.2%	Most people with epilepsy are able to go swimming as long as someone is with them.
14	19	62.2%	Over half the population with epilepsy will have had their first seizure by the age of 15.
15	2	58.5%	It is possible that a person whose seizures only happen during sleep may hold a drivers licence.
16	18	57.3%	Most people with epilepsy should avoid all factory and building work.
17	3	47.6%	If a person has been seizure free for 10 years and has the correct licence, he/she is allowed to drive heavy goods vehicles. pubic service vehicles. taxis. trains or aircraft.
18	5	40.2%	It is illegal not to disclose a diagnosis of epilepsy on all job application forms.
19	11	36.6%	Most people with epilepsy should avoid flashing lights. T.V screens. computers and V.D.U s.
20	14	25.6%	Having a diagnosis of epilepsy prevents immigration to some countries.

APPENDIX 3

ALPHA SCORES FOR INDIVIDUAL E.K.P.-P ITEMS

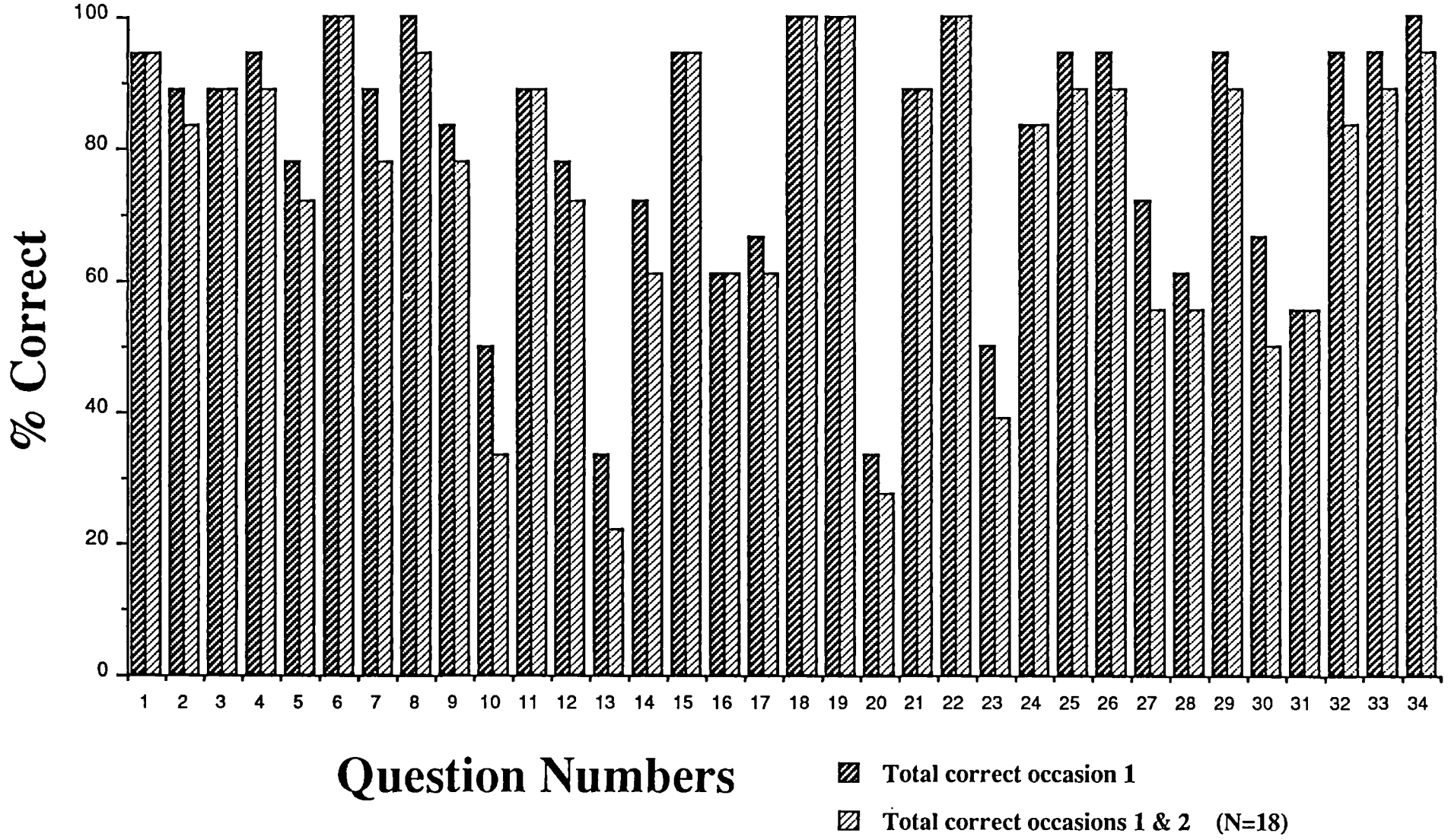
1- Medical Knowledge (Total Alpha Score Q1 - Q 34= 0.6256)

Item Number	Alpha Score	Item Number	Alpha Score
1	0.6351	18	0.6485
2	0.6081	19	0.6166
3	0.6142	20	0.6082
4	0.6064	21	0.6141
5	0.6133	22	0.6262
6	0.6318	23	0.6502
7	0.5697	24	0.6415
8	0.6133	25	0.6379
9	0.5833	26	0.6243
10	0.6008	27	0.5893
11	0.6212	28	0.6028
12	0.6235	29	0.5998
13	0.6264	30	0.6106
14	0.5815	31	0.6585
15	0.6351	32	0.6307
16	0.6057	33	0.6272
17	0.6252	34	0.6641

2- Social Knowledge (Total Alpha Score Q1 - Q21= 0.4929)

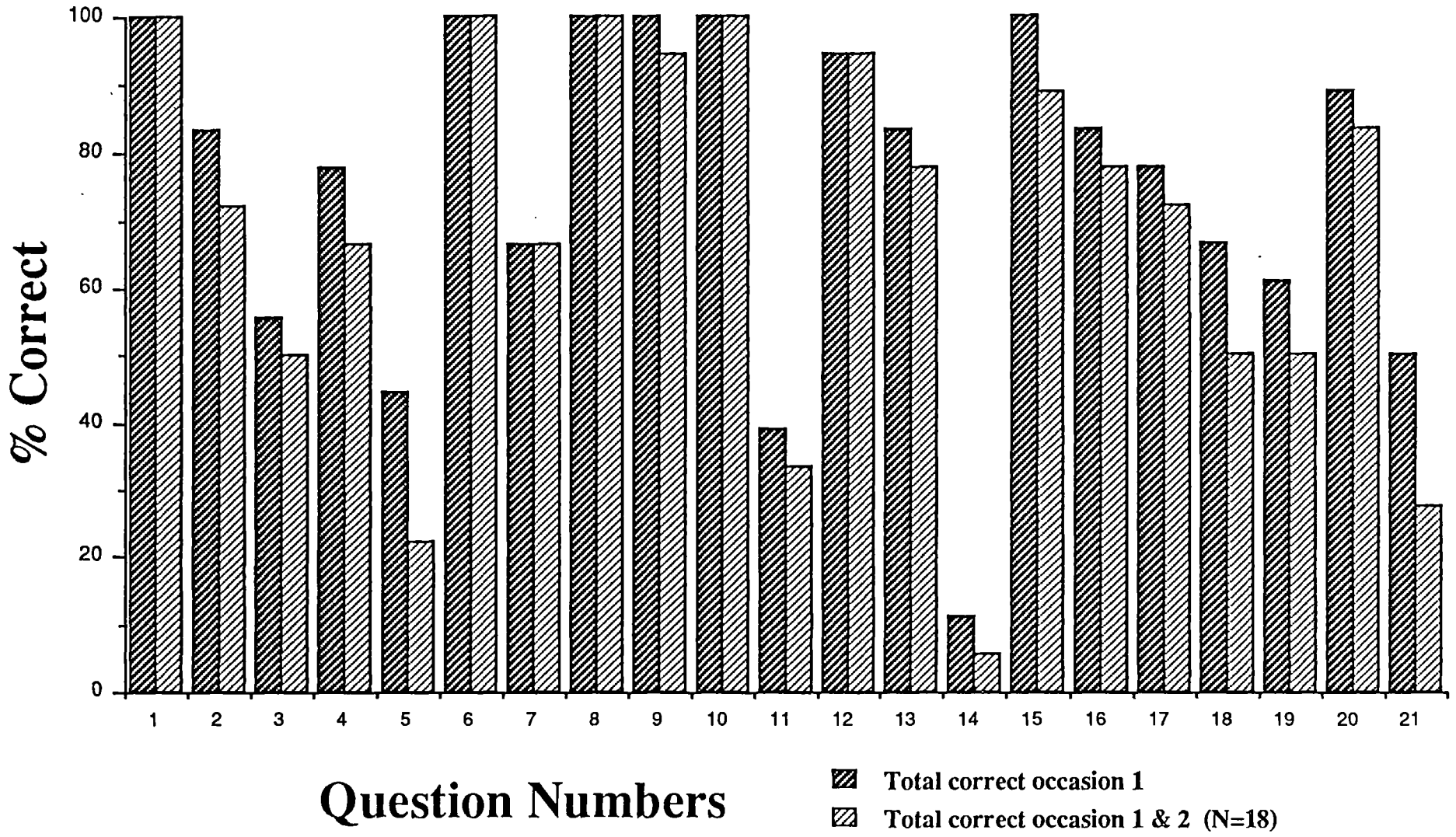
Item Number	Alpha Score	Item Number	Alpha Score
1	0.4962	11	0.4554
2	0.3914	12	0.4832
3	0.4957	13	0.4929
4	0.5074	14	0.5022
5	0.4439	15	0.4661
6	0.4962	16	0.4927
7	0.4215	17	0.5212
8	0.4827	18	0.4954
9	0.4570	19	0.5161
10	0.4262		

E.K.P.-G. - Reliability Retest Ease- Medical Knowledge



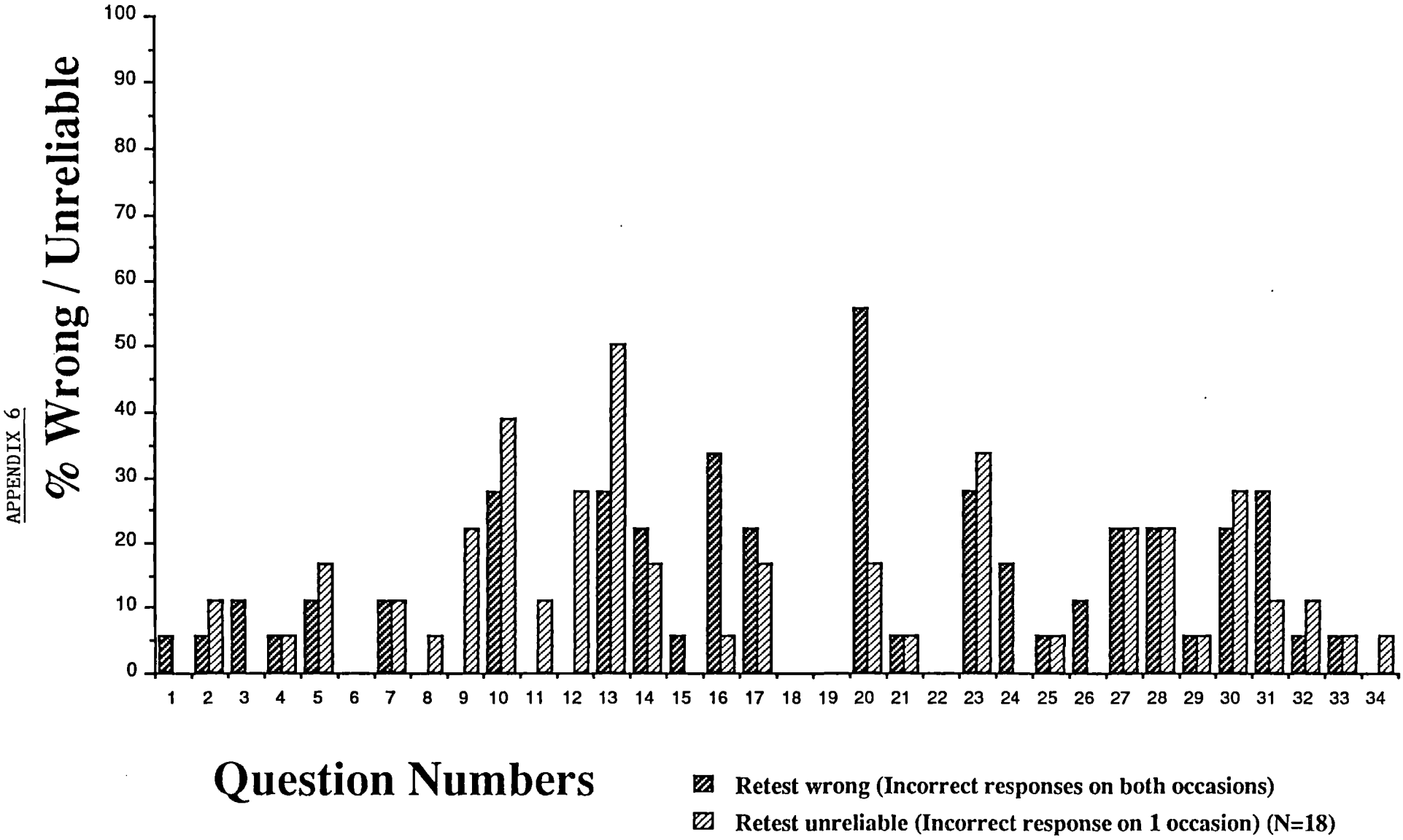
APPENDIX 5

E.K.P.-G. Reliability Retest Ease- Social Knowledge

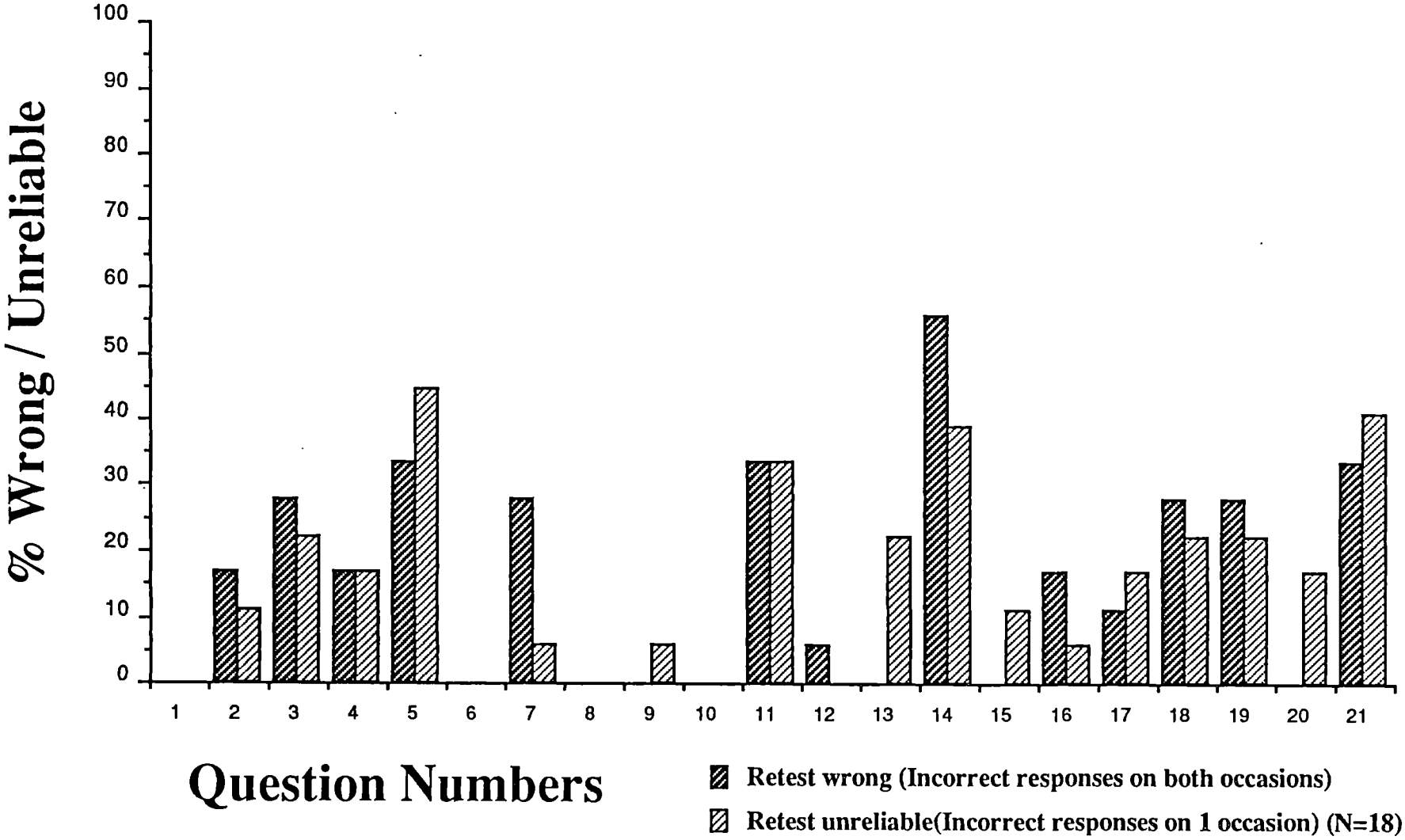


APPENDIX 6

E.K.P.-G. - Reliability Retest Wrong/Unreliable 1 Medical



E.K.P.-G. - Reliability Retest Wrong/Unreliable 2 Social



THE EPILEPSY CENTRE
QUARRIERS
THE CARING COMMUNITIES

EPILEPSY KNOWLEDGE PROFILE - PERSONAL (E.K.P.- P)

S. Jarvie, C.A. Espie, M.J. Brodie, J.M.B. Gray

SUGGESTED SCORING CRITERIA

Question 4 - E.E.G. Information

2 Point Response

(1) Both report and subject response are normal.
(2) Recognition of abnormal electrical or epileptiform activity.
(3) Recognition of focal abnormality.

• Examples of acceptable 2 point responses.

1) Respondent - There was abnormal electrical activity.
   Report - Electrical changes were consistent with recent seizures.

2) Respondent - There was more electrical activity on the left side of the brain.
   Report - ...There is evidence of a left temporal area focus.

1 Point Response

(1) Recognition that E.E.G. is abnormal but no reference to electrical activity or area of abnormality.

• Examples of acceptable 1 point responses.

1) Respondent - There was a focal abnormality shown.
   Report - ...suggestive of a right fronto temporal focus.

2) Respondent - There was a slight abnormality.
   Report - There was persistent disturbance in the right temporal lobe.

O Point Response

(1) Clearly incorrect or describes brain scan.

• Examples of 0 point responses.

1) Respondent - It showed signs of stress.
   Report - ...focal sharp wave activity in right temporal lobe.

2) Respondent - All seems normal but for little dent.
   Report - No epileptiform features.

Questions 6 to 8: Assessment of Knowledge of Current Anti-Convulsant Status

It is suggested that responses to these questions can be assessed in the manner described below. This procedure allows the computation of a total "Anti-convulsant knowledge" score with a potential maximum of 10.

	Scored Response		
	0	1	2
1 - Is the subject aware he/she is on anti-convulsant medication?	NO	YES	N/A
2 - Does he/she know how many drugs he/she is on?	NO	YES	N/A
3 - Does he/she know the name of some or all of his/her drugs?	NO	YES (For some)	YES (For all)
4 - Does he/she know the correct frequency for his/her drugs?	NO	YES (For some)	YES (For all)
5 - Does he/she know the correct dose for his/her drugs?	NO	YES (For some)	YES (For all)
6 - Does he/she know the purpose of his/her drugs? (for scoring criteria, see below)	NO	Poor desc.	Adequate desc.

(continued overleaf)

Question 8- Purpose of Anti-Convulsants

2 Point Response
Reference should be given to seizure reduction or prevention. Also, responses should display some understanding of the processes by which this is carried out.
Namely, an increase in seizure threshold or a reduction in abnormal electrical activity with minimal side effects.

• Examples of 2 Point responses
1) Respondent - To control the strange electrical waves which can some times cause fits.

2) Respondent - Prevent abnormal brain waves which would otherwise result in a fit.

1 Point Response
Reference should be given to seizure reduction or the process by which this is carried out.

• Examples of 1 Point responses
1) Respondent - To control seizures.
2) Respondent - To slow electrical activity in my brain.

O Point Response
Incorrect or ambiguous responses.

• Examples of O point responses.
1) Respondent - To help control my brain movements.
2) Respondent - To keep everything O.K.

Question 5 - Brain Scan Information

2 Point Response

(1) Both report and subject report are normal.

(2) Recognition of abnormality with reference to area of damage.

• Examples of 2 point responses.

1) Respondent - The scan was clear.
Report - Normal.

2) Respondent - There was a slight scar on right side of brain.
Report - ...evidence of atrophy of right posterior temporal lobe.

1 Point Response

1) Recognition that scan was abnormal but with no reference to the area of damage.

• Examples of 1 point responses.

1) Respondent - There was a slight scar on the brain.
Report - ...evidence of atrophy of right posterior temporal lobe.

O Point Responses

(1) Clearly incorrect or describes E.E.G..

• Examples of O point responses.

1) Respondent - The right side of the brain was damaged.
Report - ...reduced attenuation in left basal ganglia.

2) Respondent - Abnormal electrical activity.
Report - Atrophy of right temporal lobe.

APPENDIX 9

E.K.P.-P SUBJECT RESPONSES- QUESTIONS 11 TO 23

Question Number	Response: No	Yes	Failed to Respond	Sample Response
11- Can you tell when you are going to have any of your seizures?	46.3%	47.6%	6.1%	"Strange taste. deja-vu"
12- Are you aware of what happens to you during any of your seizures?	62.2%	31.7%	6.1%	"Hands stroke for a few seconds. swallowing sound"
13- Are their certain times or places where you almost always, or almost never have a seizure?	63.2%	26.0%	9.8%	"During sleep" "When having period"
14- Are you or anyone else able to stop any of your seizures from happening?	80.5%	13.4%	6.1%	"I tend to tense up and keep my mind occupied"
15- Have you ever injured yourself or been in danger because of a seizure?	36.6%	57.3%	6.1%	"I have often hit my head and have burned my leg and arm"
16- Do other people always notice when you have a seizure?	32.9%	59.8%	7.3%	
17- Have you ever lost a job or failed to get a job because of your epilepsy?	70.7%	24.4%	4.9%	"I was told fits fits were disturbing to other workers"
18- Are their any activities or hobbies that you are not able to do because of your epilepsy?	52.4%	39.0%	8.6%	"Jogging as followed by an absence"

19- Are there any jobs that you would like to do but are unable to because of your epilepsy?	60.9%	29.2%	9.8%	"Police, fire service"
20- If you work, in your present job do you have to take special precautions because of your epilepsy?	85.4%	3.6%	9.8%	"Can only be on computer for a short time"
21- Are there any precautions that you take in the home because of your epilepsy?	63.4%	28.1%	8.5%	"I will not fry foods"
22- Are there any precautions that you take outwith the home because of your epilepsy?	58.5%	33.0%	8.5%	"Where possible have a companion"
23- Do you feel that you know enough about your condition?	41.4%	48.8%	9.8%	

APPENDIX 10

DEMOGRAPHY OF QUARRIERS AND WESTERN SAMPLE

	Quarriers	Western
Mean Age	39	34
Mean Age at Onset	10	19
Duration of Epilepsy	29 years	15 years
Sex		
Male	7 (50%)	41 (43.2%)
Female	7 (50%)	54 (56.8%)
Seizure Frequency		
Less than 1 per month	4 (28.6%)	33 (34.7%)
About 1 per month	2 (14.3%)	15 (15.8%)
Greater than 1 per month	2 (14.3%)	14 (14.7%)
About 1 per week	1 (7.1%)	7 (7.4%)
Greater than 1 per week	1 (7.1%)	12 (12.6%)
About 1 per day	2 (14.3%)	3 (3.2%)
Greater than 1 per day	-	4 (4.2%)
Seizure Type		
Tonic Clonic	5 (35.7%)	27 (28.4%)
Atonic	1 (7.1%)	
Myoclonic	3 (21.4%)	1 (1.1%)
Absence	8 (57.1%)	4 (4.2%)
Simple Partial		19 (20.0%)
Complex Partial	7 (50.0%)	63 (66.3%)
Secondary Gen.	7 (50.0%)	40 (42.1%)
Total Different Seizure Types		
1	-	44 (46.3%)
2	10 (71.4%)	41 (43.2%)
3	4 (28.6%)	10 (10.5%)
Number of Anti-Convulsants taken		
0	1 (7.1%)	1 (1.1%)
1	1 (7.1%)	51 (53.7%)
2	6 (42.9%)	28 (29.5%)
3	5 (35.7%)	15 (15.8%)
4	1 (7.1%)	-
Mean Verbal I.Q.	89.3 (Standard Deviation=10)	103.4 (Standard Deviation=13)

EPILEPSY RESEARCH PROJECT - APPENDIX 11 - STIGMA SCALE

Instructions Please read each statement and choose a number from the scale below to indicate how much you agree or disagree with the statement. Then write the number you have chosen in the box opposite the statement.

Totally Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Totally Agree
1	2	3	4	5	6

1) Employers I've dealt with have treated me fairly. ☐

2) People put unreasonable limits on what I can do. ☐

3) People who know I have epilepsy treat me differently. ☐

4) Most people I know are willing to be educated about epilepsy. ☐

5) It really doesn't matter what you say to people, they usually have their minds made up. ☐

6) Because of my epilepsy, I always feel I have to prove myself. ☐

THANK YOU VERY MUCH FOR YOUR HELP

APPENDIX 12 - ACCEPTANCE OF EPILEPSY/FEAR SCALES.

Instructions: Please read each statement and choose a number from the scale below to indicate how much you agree or disagree with the statement. Then write the number you have chosen in the box opposite the statement.

1	2	3	4	5	6
Totally Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Totally Agree

1) Epilepsy may limit a person in some ways, but this does not mean that he/she should give up and do nothing with his/her life. ☐

2) Because of my epilepsy, I feel miserable much of the time. ☐

3) More than anything else, I wish I didn't have epilepsy. ☐

4) Regardless of my epilepsy, I'm going to make good in life. ☐

5) Good physical appearance and physical ability are the most important things in life. ☐

6) Epilepsy prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be. ☐

7) I can see the progress I am making in life, and it makes me feel like an adequate person in spite of the limitations caused by my epilepsy. ☐

8) It makes me feel very bad to see all the things people without epilepsy can do which I cannot. ☐

9) Epilepsy affects those aspects of my life which I care about most. ☐

10) I worry that I may die as a result of a seizure. ☐

11) Though I have epilepsy my life is full. ☐

12) If a person is not entirely physically able, he/she is that much less a person. ☐

13) A person with epilepsy is restricted in certain ways, but there is much that he/she is able to do. ☐

14) There are many more important things in life than physical ability and appearance. ☐

15) There are times when I completely forget that I have epilepsy. ☐

16) You need a good and whole body to have a good mind. ☐

17) There are many things that a person with epilepsy is able to do. ☐

18) Since my epilepsy interferes with just about everything I try to do, it is foremost in my mind practically all he time. ☐

19) If I didn't have epilepsy, I think I would be a much better person. ☐

20) I worry that I may injure myself as a result of a seizure. ☐

21) My epilepsy affects me more than any of my other characteristics. ☐

22) The kind of person I am and my accomplishments in life are less important than those of people without epilepsy. ☐

23) I know what I can't do because of my epilepsy, and I feel that I can live a full and normal life ☐

24) Though I can see the progress I am making in rehabilitation, this is not very important since I can never be normal. ☐

25) In just about everything, my epilepsy is so annoying to me that I can't enjoy anything. ☐

26) How a person conducts himself or herself in life is much more important than physical appearances and ability. ☐

27) A person with epilepsy is unable to enjoy very much in life. ☐

28) The most important thing in the world is to be physically normal. ☐

29) A person with epilepsy finds it especially difficult to expand his/her interests and range of abilities. ☐

30) I believe that physical wholeness and appearance make a person what she is. ☐

31) I worry that my seizures may cause brain damage. ☐

32) Epilepsy affects a person's mental abilities. ☐

33) With my condition I know just what I can and cannot do. ☐

34) Almost every area of life is closed to me because of epilesy. ☐

35) Because of my epilepsy, I have little to offer other people. ☐

36) Besides the many physical things I am unable to do, there are many other things I am unable to. ☐

37) Personal characteristics such as honesty and willingness to work hard are much more important than physical appearance and ability ☐

38) I get very annoyed with the way some people offer to help me. ☐

39) There isn't a single area of my life that is not affected in some major way by epilepsy. ☐

40) Though I can see that people with epilepsy are able to do well in many ways, they can never lead a normal life. ☐

41) I worry that my seizures may cause a loss of ability to think clearly. ☐

42) A disorder such as mine is the worst posible thing that can happen to a person. ☐

43) No matter how hard I try, or what I accomplish, I can never be as good as a person without epilepsy. ☐

44) There is practically nothing a person with my condition is able to do and really enjoy it. ☐

45) Because of my epilepsy, I am unable to enjoy social relationships as much as I could if I did not have epilepsy. ☐

46) There are more important things in my life than those which epilepsy prevents me from doing. ☐

47) I very much want to do things that my epilepsy prevents me from doing. ☐

48) Because of my epilepsy other people's lives have more meaning than my own. ☐

49) When I think of my epilepsy, it often makes me feel so sad or upset that I am unable to think or do anything else. ☐

50) Epilepsy changes one's life completely. It causes one to think differently about everything. ☐

51) I continually dread the possibility of a seizure. ☐

52) I feel that I should be as able as the next person, even in areas where epilepsy prevents me. ☐

53) Life is full of so many things that I sometimes forget for brief periods of time that I have epilepsy. ☐

54) Because of my epilepsy, I can never do most things that most normal people do. ☐

55) I feel satisfied with my abilities, and my epilepsy doesn't bother me to much. ☐

THANK YOU FOR YOUR HELP

APPENDIX 13 - E.K.P.-G.

-EPILEPSY RESEARCH QUESTIONNAIRE-

Your help with the following questionnaire would be much appreciated.

In the first 2 sections there are a number of statements about epilepsy, some of which are true, some false. Beside each statement is a box. If you think the statement is true put a "T" in the box, if you think it is false put an "F".

If you are not sure whether an item is true or false answer what you think is most likely to be the case. Please answer all questions.

In the third section there are some questions about your own condition. Again, please attempt all questions.

There are many names used to describe an epileptic attack, e.g "fit", "turn", "seizure", or you may have your own name. In the following statements the term "seizure" is used to describe an epileptic attack.

All information will be treated in the strictest confidence.

Thank you very much for your help

SECTION 1- MEDICAL ASPECTS OF EPILEPSY

	T	F
(1) Epilepsy is always caused by brain damage		
(2) Epilepsy is not infectious		
(3) Epilepsy is a symptom of mental illness		
(4) All people with epilepsy have similar symptoms		
(5) Almost anyone can have a seizure given the appropriate circumstances		
(6) An E.E.G can be used to help diagnose epilepsy		
(7) If an E.E.G is abnormal, this is a definite sign of epilepsy		
(8) An E.E.G is designed to detect electrical activity from the brain		
(9) All people with epilepsy lose consciousness during seizures		
(10) An epileptic seizure can be described as a temporary lack of oxygen to the brain		
(11) Some seizures may last for a matter of seconds and not be noticed by others		
(12) All seizures affect both sides of the brain		
(13) Certain forms of brain damage always cause epilepsy		
(14) A normal E.E.G means that you do not have epilepsy		
(15) For most people, doctors can effectively treat epilepsy with drugs		
(16) All those who start drugs for their epilepsy have to take them for life		
(17) Increasing the dose of anti-epileptic drugs increases the chances of side-effects		
(18) An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain		
(19) In order for anti-epileptic drugs to be successful, they must be taken regularly		

	T	F
(20) If you forget to take anti-epileptic drugs for a day, it is usually O.K to take 2 doses together		
(21) Some people get a warning or feeling shortly before a seizure		
(22) Blood samples can be used to measure the concentration anti-epileptic drugs in the system		
(23) People taking a combination of anti-epileptic drugs are more likely to have side-effects than those on only one		
(24) Most peoples seizures are well controlled soon after starting regular drug treatment		
(25) It is always helpful to take extra doses of anti-epileptic drugs when not feeling well		
(26) If seizures stop with anti-epileptic drugs, this means your epilepsy has beeen cured		
(27) Few people with a diagnosis of epilepsy are on anti-epileptic drugs		
(28) Some people have been taught to control their seizures by psychological methods		
(29) There is no need to continue taking anti-epileptic drugs if your seizures stop		
(30) Brain surgery is still used as a method of preventing seizures		
(31) Most mothers on anti-epileptic drugs are able to breastfeed		
(32) Too much alcohol may make seizures more likely		
(33) Most seizures result in brain damage		
(34) Stress may cause some seizures		

SECTION 2- SOCIAL ASPECTS OF EPILEPSY

	T	F
(1) If you drive you must inform the Driving and Vehicle Licensing Centre (D.V.L.C) about the diagnosis of epilepsy		
(2) It is possible that a person whose seizures only happen during sleep may hold a drivers licence		
(3) If a person has been seizure free for 10 years and has the correct licence he/she is allowed to drive heavy goods vehicles, public service vehicles, taxis, trains or aircraft		
(4) People with epilepsy are able to join the armed forces, police and fire service in an active capacity		
(5) It is illegal not to disclose a diagnosis of epilepsy on all job application forms		
(6) Most children with epilepsy can attend normal schools		
(7) If a person with epilepsy has a seizure you should put a hard object, such as a spoon or pen in his/her mouth		
(8) If a person with epilepsy has a simple, uncomplicated seizure, there is no need to call a doctor or ambulance		
(9) People with epilepsy are more prone to violent anti-social behaviour than those without epilepsy		
(10) Most people with epilepsy are of low intelligence		
(11) Most people with epilepsy should avoid flashing lights, T.V screens, computers and V.D.U s		
(12) Most people with epilepsy are capable of full-time employment		
(13) Most people with epilepsy are able to go swimming as long as someone is with them		
(14) Having a diagnosis of epilepsy prevents immigration to some countries		
(15) Most people with epilepsy should avoid taking an active part in most sports		
(16) Most people with epilepsy should avoid working with open machinery		

(contd)

T	F

(17) Most people with epilepsy should avoid working at heights

(18) Most people with epilepsy should avoid all factory and building work

(19) Over half of the population with epilepsy will have had their first seizure by the age of 15

(20) In medical terms, epilepsy is a fairly recent phenomenon

(21) What proportion of the population do you believe have active epilepsy? (Please circle below)

1 in 20
1 in 100
1 in 200
1 in 500
1 in 1000

SECTION 3- ABOUT YOUR CONDITION

(1) Do you have seizures or fits? (yes/no)

(2) Do you accept that you have epilepsy? (yes/no)

(3) (a) Do you know the medical name for your type of seizures? (yes/no) (If no,please go on to Q4)

(b) If yes, please list-

(4) (a) Have you ever had an E.E.G ? (yes/no)
(If no, please go on to Q5)

(b) If yes, do you know what the results were? (yes/no)
(If no, please go on to Q5)

(c) If yes please briefly describe-

(5) (a) Have you ever had any form of brain scan for your epilepsy? (yes/no)
(If no please go on to Q6)

(b) If yes, do you know what the results were? (yes/no)

(c) If yes, briefly describe-

(6) (a) Do you take regular anti-epileptic drugs? (yes/no)
(If no, please go on to Q9)

(b) If yes, without checking, do you know the names of some or all of the drugs you are on? (yes/no)
(If no, please go on to Q7)

(c) If yes please list -

(7) (a) Without checking, do you know when to take your drugs and how much to take each day ? (yes/no)
(If no please go on to Q8)

(b) If yes, please list the time of day and amount taken (if you do not know the name and dosage a brief description- e.g tablet colour or number of tablets is O.K)

Type of Drug	Time Taken	Amount Taken

(8) (a) Do you know what your anti-epileptic drugs are supposed to do? (yes/no)
(If no please go on to Q9)

(b) If yes, briefly describe-

(9) (a) Have any methods other than drugs been used to treat your epilepsy (e.g surgery, psychological treatment)? (yes/no)
(if no, please go on to Q10)

(b) If yes, briefly describe-

(10) How often would you say you have seizures? (Circle the one you feel best applies to you)

Less than 1 per month
About 1 per month
Greater than 1 per month
About 1 per week
Greater than 1 per week
About 1 per day
Greater than 1 per day
Don't know

(11) (a) Can you tell when you are going to have any of your seizures? (yes/no)
(If no, go on to Q12)

(b) If yes, how?

(12) (a) Are you aware of what happens to you during any of your seizures? (yes/no)
(If no, go on to Q13)

(b) If yes, briefly describe-

(13) (a) Are there certain times or places when you almost always, or almost never, have a seizure? (yes/no)
(If no, go on to Q14)

(b) If yes, briefly describe-

(14) (a) Are you, or anyone else, able to stop any of your seizures from happening? (yes/no)
(If no, go on to Q15)

(b) If yes, briefly describe-

(15) (a) Have you ever injured yourself, or been in any danger because of a seizure? (yes/no)
(If no, go on to Q16)

(b) If yes, briefly describe-

(16) Do other people always notice when you have a seizure? (yes/no)

(17) (a) Have you ever lost a job or failed to get a job because of your epilepsy? (yes/no)

(b) If yes, briefly describe-

(18) (a) Are there any activities or hobbies that you are not able to do because of your epilepsy? (yes/no)
(If no, please go on to Q19)

(b) If yes, briefly describe-

(19) (a) Are there any jobs that you would like to do, but are unable to because of your epilepsy? (yes/no)
(If no, go on to Q20)

(b) If yes please describe-

(20) (a) If you work, in your present job, do you have to take special precautions because of your epilepsy? (yes/no)
(If no go on to Q21)

(b) If yes, briefly describe-

(21) (a) Are there any precautions that you take in the home because of your epilepsy? (yes/no)
(If no, go on to Q22)

(b) If yes, briefly describe-

(22) (a) Are there any precautions that you take outwith the home becouse of your epilepsy? (yes/no)
(If no, go on to Q23)

(b) If yes, briefly describe-

(23) Do you feel that you know enough about your condition?

Are there any comments that you wish to make about this questionnaire?

THANK YOU ONCE AGAIN FOR YOUR HELP

APPENDIX 15 - HEALTH LOCUS OF CONTROL SCALE

Here are a number of ways that people feel about themselves when they are ill. You may agree or disagree with them. Please circle the number opposite each statement which shows how much you agree or disagree with it.

Here are two examples:

EXAMPLE 1

	STRONGLY DISAGREE	MILDLY DISAGREE	DISAGREE	AGREE	MILDLY AGREE	STRONGLY AGREE
I feel that I have little influence over the things that happen to me.	(1)	2	3	4	5	6

The first example shows that you have circled 1, which means that you strongly disagree with what the statement says.

EXAMPLE 2

	STRONGLY DISAGREE	MILDLY DISAGREE	DISAGREE	AGREE	MILDLY AGREE	STRONGLY AGREE
There really is no such thing as "luck"	1	2	3	(4)	5	6

The second example shows that you have circled 4, which means that you agree, but not strongly.

Please read through the 11 statements overleaf and circle the number which describes best how you feel about each statement.

	STRONGLY DISAGREE	MILDLY DISAGREE	DISAGREE	AGREE	MILDLY AGREE	STRONGLY AGREE
1. If I take care of myself, I can avoid illness.	1	2	3	4	5	6
2. Whenever I am ill, it is because of something I have done, or not done	1	2	3	4	5	6
3. Good health is largely a matter of good fortune.	1	2	3	4	5	6
4. No matter what I do, if I am going to be ill, I will be ill.	1	2	3	4	5	6
5. Most people do not realise the extent to which their illnesses are controlled by accidental happenings.	1	2	3	4	5	6
6. I can only do what my doctor tells me to do.	1	2	3	4	5	6
7. There are so many strange diseases areound that you can never know how or when you might pick one up.	1	2	3	4	5	6
When I feel ill, I know it is because I have not been getting the proper exercise or eating right.	1	2	3	4	5	6
9. People who never get ill are just plain lucky.	1	2	3	4	5	6
10. People's ill-health results from their own carelessness.	1	2	3	4	5	6
11. I am directly responsible for my health.	1	2	3	4	5	6

- - - - - - - - - - -

APPENDIX 16 - SELF-EFFICACY SCALE .

EPILEPSY RESEARCH PROJECT - S.E SCALE

Instructions:.

Here are a number of ways that people feel about themselves. you may agree or disagree with them. Please write the number which shows how much you agree or disagree in the box beside each item.

Strongly Disagree	Mildly Disagree	Disagree	Agree	Mildly Agree	Strongly Agree
1	2	3	4	5	6

1) When I make plans, I am certain I can make them work. ☐

2) One of my problems is that I cannot get down to work when I should. ☐

3) If I can't do a job first time, I keep trying until I can. ☐

4) When I set important goals for my self, I rarely achieve them. ☐

5) I give up on things before completing them. ☐

6) I avoid facing difficulties. ☐

7) If something looks too complicated, I will not even bother to try it. ☐

8) When I have something unpleasant to do, I stick to it until I finish it. ☐

9) When I decide to do something, I work on it right away. ☐

10) When trying to learn something new, I soon give up if I am not initially successful. ☐

11) When unexpected problems occur, I don't handle them well. ☐

12) I avoid trying to learn new things when they look to difficult for me. ☐

13) Failure just makes me try harder. ☐

14) I feel insecure about my ability to do things. ☐

15) I am a self reliant person. ☐

16) I give up easily. ☐

17) I do not seem capable of dealing with most problems that come up in life. ☐

18) It is difficult for me to make new friends ☐

19) If I see someone I would like to meet, I go to that person instead of waiting for him or her to come to me. ☐

20) If I meet someone interesting who it is hard to make friends with, I'll soon stop trying to make friends with that person. ☐

21) When I'm trying to become friends with someone who seems uninterested at first, I don't give up easily. ☐

22) I do not handle myself well in social gatherings. ☐

23) I have aquired my friends through my personal abilities at making friends. ☐

THANK YOU FOR YOUR HELP

EPILEPSY RESEARCH PROJECT - **SELF-EVALUATION QUESTIONNAIRE**

Developed by C. D. Spielberger, R. L. Gorsuch and R. Lushene

STAI FORM X-1

NAME _____ DATE _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *feel* right now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I am regretful	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel rested	①	②	③	④
9. I feel anxious	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel "high strung"	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel over-excited and "rattled"	①	②	③	④
19. I feel joyful	①	②	③	④
20. I feel pleasant	①	②	③	④

SELF-EVALUATION QUESTIONNAIRE

STAI FORM X-2

NAME _____ DATE _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I tire quickly	①	②	③	④
23. I feel like crying	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I am losing out on things because I can't make up my mind soon enough	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I am inclined to take things hard	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I try to avoid facing a crisis or difficulty	①	②	③	④
35. I feel blue	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

APPENDIX 18

EPILEPSY RESEARCH PROJECT - B.D.I. SCALE.

Instructions.

Here are a number of ways that people feel about themselves. For each group of statements please circle the number beside the statement you feel is most right for you.

0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad or unhappy that I can't stand it.

0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless and that things cannot improve.

0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.

0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.

0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.

0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

0 I don't cry anymore than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.

0 I am no more irritated now than I ever am.
1 I get annoyed or irritated more easily than I used to.
2 I feel irritated all the time now.
3 I don't get irritated at all by the things that used to irritate me.

12 ( ) 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.

13 (3) 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions than before.
3 I can't make decisions at all anymore.

14 ( ) 0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly.

15 ( ) 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

16 ( ) 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17 ( ) 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18 ( ) 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

19 ( ) 0 I haven't lost much weight, if any, lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less. Yes___No___

20 ( ) 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems, that I cannot think about anything else.

21 ( ) 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

EPILEPSY RESEARCH PROJECT - APPENDIX 19
SOCIAL QUESTIONNAIRE

Please underline the most appropriate answer.

A. HOUSING (Everyone answer)

1.	Are your housing conditions adequate for you and your family's needs?	Adequate	Slightly Inadequate	Markedly Inadequate	Severely Inadequate
2.	How satisfied are you with your present accommodation?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfie

B. WORK (For all men and women working outside the home)

☐ Tick box if nc applicable

3.	How satisfied are you with your present job?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfie
4.	Do you have problems getting on with any of the people at your work?	No Problems	Slight Problems	Marked Problems	Severe Problems

(For housewives with no outside work)

☐ Tick box if nc applicable

5.	How satisfied are you with being a housewife?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfie

(For housewives with a full or part-time job outside the home)

☐ Tick box if nc applicable

6.	How satisfied are you with working and running a home?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfie

(For those who are not working - Retired, unemployed, or off sick)

☐ Tick box if nc applicable

7.	How satisfied are you with this situation?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfie

C. FINANCIAL CIRCUMSTANCES (Everyone answer)

8.	Is the money coming in adequate for you and your family's needs?	Adequate	Slightly Inadequate	Markedly Inadequate	Severely Inadequate
9.	Do you have any difficulties in meeting bills and other financial commitments?	No Difficulties	Slight Difficulties	Marked Difficulties	Severe Difficulties
10.	How satisfied are you with your financial position?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

D. SOCIAL CONTACTS (Everyone answer)

11.	How satisfied are you with the amount of time you are able to go out?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied
12.	Do you have any problems with your neighbours?	No Problems	Slight Problems	Marked Problems	Severe Problems
13.	How many friends do you have?	None	A few	Many	

☐ Tick box if not applicable

14.	Do you have any problems getting on with any of your friends?	No Problems	Slight Problems	Marked Problems	Severe Problems

☐ Tick box if not applicable

15.	How satisfied are you with the amount of time you see your friends?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied
16.	Do you have any problems getting on with any close relative? (include parents, in-laws, or grown-up children)	No Problems	Slight Problems	Marked Problems	Severe Problems
17.	How satisfied are you with the amount of time you see your relatives?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

E. MARRIAGE AND BOY/GIRLFRIENDS

18.	What is your marital status?	Single	Married/ Cohabiting	Widowed	Separated	Divorced

(For all those who are married or have a steady relationship)

☐ Tick box if not applicable

19.	Do you have any difficulty confiding in your partner?	No Difficulty	Slight Difficulty	Marked Difficulty	Severe Difficulty
20.	Are there any sexual problems in your relationship?	No Problems	Slight Problems	Marked Problems	Severe Problems
21.	Do you have any other problems getting on together?	No Problems	Slight Problems	Marked Problems	Severe Problems
22.	How satisfied in general are you with your relationship?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied
23.	Have you recently been so dissatisfied that you have considered separating from your partner?	No	Sometimes	Often	Yes planned or recent separation

(For all those who are not married/do not have a steady relationship)

☐ Tick box if not applicable

24.	How satisfied are you with this solution?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

F. FOR THOSE WITH CHILDREN UNDER 18

☐ Tick box if not applicable

25.	Do you have any difficulties coping with your children?	No Difficulties	Slight Difficulties	Marked Difficulties	Severe Difficulties
26.	How satisfied do you feel with your relationship with the children?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

FOR THOSE WITH CHILDREN OF SCHOOL AGE

Tick box if not applicable ☐

27. Are there any problems involving your children at school?	No Problems	Slight Problems	Marked Problems	Severe Problems

FOR ALL THOSE WITH OTHER ADULTS LIVING WITH THEM (INCLUDING RELATIVES BUT EXCLUDING SPOUSE)

Tick box if not applicable ☐

28. Do you have any problems about sharing household tasks?	No Problems	Slight Problems	Marked Problems	Severe Problems
29. Do you have any difficulties with the other adults in your household?	No Difficulties	Slight Difficulties	Marked Difficulties	Severe Difficulties
30. How satisfied are you with this arrangement?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

G. LEGAL MATTERS (Everyone answer)

31. Do you have any legal problems? (Custody, maintenance, compensation, etc.)	No Problems	Slight Problems	Marked Problems	Severe Problems

H. For those who are living alone

Tick box if not applicable ☐

32. Do you have any difficulties living and managing on your own?	No Difficulties	Slight Difficulties	Marked Difficulties	Severe Difficulties
33. How satisfied are you with living on your own?	Satisfied	Slightly Dissatisfied	Markedly Dissatisfied	Severely Dissatisfied

I. OTHER (Everyone answer)

34. Do you have any other social problems ~~or problems~~?	No Problems	Slight Problems	Marked Problems	Severe Problems

If so, please specify .....

APPENDIX 20 - Mill-Hill Vocabulary Scales.

SET A

PLEASE DO NOT USE A DICTIONARY

Write down in a few words the meaning of each of the following words as it has been done for the first word.

1. Continue Go on
2. Startle
3. Perfume
4. Malaria
5. Mingle
6. Fascinated
7. Brag
8. Prosper
9. Anonymous
10. Verify
11. Ruse
12. Formidable
13. Immerse
14. Docile
15. Virile
16. Sultry
17. Stance
18. Efface
19. Sensual
20. Construe
21. Conciliate
22. Garrulous
23. Latent
24. Obdurate
25. Criterion
26. Palliate
27. Adulate
28. Felicitous
29. Ambit
30. Recondite
31. Cachinnation
32. Exiguous
33. Putative
34. Manumit

SET B

In each group of six words below underline the word which means the same as the word in heavy type above the group, as it has been done in the first example:

1 **CONNECT**
accident join
lace bean
flint field

2 **PROVIDE**
harmonize commit
hurt supply
annoy divide

3 **STUBBORN**
obstinate steady
hopeful hollow
orderly slack

4 **SCHOONER**
building man
ship singer
plant scholar

5 **LIBERTY**
worry freedom
rich serviette
forest cheerful

6 **COURTEOUS**
dreadful proud
truthful short
curtsey polite

7 **RESEMBLANCE**
attendance fondness
assemble repose
likeness memory

8 **THRIVE**
flourish try
thrash reap
think blame

9 **PRECISE**
natural stupid
faulty grand
small exact

10 **ELEVATE**
revolve move
raise work
waver disperse

11 **DWINDLE**
swindle pander
diminish wheeze
linger compare

12 **LAVISH**
unaccountable selfish
romantic lawful
extravagant praise

13 **WHIM**
complain noise
tonic fancy
wind rush

14 **SURMOUNT**
mountain descend
overcome concede
appease snub

15 **BOMBASTIC**
democratic pompous
bickering cautious
destructive anxious

16 **RECUMBENT**
fugitive cumbersome
unwieldy repelling
reclining penitent

17 **ENVISAGE**
contemplate activate
surround estrange
enfeeble regress

18 **TRUMPERY**
worthless heraldry
etiquette highest
amusement final

19 **GLOWER**
extinguish shine
disguise gloat
aerate scowl

20 **PERPETRATE**
appropriate commit
propitiate deface
control pierce

21 **LEVITY**
parsimony velleity
salutary frivolity
alacrity tariff

22 **LIBERTINE**
missionary rescuer
profligate canard
regicide farrago

23 **AMULET**
savoury jacket
flirtation crest
cameo charm

24 **QUERULOUS**
astringent fearful
petulant curious
inquiring spurious

25 **TEMERITY**
impermanence rashness
nervousness stability
punctuality submissiveness

26 **FECUND**
esculent optative
profound prolific
sublime salic

27 **ABNEGATE**
contradict decry
renounce execute
belie assemble

28 **TRADUCE**
challenge attenuate
suspend establish
misrepresent conclude

29 **VAGARY**
vagabond caprice
obscurity vulgarity
evasion fallacy

30 **SPECIOUS**
fallacious coeval
palatial typical
nutritious flexible

31 **SEDULOUS**
rebellious dilatory
complaisant diligent
seductive credulous

32 **NUGATORY**
inimitable adamant
sublime contrary
numismatic trifling

33 **ADUMBRATE**
foreshadow protect
detect eradicate
elaborate approach

34 **MINATORY**
implacable diminutive
belittling quiescent
depository threatening

APPENDIX 21

Epilepsy Research Project- Subject Information

Reference No.- Patient No.-

Name- Address-

Phone No.-

D.O.B.-

Seizure Type-

Seizure Frequency-

Age and cause of onset-

Other information (Including other deficits or disabilities and I.Q scores if known)-

E.E.G. Information

Brain Scan Information

Present Drug Therapy

Drug Name	Frequency	Drug Name	Frequency

APPENDIX 22

TEST RETEST- COMPARISON OF RAW SCORES OF MEASURES PERCEPTION AND PSYCHOPATHOLOGY

		Subject				
		1	2	3	4	5
E.K.P.-G (Medical)	T	22	24	28	29	29
	R.T	26	28	25	26	30
E.K.P.-G (Social)	T	12	13	16	17	18
	R.T	12	14	13	18	18
S.T.A.I. State	T	45	27	38	35	50
	R.T	49	30	32	42	49
S.T.A.I. Trait	T	48	28	42	44	50
	R.T	59	28	40	50	54
B.D.I.	T	30	08	01	06	15
	R.T	24	08	02	09	10
Self Efficacy Scale	T	066	110	084	075	082
	R.T	060	100	094	069	089
A.D. Scale	T	227	224	266	267	162
	R.T	246	231	265	258	169
Fear of Seizures	T	09	24	08	10	27
	R.T	08	29	05	14	28
Health Locus Of Control	T	36	46	39	45	39
	R.T	30	37	39	48	26
Stigma Scale	T	19	14	13	21	23
	R.T	10	07	12	18	30
Verbal Intelligence	T	102	102	122	130	098
	R.T	103	106	122	125	099

(T=initial assessment, R.T.= retest)

APPENDIX 23

RESPONSES TO PERCEIVED CONTROL OF SEIZURES ITEMS

1-Are there certain times or places where you almost always, or almost never, have a seizure?

1) When I am menstruating I usually have more seizures.

2) Generally early hours of the morning: 4 a.m. to 6 a.m. in bed or very soon after rising.

3) I quite often feel that I am going to take a turn before I go out.

4) Early morning, when first getting up, getting into a bath, also during sleep.

5) In bed during sleep or about to slowly waken up.

6) Mostly in my own home, but have had some seizures in pubic places.

7) First sunny days of summer. Often christmas day. Perhaps because of the slight nostalgic feeling.

8) Lately this has been happening when I have been training on my rowing machine.

9) Always during the night.

10) My seizures are generally nocturnal- Happening in bed.

11) Almost never have seizures in the afternoon or evening. Usually in the morning soon after rising.

12) If I am too near T.V. or in certain discos.

13) When I play on Atari video games I take fits.

14) When I have a period.

15) Always in bed, I tend not to sleep elsewhere.

16) Usually if I am worried about something (nervous or exited). Sometimes I have a seizure if I take a drug late.

17) Greatest number of seizures are soon after wakening. If control of fits is very good then times become random.

18) I rarely have a seizure in the morning.

19) During period cycle.

20) Most places that have flashing lights.

2-Are you, or anyone else able to stop any of your seizure from happening?

1) Catching it early on- Partner talked me out of it- used relaxing techniques.

2) I always get very upset or stressed and am never alone during or before a seizure.

3) At one time I tried to control them and convinced myself it was working, but one day I woke out of a bad one and gave up with it. Sometimes if someone enters the room or says something I snap out of it.

4) When I get the aura I take Clobozam and sit down and relax.

5) By concentrating on my breathing as much as possible.

6) Sometimes if am kept working I hardly have seizures.

7) Sometimes if I am kept working I hardly have seizures.

8) Sometimes my family can talk me out of it, but not always.

9) By taking another drug.

10) Sometimes if I am able to concentrate I can walk off minor fits. I have no control over major fits.

11) I talk to myself in my mind. My teeth clamp together.

12) Probably by taking my tablets and eating proper meals and early nights.

13) Sometimes if mum or dad or whoever is in the house, but it's hardly ever.

14) Sometimes if I can can calm myself and relax it stops a seizure from happening.

15) By helping me to stay calm and talking to me and helping me to to control my breathing (taking long deep breaths). It is very exhausting and I have to sleep for a couple of hours afterwards.

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