THE ROLE OF ILLNESS REPRESENTATIONS IN THE PROCESS OF COPING AND PSYCHOSOCIAL ADJUSTMENT AMONG ADULTS WITH EPILEPSY.

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ABSTRACT

The self-regulation model (Leventhal, Nerenz and Steele, 1984) emphasises the role of cognitive representations of illness and coping efforts on patients responses to health threats. In this thesis the relationships between illness representations, coping and psychosocial adjustment were investigated among 94 epilepsy patients. The sample comprised three groups; recently diagnosed, chronic (clinic) and chronic (GP) patients.

An instrument was developed to assess patients cognitive representations of epilepsy. The protocol used yielded both qualitative and quantitative data.

Both chronic (clinic) and recently diagnosed patients exhibited significant adjustment problems. In contrast, among chronic (GP) patients psychosocial adjustment was good. Differences in coping and illness representations were found between groups. Chronic (clinic) patients were distinguished by greater reliance on wishful thinking and avoidance coping. Avoidance coping strategies were least prevalent among chronic (GP) patients. In terms of illness representations, recent onset patients were characterised by; weaker illness identity, acute timeline and perceptions of less severe consequences. Chronic (clinic) patients were characterised by; a strong illness identity, chronic timeline, perception of serious consequences and high contamination beliefs. Chronic (GP) patients also possessed a strong illness identity and chronic time perception, but on the consequences and self-illness components more closely resembled recent onset patients.

A series of multiple regression analyses indicated that illness representations explained a greater proportion of variance in; mental health, psychological distress, self-esteem and social anxiety than did the coping strategies after controlling for neuroepileptic factors. The illness representation component self-illness relationship had the strongest overall association with adjustment. Additional components making a significant contribution were; illness identity, timeline and control. There were several distinct relationships between illness representations and coping. Illness identity, blaming others, perception of serious consequences and negative self-illness appraisals were positively related to wishful thinking and avoidance coping. Among the four coping strategies assessed; avoidance, problem-focused and wishful thinking were related to adjustment. Seeking social support did not emerge as a significant predictor of adjustment. Patients with a strong illness identity, who perceived themselves as unable to contain the effects of epilepsy, utilised wishful thinking and avoidance coping emerged as having the poorest mental health and self-esteem.

This thesis demonstrates the value of the self-regulation paradigm in understanding psychosocial adjustment to epilepsy. Results are discussed with respect to operationalizing the model to investigate epilepsy, the presence of both direct effects of illness representations on adjustment and indirect effects via coping. The implications for clinical intervention work are considered.

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PART 1:

INTRODUCTION AND LITERATURE REVIEW

INTRODUCTION

Aims of the thesis

This thesis aims to use the Self-Regulation Model (Leventhal, Nerenz and Steele, 1984) to develop a measure of illness representations and investigate the role of illness representations in the process of coping and psychosocial adaptation among adults with epilepsy.

Outline of the thesis

Part 1 of the thesis comprises a literature review on; epilepsy as a chronic illness, associated psychopathology, the stress and coping paradigm and the self-regulation model. These bodies of research are brought together to highlight the contribution made by the present work. Finally, specific research questions derived from the literature are presented.

Part 2 contains three chapters. The first concerned with the operationalization of the self-regulation model for the purposes of the present work. The development of a specific instrument to measure patients cognitive representations of epilepsy is presented. The second, reports on the epilepsy study: a cross-sectional study investigating the models predictive power in a group of 94 adult epilepsy patients. In the final chapter, a summary of the main results is presented. Theoretical and clinical implications are discussed along with final suggestions for future research.

CHAPTER 1: EPILEPSY

Definition

There is reasonable consensus in neurology as to how epilepsy should be defined. It is viewed as a symptom complex rather than a disease per se. An epileptic seizure results from an abnormal paroxysmal discharge of cerebral neurones and is a finite event that in itself does not constitute epilepsy. A diagnosis of epilepsy indicates `a chronic disorder characterised by recurrent seizures` (Gastaut, 1973). There is, however, some debate as to what constitutes `recurrent`. It is common practice in the United Kingdom not to diagnose epilepsy or commence anti-epileptic drug (AED) treatment after a single seizure (Hopkins, 1988).

Given that a true epileptic disorder has been established, as opposed to non-epileptic attack disorder (NEAD) which may be psychogenic or have a physical basis, seizure classification is sought. Determination of seizure type has important etiological, treatment and prognostic implications.

Classification of epileptic seizures

Of the available classification systems, the 1981 Classification of Epileptic Seizures is considered the most pragmatic for clinical use (Porter, 1993). It is reproduced in Table 1.1. The classification is based on videotaped examples of seizures and accompanying electroencephalogram (EEG) traces.

Epileptic seizures are fundamentally divided into two groups, partial and generalised seizures. Partial seizures have clinical or electroencephalographic evidence of localised onset, while generalised seizures show a multifocal onset or lack localised onset.

One controversial aspect of classification is the meaning of `impairment of consciousness`. The definition of consciousness, ` the state of awareness of the self and the environment` (Plum and Posner, 1980) is open to much philosophical interpretation. Given this difficulty, a working definition has evolved in which *responsiveness* is the critical factor. If patients display degradation in their ability to respond to exogenous stimuli, then consciousness is considered to be altered. Although responsiveness represents a limited view of consciousness, the definition has the advantage of been testable (Porter, 1989).

Simple partial seizures show evidence of localised onset and no impairment of consciousness (responsiveness). The discharge usually occurs unilaterally with symptoms relating to the affected brain region. The 1981 classification denotes four groups of simple partial seizure (SPS): 1. SPS with motor symptoms, 2. SPS with sensory symptoms, 3. SPS with autonomic symptoms and SPS with psychic symptoms. Most commonly, patients experience either a motor event, such as clonic jerking of an extremity, or a sensory event, such as a bad odour or taste (Porter, 1993)

Table 1.1: 1981 International classification of epileptic seizures.

I. PARTIAL SEIZURES (seizures beginning locally)
- A. Simple partial seizure (consciousness not impaired)
  - 1. With motor symptoms
  - 2. With somatosensory symptoms
  - 3. With autonomic symptoms
  - 4. With psychic symptoms
- B. Complex partial seizures (with impairment of consciousness)
  - 1. Beginning as simple partial seizures and progressing to impairment of consciousness
    - a. With no other features
    - b. With features as in A. 1-4
    - c. With automatisms
- C. Partial seizures secondarily generalised

II GENERALISED SEIZURES (bilateral symmetrical and without local onset)
- A. 1. Absence seizure
  - 2. Atypical absence seizure
- B. Myoclonic seizure
- C. Clonic seizure
- D. Tonic seizure
- E. Tonic-clonic seizure
- F. Atonic seizure

III UNCLASSIFIED EPILEPTIC SEIZURE (inadequate or incomplete data)

Abstracted from: Commission on Classification and Terminology of the International League Against Epilepsy. Approved in September 1981.

Complex partial seizures (CPS) are those attacks that show evidence of localised onset and produce altered consciousness. On occasion, a complex partial seizure will be preceded by an aura (a simple partial seizure). The clinical features of complex partial seizures are a function of their origin and spread. Attacks are logically divided into; temporal, frontal, parietal and occipital complex partial seizures. Complex partial seizures of temporal lobe origin typically begin with motor arrest followed by oroalimentary or other automatisms, last less than one minute and are followed by postictal (i.e. after seizure) confusion. Theodore (1983) defined automatisms or automatic behaviour as `complicated behaviour which requires integration of higher cortical structures`. Complex partial seizures of frontal lobe origin are typically brief with prominent motor manifestations and gestural automatisms. Complex partial seizures of parietal lobe and occipital lobe origin are uncommon, as most are simple partial sensory events (Porter, 1993).

Generalised tonic-clonic (grand mal) seizures can occur secondary to partial seizures. While this generalised seizure represents a progression from one seizure type to another the clinical nature of secondarily generalised seizure does not differ from that of a primary attack.

The generalised seizures form a heterogeneous group. Most prevalent are the tonic-clonic or grand mal seizure and the absence seizure. Tonic-clonic seizures have well defined characteristics involving muscle contraction (tonic phase) and violent spasms of the body (clonic phase). Patients also experience tachycardia, increased bladder pressure, glandular hypersecretion and postictal confusion. Absence (petit mal) seizures typically begin in childhood or early adolescence and are characterised by brief periods of unresponsiveness and various automatisms. Onset is paroxysmal with no postictal effects.

Additional generalised seizures are myoclonias and atonic seizures. Myoclonus has been defined as `quick movement of muscle`, but an unambiguous definition is lacking (Porter, 1993). Atonic seizures involve a sudden loss of postural tone. The resultant falls leave patients at risk of injury, particularly to the face and head.

Epidemiology

Despite methodological differences, there exists a high degree of consistency in incidence rates. Total population studies, defining epilepsy as recurrent unprovoked seizures, reveal incidence rates varying between 24-53 per 100 000 persons (Hauser and Kurland, 1975; Brewis, 1966; Granieri, 1983; De Graff, 1974 and Loiseau, 1987; cited in Hauser and Annegers, 1993). Higher estimates of incidence are provided, 26-70 per 100 000 persons, when single seizures are included (Loiseau, 1987; Zielinski, 1974; Juul-Jensen, 1983 and Stanhope, 1972; cited in Hauser and Annegers, 1993).

A number of studies report age-specific incidence of epilepsy. While providing data consistent with the total population studies, age-specific incidence rates reveal epilepsy to be a condition affecting all age groups with the highest incidence at the extremes of life. Age-specific rates are consistently lower during the adult years. In all studies reporting gender-specific incidence rates for epilepsy or first seizure, males are at a higher risk to develop seizures. The male / female ratio varies from 1:1 to 1:7 (Hauser and Annegers, 1993).

Prevalence rates per 1000 population vary widely, from 2.7 to 40. Although for most studies the range is 4 to 8 per 1000 (Hauser and Hesdorffer, 1990). Age-specific prevalence studies conducted in North America and Europe tend to report a consistent pattern of increasing prevalence in subsequent age groups. Other studies, particularly those from Asia, Africa and South America report the highest prevalence in the second and third decades of life. This difference in age-specific rates could possibly be explained by etiology or higher mortality among the elderly in the less industrialised countries. As with incidence studies, most prevalence studies report higher rates in males compared to females.

Etiology

The causes of seizure and epilepsy in adult life can be categorised into; acute symptomatic seizures, remote symptomatic and idiopathic seizures. The term acute symptomatic seizure was first suggested by Hauser (1982). Such seizures relate to acute encephalopathy produced by a wide range of metabolic or cerebral insults such as disorders of fluid and electrolyte balance and other disruptions of homeostasis. With remote symptomatic seizures, epilepsy develop as a chronic phenomenon in response to persisting cerebral lesion or damage.

The relationship between head injury and post-traumatic epilepsy is well documented (Chadwick, 1993). Sander et al (1990) found the commonest remote symptomatic causes of epilepsy to be vascular disease and tumour. Some aetiologies, including head injury, cerebro-vascular accident (CVA) and intracerebral infections, may produce both acute symptomatic seizures and remote symptomatic epilepsy. In the National General Practice Study of Epilepsy, 60 per cent of all patients had no identifiable cause. Although a proportion of these may have had a genetic syndrome (Sander et al, 1990).

The diagnosis of epilepsy in the adult is made on the basis of clinical evidence. While childhood epilepsy may persist into adulthood, symptomatic partial seizures with or without secondary generalisations become predominant in the adult age range. For late onset epilepsy, determination of etiology becomes an important part of management (Chadwick, 1993).

Prognosis and treatment

Although a range of factors influence prognosis, there is general agreement that a significant number of patients attain a remission of seizures sufficient to attempt anti-epilepsy drug (AED) discontinuation. In an often quoted community based longitudinal study, 70 per cent of patients were found to be in remission lasting 5 years or more at 20 year follow-up (Annergers, Hauser and Elveback, 1979). Remission rates for hospital-based samples are consistently lower, cited as between 20-30 per cent (Rodin, 1968). A recent hospital-based prospective study which followed-up patients from *onset* of their condition reported 82 per cent of patients attaining a two year remission. On the basis of prognostic studies 20-30 per cent of patients diagnosed with epilepsy can be expected to develop chronic `active` epilepsy. This gives a lifetime prevalence of 0.5 per cent (Reynolds, 1989).

The main form of treatment for epilepsy remains drug therapy. With currently available drugs, approximately 80 per cent of patients will have their seizures controlled (Richens and Perucca, 1993). This leaves a significant minority of patients who develop drug resistant epilepsy. Others will display unacceptable acute or chronic adverse reactions to their AED regimen. Advancement in understanding the neurochemical mechanisms underlying seizures permits an increasingly rational approach to the development of AED`s with greater efficacy and less toxicity.

The principle drugs used in the treatment of epilepsy include; sodium valporate, carbamazepine, phenytoin, vigabatrin, phenobarbitone and primidone. All show similar therapeutic results, but phenobarbitone and primidone tend to be used less because of their sedative effects. Drugs that have more recently entered the clinical setting and used in many cases of uncontrollable epilepsy include; oxcarbazepine, lamatrigine and gabapentin. Awareness of the hazards of polytherapy, particularly undesirable levels of toxicity and drug interactions, has produced a general policy of monotherapy.

Other treatment and advice includes learning to recognise and avoid exposure to precipitants. Typically; alcohol, sleep deprivation and stress. For a minority of patients surgery is the treatment of choice.

Summary

Epilepsy is a prevalent neurological disorder and the second most common reason for consulting a neurologist (Hopkins, 1984). Seizures can represent epilepsy or non-epileptic attack disorder (NEAD). In some cases the two conditions co-exist. NEAD can have a physical or an emotional basis. Epilepsy is defined as `a chronic disorder characterised by recurrent seizures`. The causes of epilepsy fall into three categories; idiopathic, which is probably the majority; acute and chronic cerebral insults. Given that a true epileptic disorder has been clinically established, classification is sought and AED therapy commenced. For the majority, up to 80 per cent, the prognosis is good. However, 20-30 per cent develop intractable epilepsy and may exhibit intolerance to current drugs. The psychological and social sequelae to epilepsy has commanded increasing research attention.

CHAPTER 2: PSYCHOSOCIAL ADJUSTMENT TO EPILEPSY

Introduction

This chapter presents an overview of the literature examining epilepsy and psychosocial adjustment. First, the concept of epilepsy as a high psychological risk disorder will be examined. Second, the characteristics, both physical and psychological, associated with adjustment will be discussed. The identified risk factors for psychopathology in epilepsy will be placed within the categories proposed by Hermann and Whitman (1986).

Psychopathology in epilepsy

The association between epilepsy and psychopathology has been subject to serious scientific investigation since the 1960`s. Prior to this, assessment of the interictal (i.e between seizures) psychological state of individuals with epilepsy was an enterprise long on speculation, theory and surmise (Hermann and Whitman, 1984). Early work sought to delineate a universal personality style associated with epilepsy. Tizard (1962) reviewed the literature to that date and found no support for the theory of a common epileptic personality. The available data if anything revealed the effects of institutional living on the non-representative samples studied. There was some support for the notion that different types of epilepsy, particularly temporal lobe epilepsy (TLE) were associated with different psychopathologies. Tizard`s classic paper generated research interest in the psychological risk associated with different epilepsy types.

The sizeable literature was subsequently reviewed by Hermann and Whitman (1984) who concluded `overall rates of psychopathology are increased in epilepsy relative to the healthy population, but not relative to patients with other chronic disorders`. TLE was found to bear no specific psychological risk. This important paper achieved two things. Firstly, empirical support for the epilepsy - psychopathology relationship, which was in line with studies of other chronic diseases (Earll, 1991). Secondly, the need to conceptualise this psychological response not as disease or disease-variable specific, rather as a given individual`s adaptation to illness as determined by a process involving multiple psychological and biological variables.

A range of outcome measures have been employed to examine the epilepsy-psychopathology relationship. Much of this work comes from psychiatry and seeks to determine the influence of epilepsy variables such as seizure type and epilepsy focus on mental health indices, particularly depression.

In reviewing the sizeable literature on interictal depression, Robertson and Trimble (1983) concluded that `depression is a common problem in patients with epilepsy`. In a subsequent study, Robertson (1983) reported that 40 per cent studied had an endogenous depression of moderate severity. Age at onset, seizure type, site of focus, seizure frequency and presence of lesion had no relationship to depression. Depression was seen as the probable outcome of multiple factors in genetically predisposed individuals. Kogeorgos, Fonagy and Scott (1982) evaluated psychiatric morbidity in a group of 66 epilepsy out-patients using the General Health Questionnaire (GHQ) and the Crown-Crisp Experiential Index (CCEI). Nearly half of the sample were classified as probable psychiatric cases. The type and severity of epilepsy were found to influence the degree and pattern of psychiatric morbidity. Studying a sample of hospital out-patients, Mendez, Cummings and Benson (1986) found 55 per cent of epilepsy patients and 30 per cent of matched controls reported depression. Thirty per cent of patients versus 7 per cent of controls reported prior suicide attempts. In a study using healthy controls, Robertson, Channon and Baker (1994) found depressive symptomatology to be over represented in patients with epilepsy interviewed in an outpatient clinic. In a recent review of this literature Robertson (1992) concluded `interictal depression is the most common and clinically relevant syndrome and can vary in severity from moderate to severe`. The biological predictor variables evaluated have, however, displayed an inconsistent relationship with depressive psychopathology.

Additional indices of psychopathology that have been investigated include; aggression (Rodin, 1973; Pincus, 1980; Herman, Schwartz, and Whitman, 1980); psychosis (Hermann and Schwartz, 1981; Parnas, 1982); sexual dysfunction (Blumer and Walker, 1967; Ellison, 1982) and suicide (Hawton, Fagg and Marsack, 1980; Matthews and Barabas, 1981). Whilst revealing positive findings, the literature permits few firm conclusions regarding the association between specific epilepsy variables and various interictal psychopathologies. In sum, there is much evidence in support of epilepsy as a risk factor for psychopathology. However, due to methodological problems the explanatory power of epilepsy or biological variables remains unclear.

Recent work has brought the generally accepted concept of epilepsy as a high psychological risk disorder into question. In a study examining the psychosocial functioning in patients with well-controlled epilepsy, Jacoby (1992) found high levels of adjustment and low reported levels of distress. These findings are consistent with those of Britten, Wadsworth and Fenwick (1986) and Thompson and Oxley (1989). The latter researchers presented data from the Medical Research Council's National Survey of Health and Development, a longitudinal study of a cohort born during one week in England in 1946. This rare prospective study provided follow-up data on 46 children with epilepsy until 36 years of age, relative to matched controls. During childhood, individuals` with epilepsy experienced difficulty with learning and emotional adjustment. However, counter to expectations, by adulthood few differences were apparent between the sample and controls in terms of education and socio-economic circumstances. The only difference at 36 years being a poorer self-concept among epilepsy patients. In an often quoted community study, Throstle, Hauser and Sharbrough (1989) employed the Minnesota Multiphasic Personality Inventory (MMPI) and the only measure developed specifically for epilepsy, the Washington Psychosocial Seizure Inventory (WPSI), Dodrill (1980). Patients having seizures in the past year had somewhat poorer adjustment than those without recent seizures, but even the more severe group appeared relatively well adjusted.

Additional work challenges the notion of higher psychopathology in persons with epilepsy relative to controls (Garyfallos, 1988; Edeh, Toone and Corney, 1990). In a reappraisal of the literature on psychopathology and epilepsy, Hermann and Whitman (1992) highlight the role of selection bias in existing studies. Patients with different levels of epilepsy severity tend to receive care at different locations. Current estimates of psychopathology, derived mainly from samples recruited at specialist epilepsy centres, which treat cases of greater complexity, has biased outcome in the pathological direction. There is ample work to support Hermann and Whitman`s position.

There is no doubt that for some patients, epilepsy is associated with significant psychopathology. The inaccuracies in the literature appear to have arrived from two sources. First, over-reliance on samples recruited from specialist sources, creating elevated estimates of associated psychopathology. Second, the almost exclusive use of a biomedical research paradigm. Other than variables such as; age at onset, duration or epilepsy, seizure type, seizure focus and presence of lesion, few predictor variables have commanded research attention. In the past twenty years, 79 per cent of the non demographic variables investigated empirically as potential risk factors would be subsumed under the biomedical hypothesis. Moreover these variables appear to

have weak explanatory power (Hermann and Whitman, 1986). Research on psychopathology in epilepsy has progressed in relative isolation from mainstream health psychology work examining health-related cognitions and psychological aspects of illness. Hermann and Whitman (1992) commented:

"Although many speciality areas of psychology could make contributions to patient and family care and enhance understanding of the psychological and social aspects of epilepsy, psychologists` involvement with this prevalent disorder has been modest and circumscribed."

There is growing recognition of the need to consider multiple biological and psychosocial variables in order to understand the complex association between epilepsy and adaptation. Whilst the biomedical model is inadequate, a multietiological model appears more appropriate (Smith and Baker, 1993). Such a model has been proposed by Hermann and Whitman (1986) and is presented in Table 2.1.

Table 2.1: High-risk variables for Psychopathology in epilepsy, grouped according to hypothesis

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

In spite of long standing awareness that epilepsy has considerable social and psychological consequences (National Commission for Control of Epilepsy and its Consequences, 1979), a relatively small number of studies fall under the psychosocial hypothesis. After outlining the influence of biological variables, work examining the role of psychosocial factors will be discussed.

Characteristics associated with adjustment

Biological variables - Hermann and Whitman (1986) cite eight neuroepiletic variables considered to be risk factors for psychopathology. These and other biological variables have been the major focus of interest in attempts to understand the determinants of psychopathology in epilepsy. Reviews of this literature reveal intractable methodological problems and little consistency among the findings (Hermann & Whitman, 1986, 1992; Scambler, 1989; Antonak & Livneh, 1992). Hermann and Whitman (1986) write of neuroepileptic factors: `our analysis of certain subsets of these variables suggests that they are relatively modest in terms of their overall explanatory power`.

One variable generating particular debate is duration of disorder. Chronicity has often been linked with both psychopathology and cognitive impairment. However, in the absence of longitudinal data it is difficult to disentangle the influence of chronicity from seizure control and seizure type / severity on adjustment. The presence of selection bias in the literature has further obscured the psychological sequelae among the recently diagnosed relative to chronic patients. In the study of chronic disease generally there is evidence of greatest psychological disturbance in the early stages of illness (Meyercwitz, 1980; Cassileth, 1984). A small number of studies have clearly differentiated epilepsy patients receiving care in a hospital clinic from clinic non-attendees and between well-controlled as opposed to poorly-controlled epilepsy (Edeh, Toone and Corney, 1990; Chaplin, Lasso, Shorvon and Floyd, 1992; Jacoby, 1992). Both recently diagnosed and chronic patients cared for in the community reported low levels of distress and high levels of adjustment. In the early stages of epilepsy, psychosocial effects appear closely related to the severity of the medical condition (Chaplin et al, 1992). Those patients attending hospital clinics, whose epilepsy is less well controlled, showed increased psychiatric morbidity and poorer social adjustment. It appears then, that chronicity combined with poor-control which, represents the minority of patients (20-30 per cent), is associated with maximal psychopathology.

Psychosocial variables - The multidimensional model outlined suggests several psychosocial variables, which are increasingly commanding research attention. It is this area that psychology has the potential to make an important contribution.

Several papers by Mittan and colleagues (Mittan and Locke, 1982; Mittan, Wasterlain and Locke, 1983; Mittan, 1986) have drawn attention to the role of patients beliefs about the consequences of their seizures as precursors of psychopathology. Mittan found pervasive fears of seizures in patients with epilepsy, with 70 per cent reporting fear of dying during a seizure, 45 per cent reporting they lived in continual dread of seizures and 35 per cent believing death could occur from a seizure. Patients also expressed concern about perceived long-term consequences of seizures such as mental illness and cognitive decline. Given the unpredictable and often severe nature of seizures, some of these fears appear justified. However, for other patients these concerns are based on misunderstanding or lack of knowledge. Mittan (1986) reports evidence to support an association between fear of seizures and psychosocial adjustment, with fear of seizures and fear of brain damage being significantly related to patients` daily functioning and rates of psychopathology. Two-thirds of Mittans sample were clinically depressed. Goldstein, Seidenberg and Peterson (1990) provide evidence to support Mittans formulation. Findings indicate fears and concerns about seizures are related to behavioural and emotional adjustment after controlling for the influence of neuroepileptic variables. In a recent national general practice study (Chaplin et al, 1992), 80 per cent of the 192 subjects reported fear of seizures as a problematic aspect of their condition.

Goffman (1963) defines stigma as either the `discredited`, an individual whose differentness is apparent or the `discreditable`, one whose `differentness` is not immediately evident. Given that seizure activity is transient, individuals with epilepsy maybe seen in Goffmans terminology as potentially discreditable. Patients have the choice about to whom they disclose their diagnosis. Stigma has long been thought of as a variable which predisposes to psychopathology in epilepsy. But as Hermann and Whitman (1986) point out, there is a dearth of studies evaluating this relationship. Scambler (1989) discusses the usually irreversible nature of stigma in relation to epilepsy, a condition which, for the majority has a good prognosis. When patients attain remission many continue to live with a `spoiled identity` and a persisting diagnosis of epilepsy.

In a qualitative analysis of the impact of being diagnosed as having epilepsy, Scambler and Hopkins (1986) report distress related to patients awareness of their transformation into an `epileptic`, a condition which many considered to be stigmatising. Patients` perceptions of epilepsy as stigmatising stemmed from a belief in the existence of prejudice and discrimination towards the condition among the general population, rather than actual instances of prejudice.

Scambler suggests there is little support for the `orthodox viewpoint` - that patients struggle with an epileptic identity because of public ignorance and discriminatory actions. Instead, Scambler proposed the `hidden distress model of coping`. The model distinguishes between `enacted` and `felt` stigma. Enacted stigma referring to episodes of discrimination against people with epilepsy and felt stigma referring to the shame associated with having epilepsy and fear of enacted stigma. In the Scambler and Hopkins` study the psychosocial distress experienced by epilepsy patients resulted from the high prevalence of felt as opposed to enacted stigma. The work of Jacoby (1994) supports a dichotomy between felt and enacted stigma. In a study conducted by Arnston, Droge, Norton and Murray (1986) perceived stigma was positively related to perceived helplessness, depression and anxiety, and negatively related to self-esteem and life satisfaction. In a general practice survey, 69 per cent of patients reported fear of stigma (Chaplin et al, 1992). There is then, evidence that perceptions of stigma are prevalent among patients and may contribute to the social and psychological sequelae of epilepsy. Important questions do remain. For example, the process by which patients come to see themselves as different (Jacoby, 1994) and the psychosocial effects of perceived discrimination (Scambler, 1989).

Although epilepsy is a chronic disorder, seizures occur episodically and usually dramatically. The basic nature of epilepsy is, therefore, associated with unpredictability and uncontrollability. Locus of control, originally derived from Rotter`s (1954) social learning theory has been developed into several scales and generated much research in health psychology (Marteau, 1991). Perceived control is defined by Wallston, Wallston, Smith and Dobbins (1987) as `the belief that one can determine one's own internal states and behaviour, influence one's environment and / or bring about desired outcomes`. Not surprisingly the concept of control has been applied to epilepsy. It has been reported that patients with epilepsy develop a greater external sense of control relative to healthy people (DeVellis, DeVellis, Wallston and Wallston, 1980) and diabetic patients (Matthews, Barabas & Ferrari, 1982). In a study of patient perceptions of epilepsy, 38 per cent of patients believed they had no control over their seizures. Using the Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978), Arntson et al (1986) report a positive association between external control and psychopathology in a sample of epilepsy patients. Matthews and Barabas (1986) provide comparable data on children with epilepsy. Further work is needed on the relationship between control and other patient perceptions, and on the development of external control beliefs.

Additional psychosocial variables receiving research attention include; social support (Upton, 1993; Hermann and Whitman, 1990) and life events (Neugebauer, Paik and Hauser, 1994; Temkin and Davis, 1984).

The emerging research literature evaluating the psychosocial hypothesis has, to date, been influenced little by psychological theory or research time. Psychology has been primarily concerned with the cognitive function of epilepsy patients, and more recently the development of quality of life measures to assess drug and surgical treatment effects (Baker, Jacoby, Smith, Dewey and Chadwick, 1994).

Summary

Epilepsy has traditionally been associated with a variety of psychopathologies. Recent work addressing the psychological and social sequelae of epilepsy reveals a more complicated picture and highlights the role of selection bias in many existing studies. Epilepsy patients attending specialist centres, usually due to poor seizure control, appear to have significant psychosocial difficulties relative to healthy individuals. The majority of patients, approximately 70 per cent, tend to receive care in the community and present with fewer adjustment problems. The scant evidence on recently diagnosed patients is suggestive of mild psychosocial problems. A number of important points follow from the recent discrepancies in this literature. First, epilepsy patients do not form a homogeneous group. Second, many current estimates of psychopathology, derived from samples attending specialised centres, appear elevated in a positive direction. Third, further work is needed to delineate the psychosocial effects of a recent diagnosis of epilepsy relative to chronic patients, both hospital and community based. Fourth, while the epilepsy - psychopathology association appears influenced by seizure control, the role of other biological variables and proposed psychosocial variables remains unclear.

A smaller number of studies have investigated the determinants of the epilepsy - psychopathology association. The bulk of these address the role of biological variables and reveal modest explanatory power. In response to an emerging literature revealing that factors outside the biological play a significant role in determining psychopathology in epilepsy, Hermann and Whitman (1986) organised the known or postulated risk variables into three categories; neuroepileptic, psychosocial and medication. This model has engendered an awareness of the need to conceptualise adaptation as a *process* determined by multiple, interacting variables.

However, the psychosocial hypothesis and the relationships between psychosocial and other relevant variables continues to receive limited research attention. Although psychological theory and research skills hold potential to generate a deeper understanding of the psychosocial risk associated with epilepsy, this prevalent condition continues to receive only minimal interest from psychologists.

In short, what appears lacking in the epilepsy - psychopathology literature is an investigation of the proposed psychosocial variables within an strong and unifying theoretical framework. Such a study would permit an examination of the relationships both within and between the three factors proposed by Hermann and Whitman (1986).

CHAPTER 3: COPING WITH CHRONIC DISEASE

The stress and coping paradigm

With the evolution of increasingly sophisticated models of stress, came interest in variables that mediate or moderate the stressor - strain relationship. Coping has received much attention as an intervening variable. Much of this literature investigates coping with discrete events, such as stressful medical procedures (Schmidt, 1988). Interest in applying the concept of coping to chronic disease represents a more recent development which, followed the realisation that biomedical factors alone do not adequately explain the variability in individuals` psychosocial adjustment to illness. Patients` physical and psychosocial functioning maybe significantly affected by psychological factors, including appraisal and coping with the stress of illness (Holroyd and Lazarus, 1982).

An influential conceptual framework for coping research remains that provided by Lazarus (1966) and Folkman and Lazarus (1984). Within their cognitive - phenomenological theory, psychological stress consists of three processes. Primary appraisal, is the evaluation of a demand with respect to what is at stake or its threat potential. Secondary appraisal, comprises an evaluation of the available resources to deal with the threat. Coping is seen as the cognitive or behavioural efforts made to deal with the threat. Coping efforts therefore follow stress appraisals.

The model is useful as it views coping as a process, with appraisals and coping continually influencing each other throughout the person - environment transaction. For example, belief that one has an adequate coping response or prior successful coping may lead to reappraisal of the threat as less threatening. Similarly, if ones coping efforts prove less effective than expected, than reappraisal of the threat or coping strategy may occur. Coping is therefore proposed as a dynamic process. It follows that coping efforts can vary, from correcting or mastering the threat to altered perceptions of the stressor - strain relationship.

Sarafino (1994) provides a succinct definition of coping, which draws on the Folkman and Lazarus classic model of coping. Stress is seen as `a perceived discrepancy between the demands of the situation and the resources of the person`, and coping `the process by which people try to manage the perceived discrepancy between the demands and resources they appraise in a stressful situation`.

In both definitions, coping refers to any response, cognitive or behavioural, which the individual makes in an attempt to reduce stress.

Functions of coping

To study the coping process, Folkman and Lazarus (1980) developed the Ways of Coping Checklist (WCCL). Embedded in the WCCL are two functions of coping, altering the problem causing the stress or changing the emotional response to the stressor. The first, termed problem-focused coping is aimed at reducing stress by reducing the impact of the stressor (e.g. plan a solution) or increase ones resources (e.g. learn a new skill). The second, emotion-focused coping is aimed at controlling the emotional response to the stressor (e.g. seeking social support). The majority of stressors elicit both types of coping. However, situations in which people feel something can be done, favour problem-focused coping, whereas emotion-focused coping tends to predominate when a stressor is seen as having to be endured. (Folkman and Lazarus, 1980).

Measurement of coping

The original WCCL comprised 68-items designed to assess problem-focused and emotion-focused coping. Subsequent research revealed this initial measure of coping to have limitations. First, the scale was found to be too long and contain irrelevant items (Folkman and Lazarus, 1985; Ben-Porath, Waller and Butcher, 1991). Second, the yes / no response format was substituted for a Likert scale (Felton, Revenson and Hinrichsen, 1984; Scheier, Weintraub and Carver, 1986). Third, and most fundamental, the dichotomous factor structure of the original WCCL has proven over simplistic (Carver, Weintraub and Scheier, 1989). Research typically finds the WCCL to form several factors rather than just two (Aldwin, Folkman, Schaefer, Coyne and Lazarus, 1980; Aldwin and Ravenson, 1987; Folkman and Lazarus, 1985 and Scheier et al, 1986). Common to these empirical studies is the finding that problem-focused coping forms a single scale, while emotion-focused coping comprises two or more subscales.

Vitaliano, Russo, Carr, Maiuro and Becker (1985) administered the seven factored scales derived by Aldwin et al (1980) from the original WCCL, to three groups of distressed subjects. Factor analysis revealed a revised factor structure (WCCL-R) comprising five scales; problem-focused, seeks social support, blamed self, wishful thinking and avoidance.

Whilst the original scales had respectable reliability coefficients the WCCL-R scales demonstrated greater alpha values (range 0.74 to 0.88). More importantly, the revised scales shared substantially less variance compared to the original scales. In terms of predictions from the transactional model of stress and existing data, the WCCL-R yielded consistent results. For example, when stressors were perceived as changeable or requiring more information subjects utilised more problem-focused coping. In contrast, appraisals of acceptance were associated with greater emotion-focused coping. Depression was found to be negatively associated with problem-solving and positively associated with wishful thinking. In sum, the empirically derived WCCL-R has demonstrated adequate psychometric properties, hence comprises a brief measure of five conceptually distinct coping scales. In its various forms, the WCCL has been extensively used in health research, for example, patients with diverse chronic conditions (Bombardier, Amico and Jordan, 1990), rheumatoid arthritis (Felton and Ravenson, 1984) and chronic epilepsy (Upton and Thompson, 1992).

Coping with chronic illness

In studies examining coping and adjustment to chronic disease, coping has been conceptualised firstly, as cognitive or behavioural strategies to reduce stress and secondly, appraisals or health-related beliefs such as control or causal attributions. Studies in the former group, typically draw on the Folkman and Lazarus model and its consequential measures, whereas studies concerned with beliefs and adjustment have tended to examine the role of single beliefs or look for interactions between specific beliefs and coping.

Felton, Revenson and Hinrichsen (1984) evaluated the utility of the stress and coping paradigm for explaining individual differences in psychological adjustment among 170 adults with differing chronic illnesses. Information seeking (problem-focused) was related to positive affect, whilst emotion-focused strategies (avoidance and self-blame) were related to negative affect and poorer adjustment to illness. In general, studies of coping with chronic disease have found emotion-focused coping (avoidance, wish-fulfilment and self blame) to be associated with poor adjustment (Bombardier et al, 1990; Felton and Revenson, 1984).

In the only study to examine coping among epilepsy patients, Upton and Thompson (1992) report findings consistent with the general coping literature. Whilst cognitive restructuring was associated with good adjustment, wish-fulfilment was related to poorer scores on adjustment measures.

Another distinction among coping strategies that overlaps with problem / emotion-focused is between approach and avoidance strategies (Holahan and Moos, 1985). Although most stressors appear to elicit both types of coping, individuals with more personal or environmental resources may rely more on approach and less on avoidance coping (Holahan and Moos, 1987).

There are data to suggest a relationship between the duration of illness and efficacy of coping. Suls and Fletcher (1985) compared avoidance and attention strategies in a meta-analysis of 43 previous studies. Avoidance strategies were found to be adaptive in the early stages of illness. However, with time, attention strategies became more effective than avoidance in the coping process. In their study of chronic and acute pain patients, Holmes and Stevenson (1990) found approach strategies to be more adaptive than avoidance for the chronic group but not for the recent-onset patients. Avoidance may, therefore, be an adaptive coping strategy for short-term stressors or in the early stage of chronic disease.

Patients perceptions of control over the symptoms, course and treatment of disease has received research attention. Parkes (1984) suggests that control may influence peoples appraisal of stressors, particularly in appraising their potential to alter the stressor. Studies have shown perceived personal control to be associated with; good adjustment to breast cancer (Taylor, Lichtman and Wood, 1984), recovery from cerebro-vascular accident (Partridge and Johnston, 1989), reduced depression and adaptive coping with epilepsy (Rosenbaum and Palmon, 1984). However, maintaining a belief in personal control over a severe chronic disease, which represents an uncontrollable stressor, may pose a threat to adaptation (Burlish, Carey, Wallston and Stein, 1984; Affleck, Tennon, Pfeiffer and Fifield, 1987). This finding has been replicated among a sample of chronic epilepsy patients (Rosenbaum and Palmon, 1984). At low and medium rates of seizure frequency, patients classified as high on a self-control schedule (SCS; Rosenbaum, 1980) were less depressed, less anxious and coped better with their condition compared to low SCS patients. However, high seizure frequency was associated with poor adjustment for both high and low SCS patients.

There is evidence to suggest the controllability of the stressor may influence the effectiveness of coping, with problem-focused coping being best for controllable conditions such as diabetes mellitus and avoidance coping more adaptive in uncontrollable conditions (Roth and Cohen, 1986). Using a longitudinal design, Felton and Revenson (1984) studied the effects of coping on psychological adjustment among patients with four types of chronic illness. Rheumatoid arthritis and cancer, which are not open to control and diabetes and hypertension, which seem more responsive to control efforts. Whilst both coping and control exerted independent effects on adjustment in the expected direction, no interaction was observed between emotion-focused coping and control.

Additional cognitive factors evaluated in the context of coping with health threats and chronic disease include causal attributions, particularly self blame. Attributions for the cause of a chronic illness appear to be commonly made (Taylor et al, 1984). Findings regarding self blame and adaptation have been inconsistent (Taylor, 1990). Data concerning the adaptational impact of attributions made to another person appears more uniform. In a review of this literature, Tennen and Affleck (1990) concluded that blaming others for ones illness, as opposed to self blame, is associated with poorer emotional and physical well-being. In a study of morbidity following myocardial infarction, blaming others for the initial attack was predictive of re infarction (Affleck, Tennon, Croog and Levine, 1987).

Conclusions

The psychosocial adaptation of individuals with chronic disease varies widely. For many conditions, biomedical factors alone do not adequately account for these differences. Research interest has increasingly turned to evaluating the role of stress and coping in peoples adjustment to illness. Specific models within the stress and coping paradigm include; the transactional model of stress, learned helplessness theory, control theory and social learning theory. It is generally accepted that the outcome for any coping strategy can be positive or negative depending on such factors as the timing and nature of the illness. However, the literature does reveal consistencies. Strategies such as wish-fulfilment, blaming others and cognitive and behavioural avoidance have generally been associated with poorer adjustment to disease, while personal control and problem-focused coping tend to be associated with better outcomes. Whilst the stress and coping paradigm has demonstrated utility in explaining individual differences, the amount of variance in adjustment accounted for has been modest.

In order to further elucidate the complexities of health related behaviour and adaptation to chronic disease, researchers have sought an alternative integrating theoretical framework. An important line of theory and research in social and health psychology concerns the basic question of how individuals think about and construe health threats. This is the study of health and illness representations.

CHAPTER 4: THE SELF-REGULATION FRAMEWORK

Background

Leventhal and colleagues have spent several years developing a model to describe and predict how people represent and subsequently respond to health related stressors (Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984). The model has been extended to address the issue of coping with chronic disease (Leventhal and Nerenz, 1983; Leventhal and Nerenz, 1986). In these and other papers Leventhal et al presented both reasoned argument and empirical data showing that patients employ *implicit theories of illness* to understand and regulate their health behaviour. Of the available models this seems to offer the widest framework to consider the complexities of adaptation to chronic disease (Earll, 1991). The model builds on earlier stress and social cognition models and provides a framework which, subsumes many of the psychosocial variables previously reviewed by Hermann and Whitman (1986), and found to be relevant in the epilepsy - psychopathology literature. Other descriptions for the self-regulation model include; parallel processing model, information processing model and common-sense model of illness representations (Leventhal and Nerenz, 1983). The various names for the model allude to its underlying assumptions and composition. These features will now be outlined.

A model of Illness representations

The main theme of the model is the view that patients actively construct a cognitive representation of illness and regulate health behaviour in ways consistent with this representation. There are four basis assumptions to the model (Leventhal et al, 1984):

Active processing. People are seen as active information processors who construct cognitive representations, emotional reaction and coping responses from both current illness related information and memory.

Parallel processing. The processing system comprises two pathways. One involving the creation of a cognitive representation of an illness and a coping plan to manage the threat. The second comprises an emotional response to the illness and a coping plan for the management of emotion. The two pathways interact as the individual experiences a health threat.

Stages in processing. Peoples strategies for coping with health threats follow from their representation of the problem and accompanying emotions. The results of coping are evaluated and via feedback, used to alter the individuals representation or coping. The system is therefore recursive, with coping strategies influencing the cognitive representation of disease and in turn future coping effort.

Hierarchical processing. The processing system operates at both concrete and abstract levels. For example, the representation or meaning given to a health threat, coping and appraisal involve both concrete features (a seizure) and abstract information (a diagnosis of epilepsy). Discrepancy between concrete and abstract levels may produce distress or regime non-adherence. A person who reinterprets a diagnosis of epilepsy as `faints` may not see the need to take medication or stop driving.

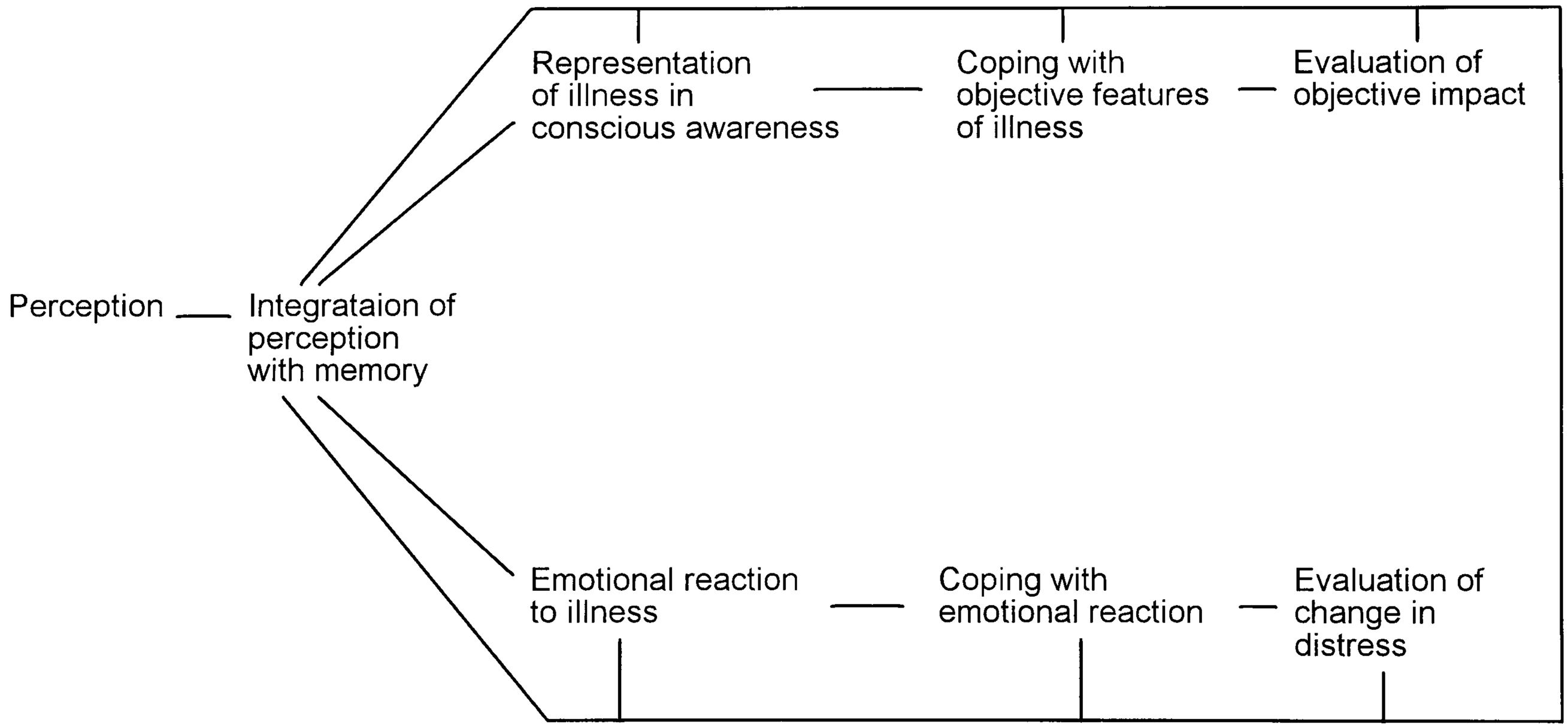
The model can be seen in Figure 4.1. The majority of the research has focused on the top or `objective` pathway, in particular the components of illness representations, their interrelationships and associations with coping and health outcomes.

Leventhal et al (1984) and Leventhal and Diefenbach (1991) propose that patients` illness representations are based on distinct components. These comprise; *identity*, *cause*, *time-line* and *consequences* of an illness. Lau and Hartman (1983) added a fifth, *cure or controllability*. In a recent review of this literature, Skelton and Croyle (1991) confirm the stability and validity of the five components.

The *identity* component consists of the patients` beliefs about possible or actual labels for the condition and the symptoms experienced. People may experience seizures, usually simple, long before a diagnosis of epilepsy is made. A diagnosis of epilepsy carries societal restrictions and has implications for the coping process.

Cause refers to patients` beliefs about the original cause of the condition. For epilepsy patients`, ideas about behavioural and environmental precipitants to seizures have causal significance. For example, patients` with epilepsy may not know why they have the condition but strongly believe that over exertion results in an attack. There exists a sizeable literature examining causal attributions which, can be utilised to inform on issues of measurement and research questions when evaluating the self-regulation model. For a review of this literature see Croyle and Barger (1993).

Figure 4.1. The Self-Regulation Model (Leventhal, Nerenz and Steele, 1984)



The *consequences* component relates to the perceived physical, psychosocial and economic consequences of illness. Epilepsy is a condition with dramatic consequences for many patients. These include; loss of a driving licence, perceived or actual stigma and discrimination, possible change of occupation, the shame of a public seizure and possible physical harm. Many variables subsumed within this component are known to influence patients` adjustment to epilepsy (Hermann and Whitman, 1986). The self-regulation model permits such variables to be examined in relation to other components of an illness representation and coping strategies.

Timeline indicates the perceived duration and course and the illness. Patients expectations fall into three categories; acute (symptomatic and curable), cyclic (symptomatic, removable but recurrent) and chronic (a stable part of the self regardless of symptoms), (Leventhal and Nerenz, 1983).

The *curability or controllability* component (Lau and Hartmann, 1983) relates to patients beliefs about cure or control over their illness. The five components were confirmed in a second study that examined illness experience over time (Lau, Bernard and Hartman, 1989).

While providing evidence that illness representations can be thought of in terms of `prototypes` that people have for their specific diseases, the work of Bishop (1991) supports the existence of the five components of illness representations.

In generalising the self-regulation model to chronic illness, Leventhal and Nerenz (1983) added the concept of *self-illness relationships* to the five basic components of illness representations. Using data obtained by Gutmann, Pollock, Schmidt and Dudek (1981) on coronary bypass patients and their own work with cancer patients, Leventhal and Nerenz (1983) proposed three ways in which the illness relationship can relate to the self-system. Firstly, *total*, where every human activity incorporates illness. A patients self-concept is tightly bound to the idea and impact of illness. Secondly, *encapsulated*, a component of the self is diseased but large areas of the self are disease free. Thirdly, *at-risk*, involves a permanent state of threat or potential for periods of symptomatic illness. From available data, encapsulation of the disease and recognition of risk, is associated with better adaptation to illness that a belief that ones relationship with disease is total. A patients involvement with epilepsy may become total when seizures occur frequently and in multiple settings. Patients who experience exclusively partial or nocturnal seizures, or have good control may see themselves as at risk, adopting an encapsulated representation of their epilepsy.

The development and coping implications of self-illness representations remains an area for investigation.

In sum, the model views health-related behaviour and adaptation as the result of an ongoing process in which, patients` integrate internal and external illness information with existing cognitive structures to form an illness representation. This representation, based around distinct components, directs coping. Appraisal of coping outcome provides feedback via which, the representation and future coping can be shaped. Emotional responses are processed in parallel to this cognitive response. The model draws on the coping literature, social cognition theory and general theories of cognition to provide a broad, adaptable and useful framework for understanding illness-related coping.

Studies of illness representations: acute and chronic disease

In their original work, Leventhal and colleagues employed semi-structured interviews combining both open-ended and specific probe questions to elicit patients illness representations. The aim being to allow patients to define the representation themselves rather than respond to specific suggestions. These and other studies have revealed findings relevant to the assumptions underlying the self-regulation model.

In the studies on hypertensive patients, Meyer (1981), cited in Leventhal and Nerenz (1983) and Meyer, Leventhal and Gutmann (1985) found the majority of patients in treatment believed that people in general could not monitor blood pressure changes. Hypertension is considered to be an asymptomatic condition. When patients were asked if *they* could tell when their blood pressure was elevated, between 71 per cent and 94 per cent indicated they could. It was concluded that patients seek symmetry between abstract labels and concrete symptoms. When given a diagnosis, symptoms are sought to serve as indicators of the underlying disease. Conversely, when symptoms are experienced, patients will seek a label to explain them. The link between labels and symptoms, taken as an example of hierarchical processing, is further illustrated by work on the adaptation of cancer patients to chemotherapy (Nerenz, 1979, cited in Meyer et al, 1985; Nerenz, Leventhal and Love, 1982). Patients whose cancerous nodes disappeared rapidly became more distressed than patients who experienced a gradual response to treatment. The results were taken to support the integration of concrete and abstract information in the formation of representations.

For some patients treatment created a discrepancy, with chemotherapy continuing in the absence of palpable signs of disease. These findings are congruent with emotion theory (Schachter and Singer, 1962).

An additional finding of interest to emerge from the studies on hypertensive patients supports the position that illness representations change and become elaborated over time. Evidence suggests that patients initially hold an acute outlook of disease, which gradually moves to a chronic model (Meyer et al, 1984).

Johnston, Marteau, Partridge and Gilbert (1990) describe a series of studies evaluating changes in parental perceptions of the controllability and seriousness towards a range of childhood chronic diseases. Parents of children with disease rated their own childs disease as less serious than both medical practitioners and other parents. The data suggest that following diagnosis, perceptions of seriousness become lessened. Taken with studies conducted by Marteau and Johnston (1986), it appears that representations may be changed in line with the experience of illness. While parental ratings of seriousness may decline in the first year post diagnosis, over time and with experience of possible complications, conditions may be seen as more serious. These data support the assumption taken by the self-regulation model, that symptoms and experience of illness may produce changes in peoples cognitive representations.

Although illness representations are influenced by multiple variables and may become elaborated over time, two recent prospective studies (Petrie, Buckley and Weinman, 1995; Pimm, Byron and Curson, 1995) reveal a picture of both change and stability in illness representations.

The origin and elaboration of illness representations are proposed as the product of several sources of information (Leventhal et al, 1984). First, the general pool of illness information current in the culture. Second, social communication or information obtained from other people including doctors. Thirdly, personal experience of illness. In a series of laboratory studies, Croyle and his colleagues, reviewed in Croyle (1992), investigated the determinants of illness cognition's. Previous experience of the disorder and belief in a high prevalence, were associated with perceptions of low seriousness. In a series of similar experiments, Baumann, Cameron, Zimmerman and Leventhal (1989) provide data consistent with the idea that patients engage in some form of cognitive activity in order to update their representations of illness.

A range of variables including; symptoms, label, prior beliefs about a given disease and relevant environmental cues were influential in the elaboration of patients representations. The assumptions underlying the self-regulation model do, therefore, have some empirical support. However, further work is needed to integrate the ubiquitous concept of cognitive appraisal into models of coping (Croyle, 1992).

Illness representations and coping

According to the model, coping is directed by the illness representation. Leventhal and his colleagues have produced data to support this relationship. For example, Meyer et al (1985) studied the effects of illness representations on treatment regime adherence among hypertensive patients. Those who believed treatment had beneficial effects on their symptoms were more compliant with treatment and had lower blood pressure. Patients were likely to drop out of treatment if they believed hypertension to be an acute as opposed to chronic condition. The data illustrated the role of identity and timeline components in guiding coping behaviour.

In studies of cancer patients receiving chemotherapy (Nerenz et al, 1981), very few patients dropped out of therapy despite many being symptom free. The threat of cancer, which is intrinsic to the disease label, and social pressure from family prevented patients from stopping the unpleasant treatment (Leventhal et al, 1984). Further evidence for the influence of illness representations on adherence to treatment regimens is provided by Leventhal, (1992) and Leventhal, Diefenbach and Leventhal, (1992).

Cameron, Leventhal and Leventhal (1993) employed the self-regulation model to study the determinants of care-seeking behaviour. Compared to non care-seeking controls, care-seekers reported more symptoms. However, the presence of symptoms was not sufficient to motivate care-seeking. Those seeking care gave their symptoms higher seriousness ratings and could identify their consequences at the point of calling for care relative to symptom onset. Coping by seeking care followed from a well developed illness representation of the health threat. Lau, Bernard and Hartman (1989) found patients who possessed strong identity and cure components were more likely to cope with common illnesses by seeking medical attention.

Illness representations have also been shown to influence; health promotive behaviours (Hampson, Glasgow and Toobert, 1990; Leventhal, Prohaska and Hirschman, 1987); return to work in chronic back pain patients (Lacroix, 1991) and time taken to seek medical care following myocardial infarction (Browne and McGee, 1995).

A number of British researchers have recently investigated the associations between illness representations, coping and adjustment to disease using questionnaire measures. In accord with the model, coping was conceptualised as a mediating factor.

In a study of chronic fatigue syndrome patients, Moss-Morris, Petrie and Weinman (1996) report a range of significant relationships between illness representations, as measured by their Illness Perception Questionnaire (IPQ; see Chapter 5) and coping, as measured by the COPE scale (Carver, Scheier and Weintraub, 1989). Similar findings are reported for patients with a recent myocardial infarction (Petrie, Buckley and Weinman, 1995). Both illness representations and coping were found to be directly related to disability and psychological well-being. However, illness representations were stronger predictors of outcome than coping variables, accounting for 37 per cent and 19 per cent of outcome variance respectively.

A study of patients with motor neurone disease (Earll, Johnston and Mitchell, 1993) and a further study of multiple sclerosis patients (Earll and Johnston, 1994; cited in Williams, 1995) have demonstrated similar results. While illness representations are associated with coping, direct effects are found between illness representations and adjustment to disease.

In sum, recent studies using the self-regulation model to study coping and adjustment to chronic disease reveal findings that are consistent with but not strictly in keeping with predictions. Illness representations are associated with coping and subsequently outcome, as predicted. However, illness representations appear to have direct and powerful effects on adjustment, which are not mediated by coping.

There is some evidence that patients coping and adjustment can be improved by modifying illness representations. Such intervention studies have taken place with; asthma patients (Williams,1995), rheumatoid arthritis patients (Pimm et al, 1995) and diabetes patients (Gonder-Frederick and Cox, 1991).

On considering recent research based on the self-regulation model, Leventhal (1995) points out that the model is not a theory but a *framework* to guide research questions. There are no specific measures or hypotheses that follow from the model. Rather it should be operationalized to suit the condition under investigation.

Illness representations and coping with epilepsy

Health oriented researchers interested in illness behaviour require psychological models to guide and unify their inquiries. Of those available, the self-regulation model appears to offer the most comprehensive and adaptable framework in which to conduct such research. The original work of Leventhal and colleagues and recent health psychology research emerging from Great Britain provide empirical support for the models utility in predicting coping behaviour and health outcomes in chronic disease. To date, the model has not been applied to a sample of patients coping with epilepsy.

Psychological phenomena in neurological disorders generally and epilepsy specifically have frequently been considered only within disease categories, rather than psychological categories (Earll, 1991). Hermann and Whitman (1986) state the need to consider both biomedical and psychosocial factors in order to understand patients adaptation to epilepsy. Many of these psychosocial variables can be subsumed within the illness representation components integral to the self-regulation model.

Hence it was decided to assess the illness representations among epilepsy patients and use the self-regulation model to investigate the process of coping and adaptation to epilepsy.

Research questions

Research questions following from the self-regulation model are presented below:

(1) a) How do the components of the illness representation relate to each other?
b) Which demographic / neuroepileptic variables influence illness representations?
c) Are there group differences in cognitive representations of epilepsy?
d) How do epilepsy patients cope with their condition?
e) What are the mental health outcomes?

(2) a) Are there differences in coping style between the three groups studied?
b) Are there group differences in measures of mental health?
c) Do the groups differ in self-esteem or social anxiety?

(3) Is the self-regulation model of use in understanding the relationships between the variables measured?:
a) Are patients representations associated with coping?
b) Do illness representations predict mental health outcomes?
c) Is coping associated with mental health outcomes?
d) Do illness representations predict coping efforts, which in turn predict mental health outcomes?

PART 2:

APPLYING THE SELF-REGULATION FRAMEWORK TO EPILEPSY

CHAPTER 5: OPERATIONALIZATION OF THE SELF-REGULATION MODEL FOR THE EPILEPSY STUDY

Introduction

The second part of this thesis comprises two sections. First, the development of an instrument to measure illness representations in epilepsy patients will be outlined. Second, data are presented from a cross-sectional study evaluating the role of illness representations in the process of coping and adjustment to epilepsy

In order to integrate existing variables known to influence the epilepsy - psychopathology relationship into the self-regulation framework it was necessary to develop a specific measure for use with this patient group. After outlining existing measures, this chapter describes the development of a new measure of illness representations for the purpose of this thesis.

Measurement of illness representations

The original data obtained by Leventhal and colleagues were qualitative, obtained from semi-structured interviews (Leventhal and Nerenz, 1985). The aim being to allow patients to define the representation rather than suggesting specific attributes for them to respond to. While these studies yielded important results, the approach taken is time consuming and produces variation in the quality of responses. As interest in illness representation has gathered pace, researchers have sought to develop quantitative questionnaire measures which, are quick to administer, open to psychometric validation and can overcome problems of comparing data between studies.

One such measure, the Implicit Models of Illness Questionnaire (IMIQ; Turk, Rudy and Salovey, 1986) comprises 38 items scored on a nine point likert scale. Although the IMIQ was based on the self-regulation model, its four subscales (seriousness, personal responsibility, controllability and changeability) do not correspond with those proposed by Leventhal. Turk et al (1986) claimed their data oppose the notion of five illness representation components. As pointed out by Bishop (1991), Turk et al (1986) provides statistically defined dimensions which simply comprise regroupings of Leventhals conceptually defined components. The two approaches examine different, but complementary aspects of the same phenomena (Bishop, 1991).

A more recently developed questionnaire is the Illness Perceptions Questionnaire (IPQ; Moss-Morris, Petrie and Weinman, 1996; Weinman, Petrie, Moss-Morris and Horne, 1996). The scale was theoretically derived to assess the five illness representation components set out by Leventhal and colleagues. Test items were either generated by the authors or obtained from interviews with patients from seven illness groups. Preliminary psychometric data are presented by Weinman et al (1996).

It seems clear that there are merits to both the interview and the questionnaire approach. However, available questionnaire measures, although appropriate, were deemed to be too constricting for inclusion in the present study. It was decided to develop a new measure for use exclusively with epilepsy patients. The approach taken was that of combining open-ended questions with rating scale items and administer the instrument in an interview format. Item generation was theoretically driven by the distinct components proposed by Leventhal et al (1984) but several sub components were added to include variables known to be associated with adjustment in the wider epilepsy-psychopathology literature. Such variables include; fear of seizure and perceived stigma, subsumed under the *consequences* component; blaming others, subsumed under the *causal* component and external control, subsumed under the *control* component. The rationale behind the instrument being to engage patients` in a smooth flowing interview, obtaining both spontaneous verbal responses and scores for each illness representation component.

Both the open-ended questions and specific items to be rated were derived from three sources; patients diagnosed with epilepsy, existing scales and the author. The patient generated items were obtained from interviews with members of a local British Epilepsy Association support group. All items were selected to reflect the Leventhal groups description of illness representation components (Leventhal and Nerenz, 1985). The specific items were scored on a seven point scale ranging from `strongly disagree` to `strongly agree`. Patients were given this response scale at the beginning of the interview. On the basis of pilot work, changes were made to promote the instruments comprehensibility and reduce its administration time.

In a recent study Weinman et al (1996) administered both a structured interview and the IPQ to a group of 52 diabetic patients. A close fit was found between interview and questionnaire data. However, patients who were interviewed first found the IPQ easier to complete. This was believed to be due to a `priming effect`, with the interview serving to activate the relevant illness schemata.

It is suggested that open - ended questions relating to the illness representation components can usefully precede administration of the IPQ. This suggestion receives support from Bishop (1991) who conducted a series of studies examining the cognitive processes involved in interpreting illness information. Subjects could process illness information faster when the information presented closely matched what they already knew about the underlying disease, or their disease prototype.

The full interview with instructions to subjects and response scales is shown in Appendix 1. All items marked with an asterisk are reversed scored. The six illness representation components making up the instrument are briefly described below.

The *identity* scale is comprised of an open-ended question about symptoms experienced in the last six months, followed by specific items on three subscales. `Epilepsy symptom severity` comprises twenty epilepsy symptoms derived from the International Classification of Epileptic Seizures (1981). `Non-epilepsy symptom severity` includes six non-specific symptoms, such as tiredness, loss of appetite and breathlessness. These symptoms were chosen to represent diffuse physical symptoms unrelated to either seizure activity or AED side effects. Symptoms elicited from open questions and both sub-scales were rated for severity (1 `very mild` to 5 `very severe`) and frequency (1 ` < 3 mthly` to 5 `daily`). The scales correlated strongly (0.9), hence only the severity scale was used in the analyses. Thirdly, the `label` scale comprises three items to assess patients belief that their attacks represent epilepsy as opposed to non epileptic attacks. Items on the latter scale were rated 1 `strongly disagree` to 7 `strongly agree`. The *identity* scale was designed to embody the concept of hierarchical processing, which is integral to the self-regulation model and receives support in the literature reviewed in Chapter 4.

The *causal attribution* scale firstly asks patients an open-question about the cause of their epilepsy and about events that trigger individual seizures. Patients were generally able to give an account of both etiology and precipitants. The causal beliefs scale comprises six subscales; `personal responsibility`, `blaming others`, `environment`, `stress`, `genetic` and `chance`. All items were rated on the seven point agree-disagree scale. Originally, items measuring chance and genetic causal beliefs were pooled into a single scale. On the basis of the reliability analysis this scale was split into single items for each causal belief.

After presenting patients with an open-ended question about the expected duration of their epilepsy, the *temporal course* scale comprises five items to be rated on the seven point agree-disagree scale. The scale was designed on the concept of; `acute`, `cyclic` and `chronic` time perceptions. Analysis revealed a good level of distinction between these beliefs. Each can be scored positively. Alternatively, with reverse scoring of the marked items, the scale can be collapsed to yield a single score indicating a chronic / cyclic time perception.

The *consequences* scale comprises four sub-scales each preceded by an open-ended question which, produced disclosures of usually sentient personal information. The physical sub-scale draws on Mittan`s (1986) concept of `fear of seizure`, discussed in Chapter 2. The scale includes such items as; belief that seizures may cause swallowing of the tongue and over time, some loss of memory. The `perceived` and `enacted stigma` sub-scales were influenced by Scambler`s (1986) qualitative work on peoples experience of epilepsy. This literature is reviewed in Chapter 2. Patients were required to rate items about their perceptions of differentness to other people and their actual experience of stigma in various settings. The fourth sub-scale examines a related concept, that of `perceived discrimination`, particularly in the area of employment. Items here were intended to elicit patients beliefs about restrictions with regard to; driving, work and social situations. Patients rated all items on the seven point agree-disagree scale.

The *control* scale comprises three sub-scales; `internal`, `external` and `chance / fate`. Each are preceded by an open-ended question and patients answers documented. All three sub-scales are rated on the seven point scale and scored in a positive direction.

It was decided to develop the concept of types of *self-illness relationships* discussed by Leventhal and Nerenz (1983). See Chapter 4. Given that epilepsy varies in; seizure type, seizure severity and psychosocial impact, it was considered important to examine to what degree patients can `encapsulate` their condition. For example, patients will view their generalised epilepsy differently if seizures are exclusively nocturnal. Similarly, some patients receive adequate warning of an impending seizure, usually in the form of a simple partial seizure, to enable them to seek a safe / private environment. There are then, factors inherent to epilepsy that may influence patients` perceptions of their condition in relation to their self systems. An open question about how big a part epilepsy plays in a patients life is followed by two sub-scales. First, `role contamination` elicits patients ratings of the impact of epilepsy on distinct areas of living.

Second, a brief scale was developed to examine `containment of disability effects`. Items on the latter scale were modified from the Sickness Impact Scale (Linkowski, 1971) and the Acceptance of Illness Scale (Upton, 1995). All items are rated on the seven point agree-disagree scale.

Using data collected from a sample of 94 epilepsy patients the scales were analysed for their internal consistency. On the basis of this analysis a total of eight items were dropped from different sub-scales. Reliability data for the final version of the instrument are presented in Table 5.1.

Table 5.1: Internal consistency (Cronbachs alpha) and number of items for the illness representation scales.

SCALE	Sub-scale	No. items	Alpha
Identity:	epilepsy symptom severity	20	.81
	non-epilepsy symptom severity	6	.63
	label	2	.72
Cause:	personal responsibility	6	.77
	blame others	5	.81
	environment	2	.57
	stress	2	.79
	genetic	single item	
	chance	single item	
Timeline:	timeline	5	.82
	acute	2	.69
	cyclic	single item	
	chronic	2	.81
Consequences:	physical	5	.78
	perceived stigma	6	.77
	enacted stigma	3	.79
	perceived discrimination	7	.72
Control:	personal	5	.78
	external	3	.70
	chance / fate	2	.76
Self-Illness relationship:	role contamination	6	.80
	containment	5	.79

Scoring and administration

To score the identity scale, each symptom is rated form 1 `very mild` to 5 `very severe` (severity scale) and 1 `<3 mthly` to 5 `daily` (frequency scale). Total scores represent the sum of the symptom responses.

All of the remaining sub-scales are rated from 1 `strongly disagree` to 7 `strongly agree` and scored in a positive direction. Certain items, marked with an asterisk are reversed for scoring (see Appendix 1). Sub-scale items are summed to give total scores.

The interview began by obtaining; demographic, neurological and medication information from patients. Participants were then told that they would be asked both open-ended questions and read statements to be rated from the scales in front of them. In keeping with the interview protocol adopted by Meyer et al (1985) patients were told to say what they thought was true for *their* epilepsy, as opposed to epilepsy in general. Patients had no difficulty with this distinction. Answers to the open-ended questions were transcribed. Administration time ranges between 20-30 minutes. For some patients prompting is required to maintain the flow of the interview.

Conclusions

In this chapter, the development of a measure for assessing patients cognitive representations of epilepsy is outlined. There are two main reasons for constructing this new measure. Firstly, the limited applicability of existing instruments to the epilepsy population and secondly, the advantages offered by combining qualitative and quantitative approaches to measurement. The measure was designed to assess the distinct components of illness representations proposed by Leventhal and his colleagues. Additional variables known to influence adjustment to epilepsy have been incorporated within the illness representation components. The self-regulation framework (Leventhal et al, 1984) incorporates this degree of pliancy.

The instrument elicits both spontaneous verbal responses and scores from rated items, with administration taking the form of an interview. This format was agreeable to patients and took between 20-30 minutes. The data presented suggest the scales have satisfactory internal consistency. Further work to establish the instruments psychometric status is needed. However, the measure was deemed to be sufficiently developed for inclusion in this thesis.

CHAPTER 6: THE CROSS-SECTIONAL STUDY: METHOD AND RESULTS

Introduction

The literature reviewed over Chapters 1 to 5 points to a range of variables influential in patients adjustment to chronic illness. The focus of this psychological endeavour is to understand why individuals adapt differently to similar disease episodes and to promote coping for those experiencing difficulty. Coping with chronic neurological illness generally and epilepsy specifically has received minimal research interest from health oriented psychology. The self-regulation model places emphasis on the role of patients cognitive representations in coping and adjustment to disease. The model offers a wide framework which, integrates the concept of illness representations with existing work on coping with disease and coping with epilepsy. No studies have investigated the relationship between patients cognitive representations, coping and adjustment to epilepsy.

In this study, the relationships between illness representations, coping strategies and adjustment among adult epilepsy patients were of interest. More specifically, this work utilises a measure of illness representations developed for use with epilepsy patients, investigates the relationship between components of the illness representation and examines their influence on coping, mental health, self-esteem and social anxiety / distress.

Recent studies in the epilepsy-psychopathology literature point to the role of selection bias in elevating estimates of psychological risk associated with the condition. With regard to this debate, the present work contrasts adjustment among recently diagnosed patients relative to chronic patients cared for in hospital clinics and chronic patients receiving care in the community.

Detailed research questions are presented in Chapter 4.

Subjects

The sample consisted of 94 patients with a diagnosis of epilepsy. Patients were excluded from the study on the basis of the following criteria:

i) presence of a learning disability
ii) presence of a second chronic illness
iii) age under 16 years

The sample comprised three groups; recently diagnosed patients recruited from hospital clinics (recent), chronic epilepsy patients recruited from hospital clinics (chronic - clinic) and chronic patients recruited via their general practitioners (chronic - GP). There is no consensus in the literature as to what constitutes a recent diagnosis. In the present study, duration of epilepsy of 12 months or less was classified as recent onset.

The clinic patients were attending either St James University Hospital, Leeds; the Leeds General Infirmary or Bootham Park Hospital, York, for medical management of their epilepsy. The GP sample were recruited from a total of five surgeries in the Leeds area. All patients were receiving anti epileptic drugs. Data on sample recruitment are displayed in Table 6.1. During a data collection period of ten months, a total of 79 recently diagnosed patients met the criteria for inclusion in the study. Of these 79 patients, 38 (49 per cent) failed to attend the clinic. Of the 40 patients invited to participate in the study, 21 patients (52 per cent) agreed and 19 patients (47 per cent) declined to help. A total of 348 chronic epilepsy patients attending the clinics were considered suitable for inclusion in the study. Of these 348 patients, 92 (26 per cent) failed to attend. Sixty-eight patients were invited to participate in the study, 47 (69 per cent) agreed and 21 (31 per cent) declined. Chronic patients recruited via general practitioners were contacted by letter. Of the 70 letters sent, 26 patients (37 per cent) agreed to participate. Forty four patients either returned their letter and declined to help or did not respond.

Table 6.1: Patients recruited to the study over a ten month period.

	Group:		
	Recent.	Chronic (clinic)	Chronic (GP)
No. fit study criteria	79	348	N/A
Fail to attend clinic	38 (49%)	92 (26%)	N/A
No. invited to study	40	68	70
Agree to participate	21 (52%)	47 (69%)	26 (37%)
declined to participate	19 (47%)	21 (31%)	44 (63%)

The final sample consisted of; 21 recently diagnosed patients, 47 chronic patients attending a hospital clinic and 26 chronic patients receiving care via their GP.

Participation in the study was voluntary and unrelated to both medical care and patients appointment times.

Measures

Illness representations - The distinct components of illness representations proposed by Leventhal and Nerenz (1984) formed the framework for the development of an interview to measure patients cognitive representations of epilepsy. The protocol comprised both open-ended questions to elicit patients spontaneous responses followed by specific items to assess patients illness perceptions along the six representation components. The development of the instrument is outlined in Chapter 5 and the full interview with instructions to patients contained in Appendix 1.

Demographic variables - Contained within the interview were questions to obtain demographic data; age, gender, years in education, financial status, occupation, marital status and number of dependants.

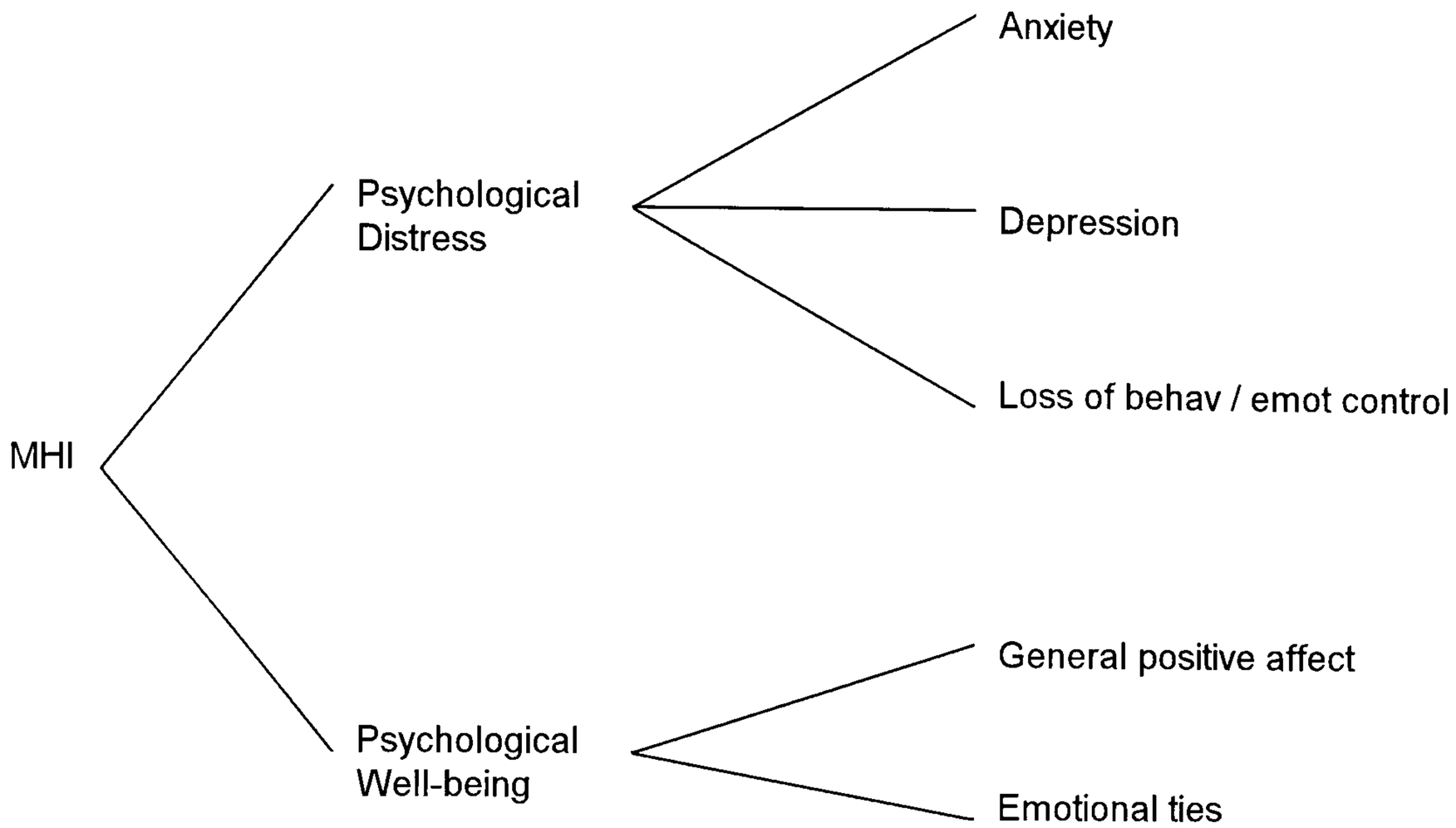
Neuroepileptic variables - In accord with the model proposed by Hermann and Whitman (1986), reviewed in Chapter 2, a range of neurological and medication data were recorded. A combination of questions to patients corroborated with medical notes determined patients; age of illness onset, time since last seizure, seizure frequency, duration of disorder, aetiology, seizure type, number of AED`s and medication type.

Coping strategies - The revised Ways of Coping Checklist (WCCL-R; Vitaliano et al, 1985) was used to assess coping. The measure is reviewed in Chapter 3. Four of the five scales were employed; problem-focused coping, seeks social support, wishful thinking and avoidance. The three items comprising the blamed-self scale were dropped due to conceptual overlap with items on the personal responsibility scale of the interview. The measure has demonstrated acceptable levels of internal consistency, construct validity and criterion validity. The revised WCCL scales share substantially less variance than those of the original measure (Vitaliano et al, 1985).

Patients were given the scale items on printed cards and told that `each card briefly describes a way of coping`. Participants were then instructed to `tell me how often you use each method to cope with your attacks by putting the cards on one of the four piles`. The four response options were; `never`, `hardly ever`, `yes sometimes` and `yes quite a lot`, scored 1 to 4 respectively.

Mental health - Patients completed the 38-item Mental Health Inventory (MHI). Veit and Ware (1983) developed the instrument to reflect the multidimensional nature of mental health. The MHI was field-tested on large groups (N=5089) and data explored to determine the instruments factor structure. Veit and Ware demonstrated that the best interpretation of the MHI was a hierarchical factor model composed of a general mental health factor, a higher order factor defined as psychological distress and psychological well-being and five lower order factors. The factor structure is presented in Figure 6.1. Using confirmatory factor analytic methods, Tanaka and Huba (1984) provided evidence in support of the factor structure proposed by Veit and Ware.

Figure. 6.1: Mental Health Inventory structure.



Items are rated on five or six point likert scales and positively scored. Given the instruments factor structure there are several scoring options which, to reduce the potential for error was done by recoding and combining items on a computer. The satisfactory psychometric properties of the MHI are discussed by McDowell and Newell (1987). The MHI has been shown to successfully distinguish between clinical and non clinical samples (Rosenthal, Downs, Arheart, Deal, Downs and Rosenthal, 1991) and has proven sensitive to change in seizure frequency among postoperative epilepsy patients (Hermann, Wyler, Ackerman and Rosenthal, 1989).

Self-esteem - Patients completed the 10 item self-esteem scale (Rosenberg, 1967). Items were rated on a four-point agree-disagree scale and summed to provide an index of self-esteem. Total scores ranged from 0 (low self-esteem) to 40 (high self-esteem). The internal consistency of the scale in the current study was 0.85. The scale was easy to administer and has previously been used in studies of epilepsy patients.

The Social Avoidance and Distress Scale - (Watson and Friend, 1969) was used to assess social anxiety / distress in response to epilepsy. The original scale comprised 28 items with a true / false response format and test-retest reliability of 0.79. The scale was shortened for use in the present study. Six items were dropped from each scale. Items were excluded on the basis of length and clarity of meaning.

A Total of 16 items were used in the present study giving a reliability of 0.68. Total scores ranged from 0 (low social anxiety) to 16 (high social anxiety).

Procedure

Ethical approval for the study was obtained from Leeds Healthcare / United Leeds Teaching Hospitals NHS Trust and the York Neurology Unit, special centre for epilepsy.

Clinic patients eligible for inclusion in the study were identified by reading the medical notes prior to commencement of the clinic. For certain recently diagnosed patients it was necessary to obtain additional information from the neurologist. Patients were excluded on the basis of the criteria documented in Chapter 6. On arrival at the clinic suitable patients were presented with an information sheet (Appendix 2) and invited to participate in the study. Those patients agreeing to participate were interviewed in a quiet-room attached to the clinic following their medical consultation.

The interview commenced with a summary of the procedure, an invitation for questions and the attainment of informed consent. Information on patients demographic and neuroepileptic status preceded the interview to elicit patients cognitive representations of epilepsy. Patients then completed the coping measure and the three questionnaires, assessing; mental health, self-esteem and social anxiety. Data collection took between 40-50 minutes. At the end of the interview patients were invited to ask further questions or allowed a brief period (5-10 minutes) to discuss their experience of taking part in the research.

Patients recruited from GP surgeries were contacted by letter. The five GPs assisting the project sent out the information sheet and a further letter containing a response slip (Appendix 3) to selected epilepsy patients. This information about the study was sent together with a brief letter from the GP. All patient information was anonymous to the researcher. Patients agreed to participate in the study by returning the slip in a SAE provided. Those patients who agreed to help were then contacted by telephone and interviews arranged either at the surgery or the patients home.

RESULTS

Data were entered and analysed using a Windows version of SPSS. The entered data were checked for accuracy using frequency analysis. No data was missing. All data were checked for assumptions of normality and homogeneity of variance prior to parametric analyses.

Results are reported in the following order. First, the sample characteristics in terms of demographic and neuroepileptic data are summarised. Second, data are presented relating to the specific research questions. These comprise, the relationships between illness representations and the influence of neuroepileptic factors on cognitive representations. Group differences in illness representations, coping and psychosocial adjustment. Finally, the associations between illness representations, coping and psychosocial adjustment. Interim summaries are provided at the end of each section.

Sample characteristics

Demographic data - The demographic data for the patients included in the study are presented in Table 6.2. Fifty-two per cent of the sample were male and 48 per cent were female. The mean age of patients was 38.5 years, with a range of 16 years to 80 years. The number of years patients had spent in education after 16 years of age ranged from 0 years to 9 years, with a mean of 1.8 years. Sixty-three patients had spent a maximum of one year in education. The majority of patients (41) received a household income between 10-20 thousand pounds per annum. Thirty of the 94 patients lived on an income of less then 10 thousand pounds per annum. Sixty-six patients were employed, 20 professional and 46 non-professional. Twenty patients were unemployed at the time of interview and 8 were in full-time education.

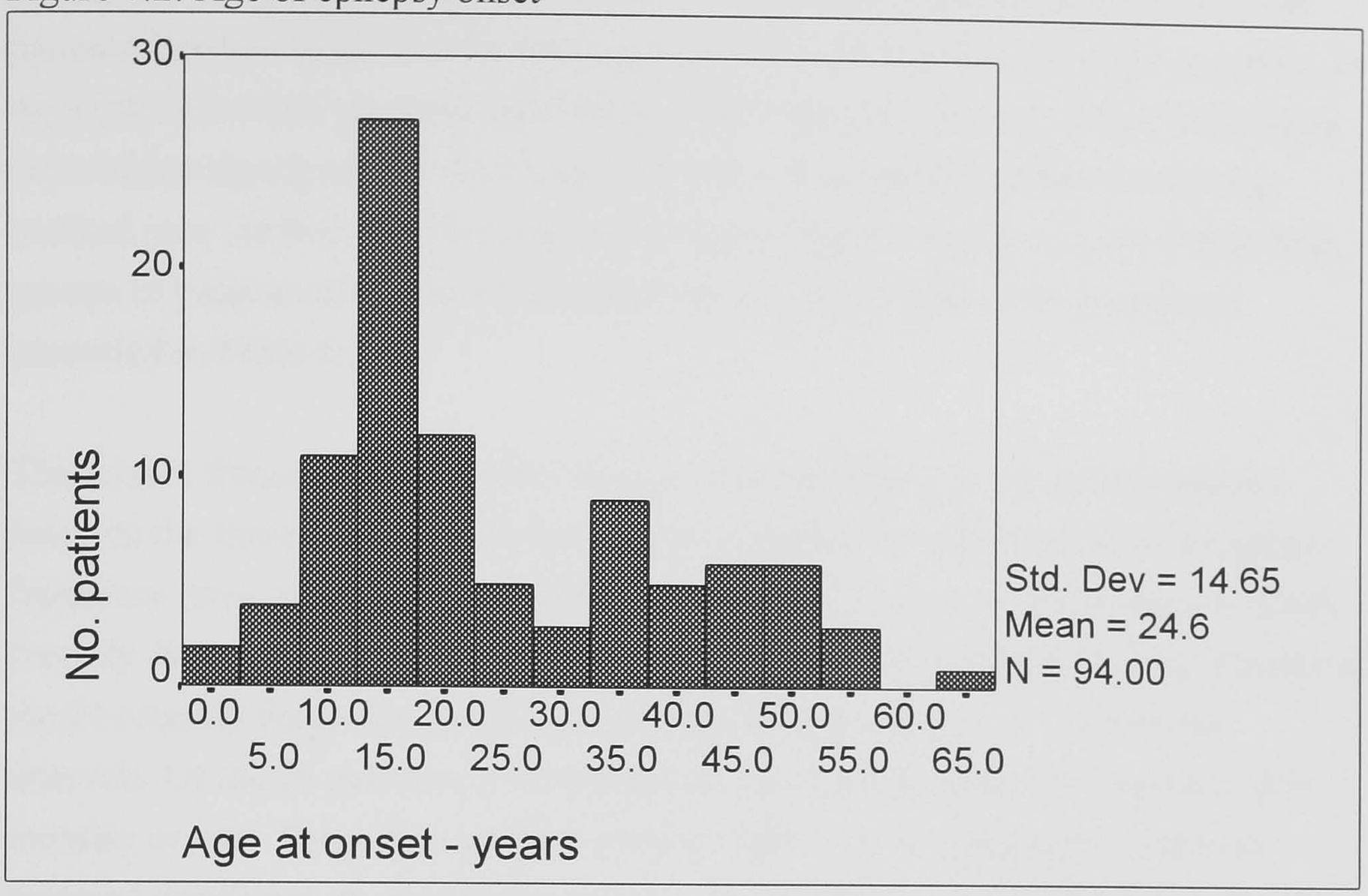
There were no significant differences between the groups in terms of age (F=2.74, $df_{2,91}$. ns) or occupational status (x^2=3.09, df_{2}. ns). However, chronic patients recruited in the clinic reported significantly fewer years in education (F=3.41, $df_{2,91}$. P <.05).

Table 6.2: Demographic data for the three groups and all patients.

		Group:		
	All patients	Recent.	Chronic (clinic)	Chronic (GP)
N.	94	21	47	26
Age (Mean, SD).	38.5 (13.5)	35.0 (13.3)	37.5 (11.9)	43.4 (14.8)
Age range.	16-80	17-64	17-64	16-80
Sex ratio (M:F).	49:45	11:10	21:26	17:9
Yrs. Education since 16. (Mean).	1.8	2.2	1.3	2.5
Financial status (median).	£10-20K	£10-20K	£10-20K	£10-20K
Occupation (employed: unemployed/student).	66:28	12:9	32:15	22:4

Neuroepileptic data - The age of onset of patients epilepsy ranged from under 1 year old to 65 years old, with a mean age at onset of 24.6 years. As shown in Figure 6.2, adolescence represents a peak time period for epilepsy onset, with a later smaller peak during late adulthood. This pattern being a good representation of adolescence and maturity onset epilepsy.

Figure 6.2: Age of epilepsy onset



As shown in Table 6.3 age of epilepsy onset differed significantly between the groups (F=8.74, $df_{2,91}$, p <.001). Chronic patients attending the clinic had the earliest onset, with a mean age of 19.6 years. For recently diagnosed and chronic (GP) patients, age of epilepsy onset was 34.5 years and 25.3 years respectively.

Table 6.3: Age of epilepsy onset and number of days since last seizure for the three groups.

	Group:			
	Recent.	Chronic (clinic)	Chronic (GP)	F
N.	21	47	26	
Age of onset (Mean, SD)	34.5(13.3)	19.6(12.1)	25.3(16.0)	8.74***
Median (Days since last seiz.)	34	14	540	
Range (Days since last seiz.)	1-300	1-900	1-3420	

Note: ***p<0.001

The number of days since the last seizure varied widely between the clinic and GP patients. Median values for the three groups were; 34 days (recent onset patients), 14 days (chronic-clinic patients) and 540 days (chronic-GP patients). These differences were highly significant (x^2=24.21, df_2. P<.001). As expected, patients receiving medical care via their GP demonstrated a higher degree of seizure control than both groups of patients attending the hospital clinics. Data for the three groups are presented in Table 6.3.

The seizure frequency data further attest to the differences in control of seizures between the three groups. Chronic patients attending the clinic reported the highest frequency rates, with 33 of the 47 patients reporting at least monthly seizures. Both recently diagnosed and GP patients groups reported lower frequency rates. Twelve of the 21 recently diagnosed patients were experiencing seizures at 1-6 monthly intervals. Of the 26 patients in the GP group, 19 reported a seizure frequency of 6 monthly or less. These data are presented in Table 6.4. Nonparametric analysis revealed significant group differences (x^2= 27.24, df_2. p <.001). The Clinic group, therefore, comprise both those patients with intractable epilepsy and patients with moderate to good seizure control attending clinic for review. The GP sample appears more homogeneous with all patients in a good state of remission.

Table 6.4: Number of patients reporting given seizure frequency

	Group:		
	Recent	Chronic (clinic)	Chronic (GP)
N	21	47	26
> daily	2	2	0
>weekly	2	16	2
>monthly	4	15	2
1-6 monthly	12	8	3
<6 monthly	1	6	19

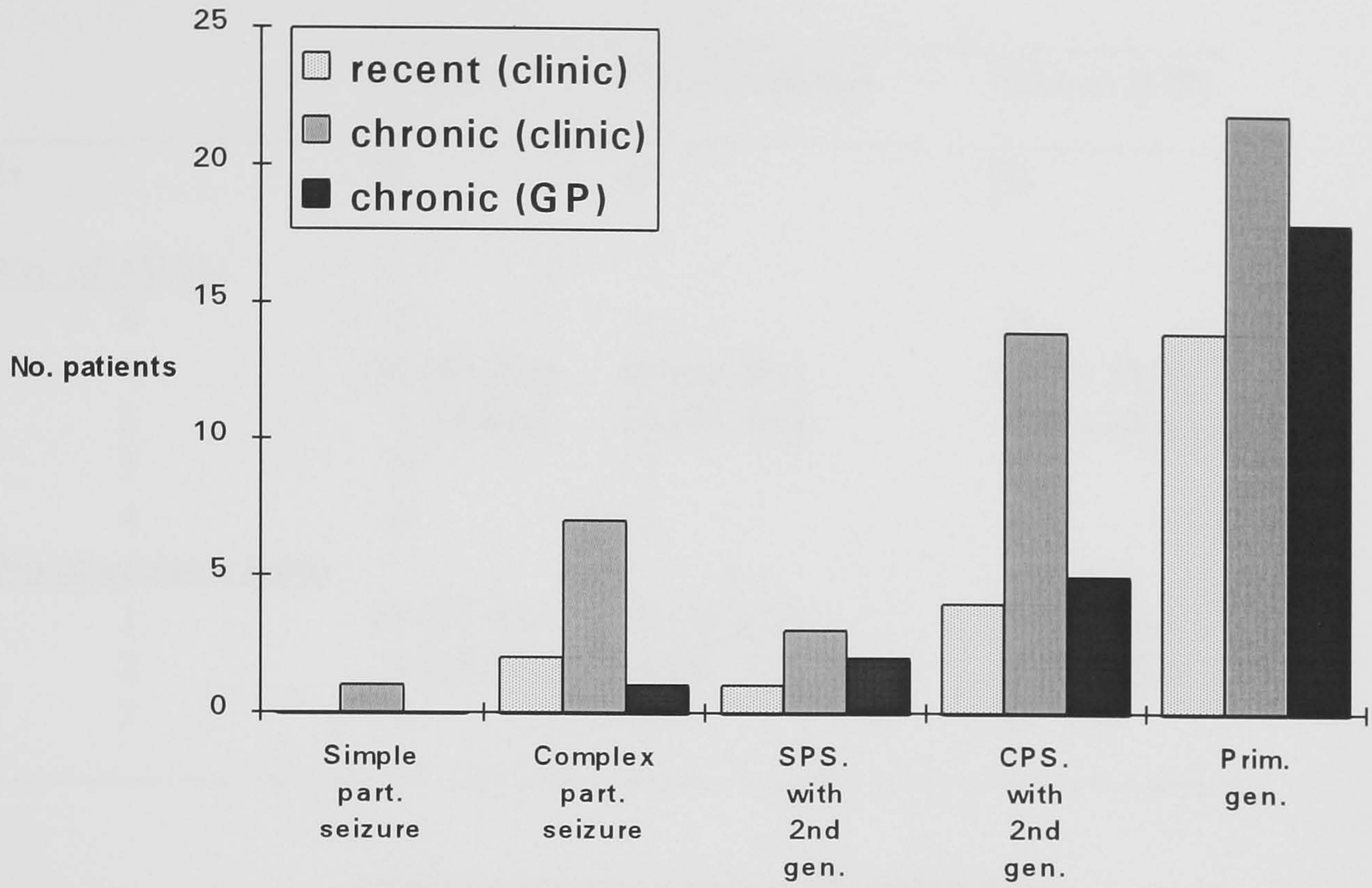
The mean length of time since diagnosis for the recently diagnosed group was 4.5 months, SD=3.3 months. There was little difference in the duration of diagnosis between the chronic epilepsy patients; 190.7 months, SD=142.2 (chronic-clinic) and 200.5 months, SD=151 (chronic-GP). These data are presented in Table 6.5.

Table 6.5: Time since diagnosis in months.

	Group:		
	Recent.	Chronic (Clinic)	Chronic (GP)
N	21	47	26
Mean time since diagnosis.	4.5	190.7	200.5

A total of 54 patients (14, recent onset; 22, chronic-clinic and 18, chronic-GP) had received a diagnosis of primary generalised epilepsy. Twenty three patients (4, recent onset; 14, chronic-clinic and 5, GP) had a diagnosis of complex partial seizures with secondary generalised seizures. Ten patients were receiving treatment for complex partial seizures (2, recent onset; 7, chronic-clinic and 1, GP). Just 1 patient presented with simple partial seizures and 6 patients (1, recent onset; 3, chronic-clinic and 2, GP) attended for the treatment of simple partial seizures with secondary generalised seizures. These seizure-type categories follow the 1981 International Classification of Epileptic Seizures and are consistent with those used in MRC drug-withdrawal studies. Seizure-type data are presented in Figure 6.3.

Figure 6.3: Seizure type



The majority of recently diagnosed patients (N=15) were experiencing just one type of seizure. However, 6 of the 21 patients in the recent group were experiencing secondary generalised seizures. Thirty of the 47 chronic patients attending the clinic were been treated for multiple seizure types. Nine patients in the GP sample were experiencing a single type of seizure, whilst 17 GP patients were receiving treatment for two seizure types. These data are presented in Table 6.6. Nonparametric analysis revealed significant group differences in the number of seizure types (x^2=10.19, df_2. p <.05) indicating the high incidence of single seizure epilepsy among recently diagnosed patients relative to both chronic groups. Of the 21 recently diagnosed patients, 18 were receiving a single anti-epileptic drug (AED) type. Among the chronic patients attending the clinic, 27 patients were been treated with two of more AED`s. The majority of GP patients (N=16) were receiving a single AED. Significantly more chronic epilepsy patients were receiving multiple AED`s relative to newly diagnosed patients (x^2=10.1, df_2. p <.05).

The majority of patients studied were receiving treatment for idiopathic epilepsy (N=84). The remaining 10 patients were classified as suffering from symptomatic epilepsy.

Table 6.6: Number of Anti epileptic drugs and number of seizure types.

	Group:		
	Recent.	Chronic (clinic)	Chronic (GP)
N	21	47	26
<u>No. of AED`s</u>			
0	2	1	0
1	18 (85.7%)	19 (40.4%)	16 (61.5%)
2	1 (4.8%)	19 (40.4%)	8 (30.8%)
3	0	7	2
4	0	1	0
<u>No.of seizures types</u>			
1	15 (71.4%)	17 (36.2%)	9 (34.6%)
2	6 (28.5%)	28 (59.9%)	17 (65.4%)
3	0	2	0

<u>Interim summary of sample characteristics</u>

Analysis of the demographic data revealed few differences between the three patient groups. Chronic patients attending the clinic did report significantly fewer years in education since 16 years of age. The age at onset data reflected the typical age-specific incidence pattern, with peaks representing adolescence and maturity onset.

The neuroepileptic data revealed clear differences between the groups studied. Relative to chronic patients, recently diagnosed patients were characterised by; later onset, reduced seizure frequency rates, single seizure type and mono drug therapy. The mean duration of diagnosis for recent onset patients was 4.5 months.

Contrasting the neuroepileptic data on the two chronic groups revealed a picture of better seizure control among patients cared for by their GP. Chronic patients attending the clinic had significantly higher seizure frequency rates and a shorter time period since last seizure. The two groups did not differ significantly in terms of duration of diagnosis and the number of seizure types.

The predominant seizure type in all groups was primary generalised epilepsy.

Data relating to specific research questions:

1(a) : How do the components of the illness representation relate to each another?

Bivariate correlations were calculated to explore the relationships between the illness representation components. The three groups were combined for analysis. As the study employed a newly developed illness representations measure, all variables were entered into an initial analysis. The correlations computed were associated with an inflated risk of Type 1 error. However, given the exploratory nature of the analysis a bonferroni type adjustment was not applied. These data are presented in Table 6.7.

Epilepsy symptom severity was strongly correlated with the presence of non-epilepsy symptoms ($r = .54$, $p < .001$) and belief in physical consequences to seizure ($r = .45$, $p < .001$). Epilepsy symptom severity was unrelated to belief in an epilepsy label ($r = .20$). A strong epilepsy identity as reflected by symptom severity was also correlated with perceptions of stigma ($r = .22$, $p < .05$) and perceived discrimination ($r = .24$, $p < .05$). A strong belief in an epilepsy label was positively associated with chronic timeline ($r = .21$, $p < .05$) and negatively associated with; personal responsibility ($r = -.35$, $p < .001$), acute timeline ($r = -.51$, $p < .001$) and fatalistic control beliefs ($r = -.22$, $p < .05$).

Among the causal components, personal responsibility was associated with stress ($r = .50$, $p < .001$), whilst belief in a genetic cause was associated with chance ($r = .25$, $p < .05$). The causal beliefs of personal responsibility and stress were correlated with an acute time perception, ($r = .27$, $p < .01$) and ($r = .33$, $p < .01$) respectively. Further, personal responsibility was associated with internal control beliefs ($r = .46$, $p < .001$) and stress negatively associated with perceptions of external control ($r = -.40$, $p < .001$). The causal attribution of blaming-others was correlated with; perceived physical consequences ($r = .33$, $p < .01$), role contamination ($r = .31$, $p < .01$) and negatively associated with perceptions of containment ($r = -.26$, $p < .05$).

Table 6.7: Intercorrelations between the Illness representation components

		Identity				Cause			Timeline		
	Ep. symp.	Non-Ep	Label	P.R.	B.O.	Stress	Genet.	Chance	Acute	Cyclic	Chronic
Identity:											
Ep. symp	1.00	.54***	.20	-.05	.11	-.21*	.02	.03	-.25*	.15	.22*
Non-Ep		1.00	.02	.09	.15	.02	.07	.11	-.18	.03	.21*
Label			1.00	-.35***	.15	.02	-.04	.11	-.51***	.23*	.21*
Cause:											
PR				1.00	.18	.50***	.00	.12	.27**	-.14	-.14
BO					1.00	.21*	.13	.00	.07	-.01	-.03
Stress						1.00	.01	.03	.33**	-.12	-.31**
Genetic							1.00	.25*	-.08	.05	.18
Chance								1.00	-.02	.08	.13
Timeline:											
Acute									1.00	-.41***	-.62***
Cyclic										1.00	.47**
Chronic											1.00

NOTE : (EP) Epilepsy. (PR) Personal responsibility. (BO) Blame others. (P) Physical. (PS) Perceived stigma. (ES) Enacted stigma. (PD) Perceived discrimination.
*p < 0.05, **p < 0.01, ***p < 0.001.

Table 6.7 (continued): Intercorrelations between the Illness representation components

	Consequences:				Control:			Self-illness:	
	P	PS	ES	PD	Int.	Ext.	Fatal.	Role con.	Contain.
Identity:									
Ep. symp	.45***	22*	.11	.24*	.11	-.17.	-.01	.13	.02
Non-Ep	.39***	.35***	.20	.48***	-.13	.10	.19	.32***	-.32***
Label	.12	-.03	.00	.18	-.05	.16	-.22*	.05	-.09
Cause:									
PR	.17	.08	.08	-.06	.46***	-.23*	.10	.02	-.07
BO	.33**	.20	.15	.18	.11	-.13	.09	.31**	-.26*
Stress	-.04	-.02	.02	-.14	.17	-.40***	.21	.03	.00
Genetic	.11	.12	.07	.27**	.13	-.07	-.02	.24*	-.14
Chance	.13	.10	.11	.05	.11	.13	.15	.12	-.03
Timeline:									
Acute	-.10	-.17	-.28**	-.36***	.13	-.16	.11	-.32**	.19
Cyclic	-.02	.15	.16	.19	-.05	.17	.08	.13.	-.04
Chronic	.21*	.26*	.25*	.33***	-.05	.39***	.00	.33***	-.31**
Consequen:									
P	1.00	.25*	.16	.30**	-.07	.13	.05	.24*	-.19
PS		1.00	.66***	.62***	.13	.26*	.19	.55***	-.55***
ES			1.00	.52***	.07	.16	.13	.51***	-.42***
PD				1.00	.07	.11	.18	.71***	-.59***
Control:									
Internal					1.00	-.12	.06	.09	-.12
External						1.00	-.18	.15	-.16
Fatalism							1.00	.08	-.04
Self-Illness									
Role contam.								1.00	-.71***
Contain									1.00

NOTE : .
(EP) Epilepsy
(PR) Personal responsibility
(BO) Blame others
(P) Physical
(PS) Perceived stigma
(ES) Enacted stigma

*p < 0.05
**p < 0.01
***p < 0.001

As expected, belief in an acute timeline was strongly negatively correlated with cyclic ($r = -.41$, $p < .001$) and chronic ($r = -.62$, $p < .001$) time perceptions. An acute time perception was strongly negatively associated with; experience of stigma ($r = -.28$, $p < .01$), perceived discrimination ($r = -.36$, $p < .001$) and role contamination ($r = -.32$, $p < .01$). Chronic timeline was positively correlated with these variables; experience of stigma ($r = .25$, $p < .05$), perceived discrimination ($r = .33$, $p < .001$) and role contamination ($r = .33$, $p < .001$). Moreover, a chronic time perception was associated with; physical consequences ($r = .21$, $p < .05$), perceived stigma ($r = .26$, $p < .05$), belief in external control ($r = .39$, $p < .001$) and negatively correlated with containment of disability effects ($r = -.31$, $p < .01$).

Among the consequences components, perceived discrimination was positively associated with; physical consequences ($r = .30$, $p < .01$), perceptions of stigma ($r = .62$, $p < .001$) and experience of stigma ($r = .52$, $p < .001$). Additionally, belief in stigma, discrimination and experience of stigma were all strongly positively associated with role contamination ($p < .001$) and negatively correlated with perceptions of disability containment ($p < .001$). Also of interest was the correlation between perceived stigma and external control ($r = .26$, $p < .05$). As expected, perceptions of role contamination were associated with perceived inability to contain the effects of epilepsy ($r = -.71$, $p < .001$).

<u>1(b) : Which demographic / neuroepileptic variables influence illness representations ?</u>

Kendall correlation coefficients were calculated to investigate the relationships between illness representation components and demographic / neuroepileptic variables. These data are presented in Table 6.8. The groups were combined for analysis.

Females had a stronger illness identity in terms of epilepsy symptom frequency and reported non-epilepsy symptoms. All other correlations for gender and age were non-significant. An increased number of years in education was associated with a strong belief in an epilepsy label ($r = .19$, $p < .05$) and containment of disability effects ($r = .17$, $p < .05$). Years spent in education was negatively correlated with; blaming others ($r = -.17$, $p < .05$), environmental cause ($r = .17$, $p < .05$), and experience of stigma ($r = .22$, $p < .01$). Time since last seizure was negatively related to; symptoms ($r = -.42$, $p < .001$), perceived discrimination ($r = -.22$, $p < .01$) and stigma ($r = -.19$, $p < .01$).

Further, time since last seizure was inversely related to role contamination ($r = -.31$, $p < .001$). Significant positive associations were found between time since last seizure and containment ($r = .25$, $p < .01$) and acute time course ($r = .24$, $p < .01$). The latter correlation indicating the belief in a lasting remission among patients with good seizure control.

As expected, duration of epilepsy was positively associated with a chronic time perception ($r = .27$, $p < .01$) and negatively correlated with acute timeline ($r = 23$, $p < .01$). On the consequences scale, perceptions of stigma, discrimination and experience of stigma were positively correlated with duration of disorder. Also, duration of epilepsy was associated with reduced containment of illness effects and an increase in perceptions of role contamination.

Correlations between age at onset and illness representation components suggests the younger patients are when diagnosed, the stronger the conviction in an epilepsy label ($r = -.19$, $p < .05$). Although increasing age at epilepsy onset was associated with an acute time perception ($r = .17$, $p < .05$). Significant negative associations were found between age at onset and; enacted stigma ($r = .27$, $p < .001$), perceived discrimination ($r = .20$, $p < .01$) and role contamination ($r = .17$, $p < .05$).

Additional positive correlations suggested those patients with multiple seizure types had; a stronger illness identity ($r = .29$, $p < .001$), a chronic time perception ($r = .20$, $p < .05$), a strong perception of discrimination ($r = .29$, $p < .001$) and belief in an external locus for their seizure control ($r = .24$, $p < .01$).

Table 6.8: Correlations between illness representation components and demographic / neuroepileptic variables.

Illness Representation component.	Gender.	Years Ed.	Time since last seizure.	Duration of disorder.	Age onset.	No.seizure types.
Identity:						
Ep. symp. freq.	.17*	-.10	-.42***	.02	-.12	.34***
Non-epilepsy symptoms.	.19*	-.09	-.30***	.01	.04	.13
Label.	-.11	.19*	-.02	.19*	-.19*	.29***
Cause:						
Blame others	-.02	-.17*	-.13	.02	-.05	-.02
Environment	-.11	-.17*	-.14	-.02	-.00	.08
Timeline:						
Acute	.02	.00	.24**	-.23**	.17*	-.31***
Chronic	-.11	.00	-.12	.27***	-.13	.20*
Consequences:						
Enacted stigma	.02	-.22**	-.16*	.36***	-.27***	.18*
Perceived discrim.	-.06	-.15	-.22**	.24**	-.20**	.29***
Perceived stigma.	.05	-.14	-.19**	.21**	-.13	.11
Control:						
External.	-.10	-.10	-.03	.06	.00	.24**
Self-Illness:						
Containment	.07	.17*	.25**	-.12	.09	-.07
Role contam.	-.12	-.07	-.31***	.15*	-.17*	.14

Note: *p<0.05, **p<0.01, ***p<0.001.

1(c): Are there group differences in cognitive representations of epilepsy?

Tables 6.9 through 6.17 show the mean scores on the six illness representation components for the three groups of epilepsy patients. These data were analysed using multivariate analysis of variance (MANOVA). Using a Helmert contrast, differences in illness cognitions were examined between; recent onset and chronic patients (contrast 1) and chronic patients (clinic) and chronic patients (GP) (contrast 2). By combining and comparing variances in this way, group differences could be located with greater precision. Due to differences in sample sizes, tests for homogeneity of variance were conducted on all illness representation variables by group.

The groups were homogeneous on all components except non-epilepsy symptom severity (Cochran`s C = 0.54, p. 005). Homogeneity was attained by removing two outlying variables (Cochran`s C = 0.45, p .094).

The results are reported for each illness representation component. Firstly, the results of data analysis are presented. Secondly, qualitative data attained during open-ended questioning are summarised.

Identity : Table 6.9. Patients did not differ in their ratings of severity with regard to epilepsy symptoms. In terms of the frequency of epilepsy symptoms, no difference was found between recently diagnosed and chronic patients. However, chronic patients (clinic) reported a greater frequency of epilepsy symptoms compared to GP recruited patients ($t_{1,71} = 2.69$, $p < .01$). Chronic patients (clinic) also reported significantly more non-epilepsy symptoms compared to the recently diagnosed and GP patients ($F_{2,91} = 4.49$, $p < .05$). These symptoms include; tiredness / fatigue, loss of appetite, weakness, and minor infections. When asked to rate their belief in the applicability of an epilepsy label to themselves, both groups of chronic patients reported significantly stronger beliefs relative to recently diagnosed patients ($t_{1,92} = 2.90$, $p < .01$). Contrasting patients belief in an epilepsy label between the two chronic groups revealed no difference.

Prior to specific items on the label scale, which elicited patients belief about their illness identity, patients were asked an open-ended question concerning the name / diagnosis given for their symptoms / attacks. Of the 21 recently diagnosed patients, 11 said their attacks were epilepsy or could be epilepsy. Typical responses among these patients were; "Some form of epilepsy"; "Seizure - could be epileptic"; "Doctors insists it is epilepsy in spite of a normal EEG" and "I have been told I have a mild form of epilepsy". Two recently diagnosed student nurses cited their specific diagnosis. The remaining 10 recently diagnosed patients gave responses that did not include the word epilepsy, typical responses were; "They have found an abnormality in my brain and are looking into it further"; "Very mild type of fits"; "Some kind of seizure - I am not quite sure" and "Fits".

Among the 47 chronic epilepsy patients (clinic), 40 either used the word epilepsy or cited their precise diagnosis. The remaining 7 chronic patients attending the clinic used terms such as "fits" or "attack".Chronic patients recruited via their GP displayed a similarly strong identification towards an epilepsy label for their symptoms, with all but 2 patients citing their precise diagnosis and / or their specific seizure type.

Table 6.9: Illness representation mean scores (Identity) in the three groups of epilepsy patients.

Scales	Group: Recent.	Chronic (clinic).	Chronic (GP).	F
Identity:				
Epilepsy symptom severity.	26.5	30.2	34.9	1.69
Epilepsy symptom frequency.	18.3	22.9	14.0	3.70*
Contrast 1 (recent v chronic)				t 0.04
Contrast 2 (chronic - clinic v GP)				t 2.69**
Non-epilepsy symptom severity.	3.4	4.6	2.6	4.49*
Contrast 1 (recent v chronic)				t 0.62
Contrast 2 (chronic - clinic v GP)				t 2.83**
Label.	10.1	12.0	11.9	4.40*
Contrast 1 (recent v chronic)				t 2.90**
Contrast 2 (chronic - clinic v GP)				t 0.22

Note: *p<0.05, **p<0.01, ***p<0.001.

Cause : As shown in Table 6.10 there were no group differences in the causal attributions examined. In order to evaluate within scale differences, mean item scores were calculated for each scale and divided by the number of scale items to produce comparative scale scores. These values were analysed using a paired t-test. All 15 pairings were entered with a specified Bonferroni value of p <.003. These data are displayed in Table 6.11. Patients most strongly affirmed stress and chance factors as causes for their epilepsy. Fewer patients considered themselves personally responsible for their epilepsy onset. When asked to rate the causal significance of genetic factors or ascribe blame for their epilepsy to other people, patients tended to respond with disagreement.

Typical responses to the open-ended questions included; "don't know - no idea - just one of those things that happens to a percentage of the population - there were no events leading up to my epilepsy"; "I don't know - I had all the tests but they couldn't tell me the cause - there's sometimes no point in thinking about the cause"; "My epilepsy started when my parents got divorced - it could have been the stress"; "Its frustrating and mysterious - I haven't been injured and am fit and well"; "My epilepsy started when I lost my job - I think it was probably the stress".

Table 6.10: Illness representation mean scores (Cause) in the three groups of epilepsy patients.

	Group:			
Scales	Recent.	Chronic (clinic).	Chronic (GP).	F
CAUSE:				
Personal respon.	18.3	18.4	19.1	0.10
Blame others.	11.3	12.1	9.6	1.45
Environment.	4.7	4.3	4.6	0.27
Stress.	7.9	6.8	6.9	0.63
Genetic.	1.7	2.7	2.3	2.32
Chance.	4.0	4.4	4.1	0.34

Table 6.11: Illness representation (Cause) comparative scale scores.

.		Paired variables - t-value				
Scales	Items means.	BO.	Envir.	Stress.	Genetic.	Chance.
Cause:						
P R.	3.10	5.0*	4.5*	2.54	3.20*	5.15*
B O.	2.25		0.05	6.04*	0.67	8.42*
Envir.	2.25			5.44*	0.71	9.05*
Stress.	3.55				4.4*	2.64
Genetic.	2.39					8.13*
Chance.	4.30					

NOTE : (PR) Personal responsibility. (BO) Blame others. (Envir) environment.

*P < .003.

Timeline : As shown in Table 6.12, the groups differed significantly in the perception of temporal course for epilepsy. Recently diagnosed patients endorsed a strong acute time perception ($F_{2,91} = 6.96$, $p < .01$), relative to chronic patients, both clinic and GP recruited. Compared to recently diagnosed patients, both chronic groups had a significantly stronger belief in a cyclic ($t_{1,92} = 2.46$, $p < .05$) and a chronic ($t_{1,92} = 3.16$, $p < .01$) time course. The timeline scale also yielded an overall measure of cyclic / chronic time perception. On this combined scale, both chronic groups had significantly higher scores than recently diagnosed patients ($F_{2,91} = 7.55$, $p < .001$).

When asked the open-ended question, recently diagnosed patients gave such replies as; "I don't expect to have anymore seizures but need treatment for about 1 year"; "I may have more attacks but expect to be free of attacks in 6 months"; "I could have more attacks but if I take the tablets then I should be clear and off the tablets in a couple of years". Five of the 21 recently diagnosed patients cited that their diagnosis would be lifelong, whilst expressing optimism over future seizure control.

Table 6.12 : Illness representation mean scores (Timeline) in the three groups of epilepsy patients.

Scales	Group: Recent.	Chronic (clinic).	Chronic (GP).	F
Timeline:				
Temporal course.	20.9	27.2	26.0	7.55***
Acute.	7.2	4.5	5.6	6.96**
Contrast 1 (recent v chronic)				t 3.10**
Contrast 2 (chronic - clinic v GP)				t 1.61
Cyclic.	3.9	4.8	5.0	3.05
Contrast 1 (recent v chronic)				t 2.46*
Contrast 2 (chronic - clinic v GP)				t 0.51
Chronic	8.2	10.9	10.6	5.39**
Contrast 1 (recent v chronic)				t 3.16**
Contrast 2 (chronic - clinic v GP)				t 0.66

Note: *p<0.05, **p<0.01, ***p<0.001.

Consequences : Table 6.13. Group comparison revealed no differences in perceptions of physical health consequences ($F_{2,91} = 1.28$, ns). Comparing the groups on the perceived stigma scale, revealed no difference between recent onset and all chronic patients ($t_{1,92} = 1.63$, ns). However, chronic patients attending the clinic held a significantly stronger perception of stigma relative to the other groups ($F_{2,91} = 5.72$, $p < .001$). On the enacted stigma scale, assessing actual experience of stigma, chronic patients recalled significantly more instances than recent onset patients ($t_{1,92} = 2.52$, $p < .05$). Among chronic patients, enacted stigma was significantly higher among clinic patients relative to GP patients ($t_{1,71} = 1.16$, $p < .05$). Chronic patients (clinic) also endorsed significantly stronger perceptions of discrimination relative to chronic (GP) patients ($t_{1,71} = 2.98$, $p < .01$), with all chronic patients having stronger discrimination beliefs than recent onset patients ($t_{1,92} = 2.11$, $p < .05$).

Table : 6.13: Illness representation mean scores (Consequences) in the three groups of epilepsy patients.

	Group:			
Scales	Recent.	Chronic (clinic).	Chronic (GP).	F
Consequences:				
Physical.	19.6	20.8	18.9	1.28
Perceived stigma.	19.6	25.1	20.1	5.72**
Contrast 1 (recent v chronic)				t 1.63
Contrast 2 (chronic - clinic v GP)				t 2.70**
Enacted stigma.	5.8	10.1	7.5	6.62**
Contrast 1 (recent v chronic)				t 2.52*
Contrast 2 (chronic - clinic v GP)				t 1.16*
Perceived discrim.	24.9	32.2	26.3	7.72***
Contrast 1 (recent v chronic)				t 2.11*
Contrast 2 (chronic - clinic v GP)				t 2.98**

Note: *p<0.05, **p<0.01, ***p<0.001.

To contrast patients beliefs within the consequences component, item means were calculated and all 6 combinations entered into a paired t-test. Bonferroni correction yielded a least significant difference of $p < .007$. The four comparative scale scores showed epilepsy patients most strongly believed in perceptions of stigma, discrimination and physical injury as consequential to their condition.

In line with the findings of Scambler (1989), discussed in Chapter 2, patients perceptions of stigma were inflated relative to actual experience of stigma and discrimination. These data are presented in Table 6.14.

Table 6.14: Illness representation (Consequences) comparative scale scores.

Scales.	Item means	Paired variables - t-value		
		Per. stigma.	Enac. stigma.	per. discrim.
Consequences :				
Physical	4.01	1.79	6.38*	0.93
Perceived stigma	3.77		7.01*	3.43*
Enacted stigma	2.82			8.59*
Perceived discrim.	4.14			

Note : *p < 0.007.

Prior to administration of each scale on the consequences component, patients were asked open-questions and responses transcribed. Only 4 of the 47 chronic patients (clinic) did not perceive discrimination in an employment and social context. Typical responses were; "I was labelled disabled by a school careers officer - I think this has always been to my disadvantage and that I am achieving below my potential"; "not been able to drive is very restrictive for work and socially - it is difficult to explain not driving without telling people I have epilepsy"; "my employer thinks all people with epilepsy are tarred with the same brush - slow and maybe retarded" and "I have had a few attacks at work - since then people are cautious and can over-protect me".

On the experience of stigma scale, patients were asked if they think that their epilepsy in any way made them feel different to other people? Nine of the 47 chronic (clinic) patients stated that they never or no longer experienced a sense of differentness. The following are representative of those who responded positively; "I do feel different - there are less opportunities for me - sometimes I feel as if I stick out like a sore thumb, like a giant in a crowd of mini people"; "I felt ashamed at first but just try and put it to the back of my mind"; "you just can't say that you are Mr average when you have epilepsy because people treat you differently"; "I sometimes feel different - like not as full a person as I was - I now carry around epilepsy and always risk embarrassment - I think I get withdrawn into myself" and "I do not feel too different now- I think having epilepsy has made me more understanding towards other people because I think about how they perceive me".

The open-ended question for the experience of stigma scale requested patients to briefly cite any examples of unfair treatment. Twelve of the 47 chronic (clinic) patients had no personal experience of stigma. The remaining 35 patients briefly shared negative experiences. Typical scenarios were; hearing epilepsy discussed in pejorative terms, difficult interview experiences after disclosing the presence of epilepsy, actual loss of job and people being over protective towards patients.

Control : As shown in Table 6.15 there were no differences between the three groups in perceptions of factors influencing seizure control.

Table 6.15: Illness representation mean scores (Control) in the three groups of epilepsy patients.

	Group:			
Scales	Recent.	Chronic (clinic).	Chronic (GP).	F
CONTROL:				
Personal.	17.1	17.4	18.1	0.14
External.	13.3	13.2	13.5	0.05
Fatalism.	6.5	7.1	6.5	0.42

To examine within component differences, item means were entered into a paired t-test with a minimum significance level of $p < .001$. As shown in Table 6.16, patients most strongly believed their seizures could be controlled externally, via medication, as opposed to internal control or no control. Belief in personal control over the severity or frequency of seizures was comparable to the belief that seizure control is determined by chance. These findings run counter to work documenting a close relationship between seizure activity and behaviour. Epileptic seizures do not occur in a behavioural or attitudinal vacuum (Fenwick, 1992).

Table 6.16: Illness representation (Control) comparative scale scores.

Scales	Item means	Paired variables - t-value External.	fatalism.
CONTROL:			
Personal	3.51	4.85*	0.45
External	4.44		4.34*
Fatalism	3.41		

Note : *p < 0.001.

Self - Illness relationship : The impact of epilepsy on patients` self-systems was assessed by two scales; *role contamination* and *containment of disability effects*. As shown in Table 6.17, the groups differed significantly on both scales. In terms of patients role contamination perceptions, recent onset and chronic patients did not differ. However, among chronic patients, those attending the clinic had a significantly stronger contamination belief relative to GP patients ($t_{1,71} = 4.20$, $p < .001$). A similar pattern of findings emerged on the containment scale. Whilst comparison between recent onset and chronic revealed no difference, chronic patients (clinic) perceived themselves significantly less able to contain the effects of their epilepsy compared to GP patients ($t_{1,71} = 2.49$, $p < .05$)

Table 6.17 : Illness representation mean scores (Self-illness relationship) in the three groups of epilepsy patients.

Scales	Group: Recent.	Chronic (clinic).	Chronic (GP).	F
Self-illness relationship:				
Role contamination.	19.1	23.6	15.7	9.22***
Contrast 1 (recent v chronic)				t 0.13
Contrast 2 (chronic - clinic v GP)				t 4.20***
Containment.	24.8	23.7	27.7	3.10*
Contrast 1 (recent v chronic)				t 0.49
Contrast 2 (chronic - clinic v GP)				t 2.49*

Note: *p<0.05, **p<0.01, ***p<0.001.

When asked the open-ended question on role contamination, chronic patients attending the clinic typically stated; "I have managed to minimise the effects of epilepsy on my life - but it is always there - you can't ignore it and need some level of mental awareness to it"; "I am constantly trying not to allow the epilepsy to dominate my life - I am usually successful but not always"; "People who meet me have no idea that I have epilepsy - but I am constantly coping with the effects of epilepsy on my life - it effects my career - social and sexual life"; "The epilepsy remains a fairly big part in my life - it has changed me - taken away much of my self-confidence - I don't like going out on my own any more"; and "It is not such a big part in my life now as I understand more about it - but it still restricts me - slows me down".

Interim summary of group differences in illness representations

Patients cognitive representations of epilepsy are summarised in line with the contrasts employed for data analyses; recent onset relative to chronic patients and chronic (clinic) patients relative to chronic patients (GP). Further, each group will be profiled by their illness representation.

In terms of; perceived symptom severity, causal attributions, perceived physical consequences of seizure and variables influencing seizure control, recently diagnosed and chronic epilepsy patients were indistinguishable. However, recent onset patients had a significantly reduced belief in their epilepsy label, reported less non-epilepsy symptoms and endorsed a strong acute time perception. Additional components of the representation distinguishing recently diagnosed patients were; decreased perceptions of discrimination and less actual experience of stigma. Although recent onset patients perceived significantly less role contamination compared to chronic (clinic) patients, relative to both clinic and GP chronic patients, newly diagnosed patients did not differ.

Chronic patients attending a hospital clinic could be distinguished from chronic patients managed by their GP along several representation components. Clinic patients had a significantly stronger illness identity in terms of epilepsy symptom frequency and non-epilepsy symptoms. Further, clinic patients held significantly stronger perceptions of stigma, discrimination and recalled more stigma experience. Relative to GP patients, clinic patients evidenced greater involvement with their epilepsy as assessed by role contamination and perceived ability to contain the effects of epilepsy. The two groups were comparable in their belief in the applicability of an epilepsy label and a cyclic / chronic time-perception.

On those components of the illness representation showing no group differences (cause and control) within group analysis of the item means revealed the following. Patients most strongly endorsed stress and chance factors as causes for their epilepsy. Of the causal attributions examined (personal, external and fatalism) patients believed their seizure control related most strongly to external factors, such as doctors actions, as opposed to personal behaviour or chance.

In short, recently diagnosed epilepsy patients could be characterised as; been less certain about their epilepsy label in spite of comparable beliefs about seizure severity and frequency to chronic patients, having a strongly acute time perception, believing less in discrimination and stigma, and reporting less experience of stigma.

Chronic patients attending the clinic were characterised as; possessing a strong illness identity, having a chronic / cyclic time perception, believing strongly in stigma and discrimination and reporting more actual experience of stigma. Further, chronic (clinic) patients were distinguished by high contamination beliefs and perceived themselves as less able to contain the effects of their epilepsy.

On the consequences and self-illness relationship components, chronic patients (GP) more closely resembled recently diagnosed patients as opposed to chronic (clinic) patients. Namely, reduced belief in stigma, discrimination, less experience of stigma, less role contamination and good containment. Given the similar neuroepileptic status (seizure frequency and number of AED`s) between GP and recent onset patients these parallels are unsurprising. Additional cognitive representations characteristic of the GP sample were a strong illness identity and a chronic / cyclic timeline.

<u>1(d) : How do patients cope with their epilepsy?</u>

Table 6.18 shows the mean item scores for the Ways of Coping Checklist-Revised (WCCL-R). These data were entered into a paired t-test with a specified minimum significance level of $p < .007$. Patients utilisation of; wishful thinking, avoidance and problem-focused coping did not differ significantly. However, the sample were characterised by significantly higher engagement in seeking social support relative to the variant coping strategies assessed.

Contrasting the coping profile of the present sample with a sample of patients presenting disparate chronic medical conditions (Bombardier et al, 1990), patients in the present study employed a diverse range of thoughts and behaviours to cope with their epilepsy.

Table 6.18: Mean item scores for the WCCL - R.

		Paired variables - t-value		
Coping scale.	Item mean.	Wish. Think.	Avoid.	Prob-foc.
Seeks social support	3.05	4.43*	6.16*	5.61*
Wishful thinking	2.59		2.85	0.27
Avoidance	2.41			2.20
Problem-focused	2.57			

NOTE : *$p < 0.007$

1 (e) : What are the mental health outcomes?

The means, SD`s and independent t-tests between epilepsy patients and a normative group are presented in Table 6.19. The normative data were taken from a representative population sample of 5,089 respondents in the Rand Health Insurance Experiment. On all 8 MHI scales, epilepsy patients demonstrated significantly reduced mental health compared to the normative sample.

Table 6.19: All epilepsy patients and a non-clinical sample compared on the MHI.

MHI scales	Normals [a] Mean (SD)	All epilepsy patients [b] Mean (SD)	t-test
MHI index.	177.56 (25.46)	161.53 (31.09)	6.02***
Psych. distress.	47.54 (15.39)	61.89 (21.12)	8.88***
Psych. wellbeing.	59.16 (12.16)	50.41 (12.01)	6.91***
Anxiety.	19.15 (6.85)	23.24 (8.33)	5.71***
Depression.	8.05 (2.97)	9.97 (3.98)	6.17***
Loss. control	15.90 (5.57)	20.31 (7.61)	7.55***
Positive affect	45.64 (9.56)	42.22 (10.27)	3.43***
Emotional ties	9.08 (2.56)	8.19 (2.83)	3.33**

Note: [a] N = 5089; [b] N = 94.

*p<0.05, **p<0.01, ***p<0.001.

2 (a) : Are there differences in coping style between the three groups studied?

Table 6.20 shows the mean scores on the four coping strategies for the three groups of epilepsy patients. These data were analysed using multivariate analysis of variance (MANOVA). Using a Helmert contrast, differences in coping were examined between; recent onset and chronic patients (contrast 1) and chronic patients (clinic) and chronic patients (GP) (contrast 2). The groups were homogeneous for variance on all coping factors. All scales were normally distributed.

Epilepsy patients did not differ in their utilisation of problem-focused coping and seeking social support. However, group differences were apparent on the wishful thinking and avoidance coping scales. Contrasts between recently diagnosed patients and all chronic patients were not significant. Chronic patients attending the clinic were characterised by significantly greater use of wishful thinking and avoidance coping relative to chronic patients cared for by their GP.

Table 6.20: Coping strategy mean scores (WCCL-R) for the three groups of epilepsy patients.

	Group:			
Coping	Recent.	Chronic (clinic).	Chronic (GP).	F
Problem-focused	37.66	38.8	38.7	0.19
Contrast 1 (recent v chronic)				t 0.16
Contrast 2 (chronic - clinic v GP)				t 0.41
Seeks social support	17.52	18.25	19.00	0.73
Contrast 1 (recent v chronic)				t 1.05
Contrast 2 (chronic - clinic v GP)				t 0.99
Wishful thinking	19.90	22.70	17.84	6.59**
Contrast 1 (recent v chronic)				t 0.26
Contrast 2 (chronic - clinic v GP)				t 3.30**
Avoidance	23.76	25.42	21.96	3.47*
Contrast 1 (recent v chronic)				t 0.05
Contrast 2 (chronic - clinic v GP)				t 2.29*

Note: *p<0.05, **p<0.01.

2 (b) : Are there group differences in measures of mental health?

Table 6.21 shows the mean scores on the Mental Health Index for the three patient groups. MANOVA analysis with Helmert contrast revealed a number of significant group differences. Contrasting recently diagnosed patients with combined chronic patients indicated significantly reduced positive affect and psychological wellbeing among recent onset patients. All other contrasts between recent and chronic patients were non-significant. Relative to chronic (GP) patients, chronic patients attending the clinic had significantly poorer mental health scores on seven of the eight MHI scales including the underlying mental health factor. The groups did not differ in their reporting of emotional ties.

Table 6.21: Mental health mean scores (MHI) for the three groups of epilepsy patients.

MHI	Group: Recent.	Chronic (clinic).	Chronic (GP).	F
Anxiety	23.57	24.89	20.00	3.03
Contrast 1 (recent v chronic)				t 0.55
Contrast 2 (chronic - clinic v GP)				t 2.45*
Depression	11.09	10.66	7.81	5.96**
Contrast 1 (recent v chronic)				t 1.97
Contrast 2 (chronic - clinic v GP)				t 3.08**
Loss emot. control	21.57	22.25	15.77	7.32**
Contrast 1 (recent v chronic)				t 1.43
Contrast 2 (chronic - clinic v GP)				t 3.71***
Positive affect	38.62	40.02	49.11	9.77***
Contrast 1 (recent v chronic)				t 2.52**
Contrast 2 (chronic - clinic v GP)				t 2.00*
Emotional ties	7.71	7.87	9.15	2.15
Contrast 1 (recent v chronic)				t 1.14
Contrast 2 (chronic - clinic v GP)				t 1.87
Psych. distress	65.52	66.55	50.54	5.74**
Contrast 1 (recent v chronic)				t 1.38
Contrast 2 (chronic - clinic v GP)				t 3.26**
Psych. wellbeing	46.33	47.89	58.26	9.18***
Contrast 1 (recent v chronic)				t 2.44**
Contrast 2 (chronic - clinic v GP)				t 3.83***
Mental health index	153.81	154.36	180.73	7.87**

Note: *p<0.05, **p<0.01, ***p<0.001.

2 (c) : Do the groups differ in measure of self-esteem or social anxiety?

Group differences in self-esteem and social anxiety / distress were analysed using one-way ANOVA. These data are presented in Table 6.22. Chronic patients (GP) had significantly higher self-esteem and lower social anxiety / distress than the clinic groups. Chronic patients attending the clinic reported the lowest self-esteem and highest social anxiety / distress.

Table 6.22: Self-esteem and Social Anxiety and Distress (SAD) mean scores for the three groups of epilepsy patients.

Dependent variable	Group:			
	Recent.	Chronic (clinic).	Chronic (GP).	F
Self-esteem	31.71	29.47	33.50	5.67**
Social anxiety/distress	4.52	4.81	2.16	3.36*

Interim summary

Analysis of the coping data and dependant variables revealed a number of significant group differences. In terms of utilising problem-focused coping and seeking social support no differences were found between the three groups. However, chronic (clinic) patients could be distinguished by significantly greater wishful thinking and avoidance coping relative to GP patients.

Multivariate ANOVA revealed a range of group differences on the 8 MHI scales. Relative to combined chronic patients, recent onset patients displayed good adjustment on the positive affect and psychological wellbeing scales. Significant differences were found between chronic (clinic) and chronic (GP) patients on 7 of the 8 scales, with chronic (clinic) patients exhibiting the poorest mental health on all 7 contrasts. Groups did not differ on the emotional ties scale. In terms of self-esteem and social anxiety / distress, chronic (clinic) patients again displayed the poorest adjustment.

Chronic patients attending the clinic were characterised by high utilisation of wishful thinking and avoidance coping, significantly poorer mental health status on seven of the eight MHI scales, lower self-esteem and greater social anxiety. In contrast, chronic (GP) patients used less wishful thinking and avoidance coping, demonstrated relatively good mental health, reported the highest self-esteem and lowest social anxiety / distress. Recently diagnosed patients were distinguished by a coping and mental health profile that typically placed them between chronic (clinic) and chronic (GP) patients.

3): Is the self-regulation model of use in understanding the relationships between the variables measured?

In this final set of research questions, the relationships between illness representations, coping and adjustment will be examined. The self-regulation model proposes that adaptation to illness results from coping efforts which, are determined by the individuals cognitive representations of the objective features of the illness.

First, correlations between the illness representation components and coping are presented. Second, a series of hierarchical multiple regression analyses are computed to examine the models predictive power with regard to psychosocial adjustment variables.

3 (a): Are illness representations associated with coping?

Bivariate correlation coefficients were computed to investigate the relationships between illness representation components and the four coping strategies assessed. These data are presented in Table 6.23. Within the identity component, epilepsy symptom frequency was associated with wishful thinking ($r = .30$, $p < .01$) and avoidance coping ($r = .25$, $p < .05$). Non-epilepsy symptoms were similarly associated with wishful thinking ($r = .34$, $p < .01$) and avoidance (.37, $p < .001$). Belief in an epilepsy label was negatively related to avoidance coping ($r = -.25$, $p < .01$).

A number of causal beliefs were associated with coping. Personal responsibility was negatively associated with seeking social support ($r = -.22$, $p < .05$). Blaming others was positively associated with wishful thinking ($r = .27$, $p < .01$). Stress was negatively related to seeking social support ($r = -.33$, $p < .01$) and positively associated with both wishful thinking ($r = .22$, $p < .05$) and avoidance ($r = .22$, $p < .05$).

Perceptions of stigma, discrimination and experience of stigma were strongly positively related to coping by wishful thinking and avoidance ($p < .01$). Further, belief in physical consequences to seizure was related to avoidance coping ($r = .25$, $p < .05$).

Within the self-illness component, perceptions of containment of disability were negatively related to both wishful thinking ($r = -.32$, $p < .01$) and avoidance coping ($r = -.29$, $p < .01$). Belief in role contamination was related to these two coping styles in a positive direction, ($r = .27$, $p < .01$) wishful thinking and ($r = .36$, $p < .001$) avoidance coping.

Table 6.23: Correlations between illness representation components and coping variables.

Illness Representation component.	Coping (WCCL-R)			
	Problem-foc.	Social supp.	Wishful think.	Avoidance
Identity:				
Ep. symp. freq.	.00	-.03	.30**	.25**
Non-epilepsy symptoms.	-.04	-.02	.34**	.37***
Label.	-.06	.25*	-.01	-.25**
Cause:				
Per. responsibility	.17	-.22*	.08	.09
Blame others	.14	-.09	.27**	.17
Environment	.04	-.02	-.06	-.08
Stress	.10	-.33**	.22*	.22*
Genetic	.07	-.03	.10	.17
chance	.12	.02	.20*	.06
Timeline:				
Acute	.06	-.15	.06	.12
cyclic	.00	.17	-.13	-.06
Chronic	-.05	.17	.00	-.04
Consequences:				
Physical.	.03	.02	.25*	.18
Enacted stigma	.21	-.04	.31**	29**
Perceived discrim.	.04	-.12	.25**	.34**
Perceived stigma.	.22*	-.04	.35***	.34**
Control:				
Personal	.32**	-.12	.03	.02
External.	.03	.18	-.10	-.16
Fatalism	.03	-.21*	.09	.19
Self-Illness:				
Containment	-.01	-.06	-.32**	-.29**
Role contam.	.00	-.17	.27**	.36***

Note: *p<0.05, **p<0.01, ***p<0.001.

3 (b): Do illness representations predict mental health outcomes?

A hierarchical regression model was used to examine the relationships between illness representations and adjustment with the effects of neuroepilepsy variables removed. A set of five separate multiple regression equations were computed with 8 illness representations components entered as predictors. Dependent variables were; 3 of the 8 factors from the Mental Health Inventory (mental health index, psychological wellbeing and psychological distress), self-esteem and social anxiety / distress. In order to control for neuroepilepsy status, three dummy coded variables representing the three patient groups together with number of seizure types were entered into each equation first. Illness representations were entered as a second block of variables. Examination of residuals confirmed assumptions of normality.

Table 6.24 shows the unstandardized and standardized regression coefficients, adjusted R^2 and F ratio after entry of all predictor variables. Neuroepilepsy variables (group and number of seizure types) were entered first and explained; 13 per cent of the variance in mental health, 14 per cent in psychological wellbeing and 9 per cent in psychological distress. R for the regression was significantly greater than zero ($F_{3,90}$, $p < .01$) for each equation.

With the 8 illness representation variables entered as a second block, the total proportion of variance accounted for in; mental health was 41 per cent, an increase of 28 per cent; 34 per cent in psychological wellbeing, an increase of 20 per cent and 42 per cent in psychological distress, an increase of 33 per cent. After step 2, with all independant variables entered, regression ANOVA`s were significant ($F_{3,90}$, $p < .001$).

Self-esteem and social anxiety / distress were also entered as dependent variables. Neuroepilepsy factors explained 10 per cent of the variance in self-esteem, increasing to 35 per cent with the addition of illness representations and a modest 5 per cent of the variance in social anxiety, increasing to 24 per cent.

When all 10 predictors were taken into account across the five regression equations, those variables making a significant contribution were; epilepsy symptom frequency, non-epilepsy symptoms, label, timeline, external control and containment of disability effects. Within the illness representation domain of identity, epilepsy symptom frequency predicted mental health, psychological wellbeing and social anxiety in a negative direction, and psychological distress in a positive direction. Epilepsy label was a significant negative predictor of psychological distress.

Perceptions of chronic / cyclic timeline and external control predicted self-esteem. Within the self-illness component, containment was a significant positive predictor of mental health, psychological wellbeing and self-esteem and a significant negative predictor of both psychological distress and social anxiety. Overall, containment of disability effects emerged as the most consistent predictor of adjustment. Neither neuroepilepsy factor made a significant independent contribution.

Table 6.24: Multiple regression analyses of neuroepileptic factors and illness representations on mental health, self-esteem and social anxiety / distress.

	Mental Health (MHI)		Psych. Well. (MHI)		Psych. Dist. (MHI)		Self-esteem		Social Anxiety	
Variables	B	β	B	β	B	β	B	β	B	β
Neuroepilepsy factors										
Group	10.44	.15	5.26	.18	5.37	.11	2.39	.19	-1.35	-.14
No. seizure types	-4.05	-.07	-1.18	-.05	2.88	.07	1.37	.14	-.87	-.11
	Adj R^2 = .13		Adj R^2 = .14		Adj R^2 = .09		Adj R^2 = .10		Adj R^2 = .05	
	F = 5.66**		F = 6.18***		F = 4.41**		F = 4.70**		F = 2.56	
Illness Representations										
Epilepsy symptom freq.	-.50	-.22*	-.07	-.09	.37	.24*	-.07	-.18	.11	.37**
Non-epilepsy symptoms	-1.22	-.19	-.43	-.17	.79	.18	.12	.11	-.23	-.25*
Label	1.48	.13	-.46	-.10	-1.94	-.24*	-.28	-.14	-.04	-.03
Causal - stress	-1.22	-.15	-.34	-.11	.89	.16	-.17	-.13	.16	.14
Timeline	-.22	-.05	.06	.03	.29	.09	.18	.22*	-.03	-.04
Consequences - stigma	-.91	-.15	-.22	-.09	.69	.16	-.19	-.18	-.02	-.02
Control - external	.77	.10	.74	.23*	-.03	-.01	.27	.19*	-.21	-.18
Containment	1.24	.27**	.57	.32**	-.67	-.21*	.31	.41***	-.24	-.38***
	Adj R^2 = .41		Adj R^2 = .34		Adj R^2 = .42		Adj R^2 = .35		Adj R^2 = .24	
	F = 6.28***		F = 5.37***		F = 7.19***		F = 5.58***		F = 3.70***	

NOTE : *p<0.05, **P<0.01, ***P<0.001

Table 6.25: Multiple regression analyses of neuroepileptic factors and coping scales on mental health, self-esteem and social anxiety / distress.

	Mental Health (MHI)		Psych. Well. (MHI)		Psych. Dist. (MHI)		Self-esteem		Social Anxiety	
Variables	B	β	B	β	B	β	B	β	B	β
Neuroepilepsy factors										
Group	14.01	.20*	6.35	.23*	7.69	.16	1.72	.15	-1.17	-.12
No. seizure types	-8.31	-.14	-1.74	-.07	6.58	.17	1.10	.11	-.52	-.06
	Adj R^2 = .13		Adj R^2 = .14		Adj R^2 = .09		Adj R^2 = .10		Adj R^2 = .05	
	F = 5.66**		F = 6.18***		F = 4.41**		F = 4.70**		F = 2.56	
Coping										
Aviodance	-1.78	-.32**	-.74	-.34**	1.04	.27*	-.24	-.26*	.17	.22
Problem-focussed	1.16	.26**	.40	.24**	-.75	-.25*	.13	.17*	-.11	-.18
Seeks social support	-.06	-.01	-.09	-.03	-.03	-.01	.03	.03	-.17	-.16
Wishful thinking	-1.25	-.24*	-.31	-.15	.94	.26*	-.31	-.35**	.17	.23
	Adj R^2 = .36		Adj R^2 = .32		Adj R^2 = .30		Adj R^2 = .34		Adj R^2 = .22	
	F = 8.58***		F = 7.48***		F = 6.94***		F = 7.90***		F = 4.74***	

NOTE : *p<0.05, **P<0.01, ***P<0.001

3 (c): Is coping associated with mental health outcomes?

The same hierarchical regression procedure was used to examine the relationships between coping and adjustment. Neuroepileptic factors were controlled for by firstly entering dummy variables representing patient groups and number of seizure types. The four coping scales were entered as a second block. Examination of residuals confirmed assumptions of normality. These data are presented in Table 6.25. Neuroepileptic factors were entered into the five equations. R for the regression was significantly greater than zero for each dependant variable except social anxiety / distress ($F_{3,90} = 2.56$, ns). With the coping scales entered second, the amount of variance accounted for in; mental health was 36 per cent, an increase of 23 per cent; 32 per cent in psychological wellbeing, an increase of 18 per cent and 30 per cent in psychological distress, an increase of 21 per cent. The full regression equations explained 34 per cent of the variance in self-esteem, an increase of 24 per cent and 22 per cent in social anxiety / distress, a modest increase of 17 per cent. Overall, regression ANOVA`s were significant ($p<.001$). Avoidance coping was a significant negative predictor of mental health, psychological wellbeing and self-esteem. Avoidance predicted psychological distress in a positive direction. The opposite pattern emerged for problem-focused coping, being a positive predictor of mental health, psychological wellbeing and self-esteem and a negative predictor of psychological distress. Coping by seeking social support failed to made a significant contribution to adjustment. The relationships between wishful thinking and adjustment were similar to those found avoidance coping and adjustment. Namely wishful thinking was a significant negative predictor of mental health, psychological wellbeing and self-esteem and a positive predictor of psychological distress.

3 (d): Do Illness representations predict coping efforts, which in turn predict mental health outcomes?

According to self-regulation theory, illness representations guide coping, with illness outcomes / emotional adjustment determined by those coping efforts. To investigate the relationship between the variables proposed by the model a further hierarchical multiple regression analysis was conducted. After controlling for neuroepileptic factors (group and number of seizure types) the four coping variables were entered into the equation followed by 8 illness representations variables. Three higher order factors form the MHI were employed as dependant variables. These data are presented in Table 6.26.

As before, after step 2 with neuroepilepsy and coping variables in the equation adjusted R^2 = .36 (mental health); .32 (psychological wellbeing) and .30 (psychological distress). After step 3 with illness representations added to the prediction adjusted R^2 increased to .50 (mental health); .42 (psychological wellbeing) and .51 (psychological distress). The addition of illness representations significantly improved the prediction, increasing the proportion of explained variability in mental health outcomes by between 10 and 21 per cent.

Table 6.26: Multiple regression analysis of neuroepileptic factors, coping scales and Illness representations on mental health indices.

Variables	Mental Health (MHI) B	β	Psych. Well (MHI) B	β	Psych. Dist (MHI) B	β
Neuroepilepsy:						
Group	-11.36	-.15	-5.66	-.19*	5.86	.11
No. seizure types	-.43	-.07	-1.1	-.05	3.23	.08
	Adj R^2 = .13		Adj R^2= .14		Adj R^2= .09	
	F = 5.66**		F = 6.17***		F = 4.41**	
Coping:						
Avoidance	-.96	-.17	-.60	-.27*	.36	.09
Problem-focused	1.26	.29***	.39	.23**	-.87	-.29***
Seeks social supp	-.39	-.05	-.16	-.06	-.16	-.05
Wishful thinking	-.50	-.10	.02	.01	.02	.01
	Adj R^2= .36		Adj R^2= .32		Adj R^2= .30	
	F = 8.58***		F = 7.48***		F = 6.94***	
Illness Rep:						
Ep. symp. freq.	-.39	-.17	-.07	-.08	.33	.22*
Non-Ep symp.	-.73	-.11	-.22	-.09	.51	.11
Label	1.25	.10	-.71	-.16	-1.97	-.25*
Cause-stress	-.13	-.17	-.44	-.14	.92	.17
Timeline	-.25	-.05	.06	.03	.32	.10
Conseq. stigma	-1.1	-.18*	-.26	-.11	.84	.20*
Control-ext	.32	.04	.54	.16	.21	.04
Containment	.93	.20*	.45	.26**	-.47	-.15
	Adj R^2= .50		Adj R^2= .42		Adj R^2= .51	
	F = 7.21***		F = 5.41***		F = 7.43***	

Note: *p<0.05, **p<0.01, ***p<0.001.

Two coping variables contributed significantly to predictions. Avoidance coping was a negative predictor of psychological wellbeing. Problem-focused coping predicted mental health and psychological wellbeing whilst being a significant negative predictor of psychological distress. Four of the illness representation components significantly predicted mental health outcome. Psychological distress was positively predicted by epilepsy symptoms and a negatively predicted by label. Psychological wellbeing had one strong positive predictor (containment of disability effects). Stigma predicted mental health in a negative direction and containment predicted mental health in a positive direction.

Interim summary

Examination of the relationships between illness representations and coping revealed several distinct associations. The identity component, patients symptoms and belief in their epilepsy label, was negatively related to problem-focused coping and seeking social support whilst significantly related to wishful thinking and avoidance coping in a positive direction. Within the causal domain, blaming others was positively related to wishful thinking and attributions to stress negatively related to seeking social support. Perceptions of stigma and discrimination as consequential to epilepsy were strongly related to wishful thinking and avoidance coping. Belief in role contamination and perceived inability to contain the implications of epilepsy were also associated with wishful thinking and avoidance coping. Few significant relationships were identified between representations of temporal cause and coping and representations of control and coping.

Multiple regression analyses were used to calculate the extent to which illness representations predicted adjustment and coping predicted adjustment. A set of five regressions equations were computed with; mental health, psychological wellbeing, psychological distress, self-esteem and social anxiety / distress as adjustment measures. After controlling for the effects of neuroepilepsy factors (patient group and number of seizure types) illness representations predicted a greater proportion of outcome variance than the coping scales on all five measures. Those illness representation components making a significant contribution were; epilepsy symptom frequency, non-epilepsy symptoms, label, timeline, external control and containment of disability effects. Self-illness perceptions of the ability to contain the effects of epilepsy were a strong and consistent predictor of outcome.

Three coping scales were significant predictors of adjustment. Both avoidance and wishful thinking were negatively related to mental health and self-esteem whilst positive predictors of psychological distress. Problem-focused coping was a positive predictor of mental health and a negative predictor of psychological distress.

In order to test predictions from self-regulation theory that coping efforts follow from patients cognitive representations of illness and in turn predict outcome, both coping and illness representations variables were entered into a hierarchical regression analysis. Counter to strict predictions from the model, illness representations had a direct relationship with all five adjustment variables. These associations were stronger than those between coping and adjustment.

CHAPTER 7: DISCUSSION AND CONCLUSIONS

Chapter 7 comprises three sections. first a summary of the results and discussion relative to the existing literature. Second, methodological considerations are discussed. Finally, the clinical and theoretical implications of the present work are considered.

Summary and discussion of results

The study was conducted to investigate the role of illness representations and coping variables in adjustment to epilepsy among 94 diagnosed patients. The sample comprised three groups; recently diagnosed patients (< 1 year), chronic patients (clinic) and chronic patients (GP). Illness representations were operationalized by expanding the six components proposed by Leventhal and colleagues (1984) to incorporate additional variables shown to have explanatory power in the epilepsy - psychopathology literature. A new instrument combining qualitative and quantitative approaches for the measurement of cognitive representations of epilepsy was developed. Of particular interest were; group differences in cognitive representations of epilepsy and coping, and the relationships between illness representations, coping and outcome variables.

Analysis of the demographic data revealed few group differences and indicated the sample to be representative of the general population of adult epilepsy patients. In terms of the samples` neuroepileptic status, the three groups could be clearly delineated, indicating meaningful group differences in biomedical variables.

Illness Representations: Analyses of the relationships between the illness representation components revealed a pattern of associations consistent with those found by Weinman et al (1996) and Moss-Morris et al (1996) using the Illness Perception Questionnaire (IPQ). Namely, an association between a strong illness identity and perceptions of serious consequences. In the present study, a strong epilepsy identity was positively associated with perceived consequences; physical, stigma and discrimination. Also consistent with studies using the IPQ was the finding that patients with a chronic timeline were less likely to perceive their epilepsy as controllable by themselves. Perceptions of chronicity were also associated with belief in serious consequences (physical, stigma and discrimination)

A further congruent finding was the association between certain causal attributions and serious consequences. Patients who blamed others for their epilepsy perceived harmful physical consequences to their condition.

Additional significant interrelationships included, a strong negative association between identity and perceptions of an acute timeline. Patients reporting greater symptom frequency and a stronger belief in the applicability of their epilepsy label were more likely to endorse a chronic timeline. This finding supports the proposal from self-regulation theory that illness representations change over time. In line with predictions for self-regulation theory as applied to chronic illness (Leventhal and Nerenz, 1983) patients holding a strong illness identity and chronic timeline perceived greater role contamination and reduced ability to contain the effects of their condition. The correlational data, therefore, suggest that as patients symptoms and time perceptions change the relationship between the disease and the self-system undergo changes, with patients moving towards total involvement with their disease.

In terms of control beliefs, internal control was strongly related to the causal belief of personal responsibility. Perceptions of external control were negatively related to blaming others and causal attributions of stress. In keeping with the work of Arntson et al (1986) on the psychosocial consequences of epilepsy, perceptions of external control were strongly related to perceptions of stigma.

An unexpected result was the relatively weak correlation between patients perceptions of their epilepsy symptoms and belief in an epilepsy label. There is good data in support of assumptions from self-regulation theory that patients seek correspondence or symmetry between symptoms and labels (Baumann et al, 1989). It could be that patients in the present study were seeking labels for their symptoms other than epilepsy. The obtained qualitative data revealed that only 11 of the 21 recent onset patients used the word `epilepsy` when asked about their diagnosis. Further, belief in an epilepsy label was strongly negatively related to both an acute time perception and the causal belief of personal responsibility. This again supporting claims that illness representations are of a dynamic rather than static nature.

Illness representations also covaried with a number of demographic and neuroepileptic variables. Given that illness representations are assumed to originate from multiple sources including an individuals personal illness experience (Leventhal et al, 1984) such relationships were anticipated. Of particular interest were associations between time since last seizure and illness cognitions.

Time since last seizure was strongly negatively related to illness identity and strongly positively associated with both acute timeline and containment of disability effects. In a general practice study of epilepsy, Chaplin et al (1992) found similar significant associations between recency of last seizure and health beliefs. In a study investigating stigma among epilepsy patients, Jacoby (1994) reported, with one exception, perceptions of stigma to be unrelated to neuroepilepsy variables. The only significant association was between stigma and length of remission. In the present study, perceived consequences in terms of stigma and discrimination were related to a range of biomedical factors. These perceived consequences were positively related to duration of epilepsy and number of seizure types, whilst negatively associated with number of years in education, age at onset and time since last seizure. Despite debate about the extent of influence biomedical variables have over psychosocial adjustment in epilepsy (Hermann and Whitman, 1986; Scambler, 1993) the present work suggests a range of biomedical factors, especially recency of last seizure, are related to cognitive representations of epilepsy. In a review paper, Turnquist, Harvey and Andersen (1988) report a relationship between biomedical factors and both the frequency and strength of attributions about illness. Additionally, number of seizure types was associated with a strong illness identity and a chronic time perception. In sum, the covariation of patients cognitive representations of epilepsy and biomedical factors is in keeping with self-regulation theory. According to the theory subjective illness cognitions can be differentiated from objective disease variables but such disease factors can influence the internal representation of a given health threat. Other factors influential in illness representations include; the general pool of illness information in the culture and social communication. The critical issue for researchers attempting to understand the determinants of health outcomes is the relative explanatory power of pure biomedical indices of disease and patients internal representations on coping efforts and adjustment.

Given that correlations calculated between the illness representations components could be inflated by artefact effects of patient group and the predictions from self-regulation theory of changes in illness representations over time, extensive MANOVA tests were carried out to locate group differences in representations. On the identity component, patient perceptions of epilepsy symptom severity did not differ between groups. However, chronic (GP) patients reported a weaker identity for symptom frequency when compared to both clinic groups. Despite this, recently diagnosed patients had a significantly reduced belief in their epilepsy label. It would thus appear that, recently diagnosed patients have less conviction in their ascribed label while having at least comparable perceptions of symptom severity and frequency

to chronic patients. Both chronic groups had a significantly stronger belief in the applicability of their epilepsy label. In view of the generally good prognosis for the majority of patients diagnosed with epilepsy, with up to 70 per cent attaining lengthy remission (Annergers, 1979), a gradual acceptance of the diagnosis can be seen as reasonable and perhaps adaptive. However, such an illness identity may have deleterious effects on treatment regime adherence. Data obtained during recruitment indicated a clinic non-attendance rate of 49 per cent among recently diagnosed patients, as opposed to 26 per cent among chronic patients. The representational approach has demonstrated a good degree of explanatory power with regard to; adherence of patients to treatment regimes (Leventhal et al, 1992) and decisions to seek health care (Cameron et al, 1993). Implicit in a *process* model of epilepsy (Reynolds, 1989) is the position that multiple factors act to determine chronicity, rather than chronicity being inevitable for a sub-group of patients. Factors believed to influence prognosis include treatment compliance and an early response to treatment. It therefore follows, that illness cognitions may influence treatment uptake and indirectly disease prognosis. This important area remains open to future study.

In their work with cancer and hypertensive patients Leventhal and colleagues (Baumann et al, 1989) found a shift from an acute time perception to cyclic / chronic as patients moved from newly treated to continuing treatment groups. Temporal expectations had important effects on behaviour. The present data is highly congruent with the idea that experience of a condition modifies timeline representations. Patients recently diagnosed with epilepsy held a strong acute timeline relative to chronic patients. Both chronic groups perceived their epilepsy in terms of a cyclic / chronic model when contrasted to the recent onset group. It therefore appears, that continued experience of epilepsy leads patients to adopt a more chronic timeline.

On the consequences component (stigma and discrimination) group differences were also observed. Chronic patients held significantly stronger perceptions of stigma and discrimination as consequential to their condition compared to recent onset patients. These data provide further support for the position that patients elaborate their illness representations over time (Leventhal et al, 1984). However, all three patient groups differed significantly in their perceptions of stigma and discrimination, with chronic (clinic) patients holding the strongest beliefs. The latter patient group had the poorest seizure control. It appears that, both time and experience of epilepsy symptoms are influential in patients changing representations of factors consequential to their epilepsy. In a series of cross-sectional studies Johnston et al (1990) evaluated changes in parents perceptions of their children's diabetes with time.

Perceptions of seriousness declined over the first year, but with more experience of disease management and complications in later years the condition was perceives as more serious. Guttmann et al (1981), cited in Leventhal and Nerenz (1983) and Leventhal and Nerenz (1983) have conducted interview studies to investigate types self-illness relationships. Those patients who developed a chronic timeline tended to perceive their involvement with their disease as *total* or *encapsulated*. Their adaptations were very different. In the present study self-illness relationships were operationalized as; *role contamination* and *containment of disability effects*. In line with Leventhal`s work, chronicity was associated with perceptions of high contamination and low containment, with chronic (clinic) patients reporting such a pattern. However, this was not inevitability the case. Chronic (GP) patients had the lowest contamination perception and the strongest belief in their ability to contain the effects of their epilepsy. Again, the data suggest that both time and experience of disease, influence patients cognitive representations of illness.

In sum, whilst significant group differences were found in cognitive representations of; identity, timeline, consequences and self-illness relationships, no difference was observed in the causal and control components of the representation. There is debate in the literature regarding the stability of illness representation components. Self-regulation theory proposes that illness representations may become elaborated and change over time. Schober and Lacroix (1991) conclude that illness representation components combine to form a knowledge structure that is stable and invariant. The present data support recent work by Weinman et al (1996) and Pimm et al (1995) indicating both stability and change among patients illness representations. Patients perceptions of; identity, timeline and consequences seem particularly responsive to illness experience. While the factors that underpin change remain unclear, it is reasonable to a assume that the elaboration of illness representations relates to time and illness experience variables such as stability and predictability.

Epilepsy patients made causal attributions for their condition early in the disease course which, is in keeping with attribution theory (Harvey and Weary, 1981). Patients most strongly attributed their epilepsy to stress and chance as opposed to ones self, others, genetics or the environment. Causal attributions did differ between groups nor were they correlated with neuroepilepsy factors. There is support for consistency in attributional content with respect to time (Affleck, Tennen, Croog and Levine, 1987; Rudy, 1980; Taylor et al, 1984). The evidence is, however, mixed with other studies indicating covariation of causal attributions with disease variables such as severity and time since diagnosis (Turnquist et al, 1988).

A similar pattern of stability was found on the control component. Recent onset and chronic patients did not differ in their perceptions of; internal, external and fatalistic control beliefs. Within component analysis revealed patients most strongly believed their epilepsy was controlled by external sources, typically doctors. Patients in the present study, therefore, held a traditional view of epilepsy with seizure genesis the result of random and spontaneous discharge of nerve tissue. There is good evidence to support a dynamic view of epilepsy in which, seizure control is determined by interactions between organic and cognitive-behavioural factors (Fenwick, 1992).

An additional within component analysis was conducted to evaluate the distinction made by Scambler (1989) and Jacoby (1994) between felt and enacted stigma. In this dichotomy, enacted stigma refers to experience of discrimination, whereas felt stigma refers to patients perceptions and fear of enacted stigma. The present data support this dichotomy, with perceived stigma and discrimination more prevalent than actual episodes of discrimination.

Coping with epilepsy: Comparison of coping style utilisation (WCCL-R) for the entire sample revealed significantly greater seeking social support relative to; wishful thinking, avoidance and problem-focused coping. In a study evaluating coping among patients with diverse chronic conditions, Bombardier et al (1990) reported a comparable high utilisation of seeking social support. With regard to group differences, chronic (clinic) patients reported the most frequent use of wishful thinking and avoidance coping. There were no differences between the groups in the use of problem-focused strategies and seeking social support. In short, chronic patients attending hospital clinics were significantly more reliant upon wishful thinking and avoidance coping compared to chronic (GP) patients. The frequency with which recently diagnosed patients used wishful thinking and avoidance coping fell between that of the two chronic groups. Contrasts between the recent onset group and all chronic patients did not attain significance. The transactional model of stress (Folkman and Lazarus, 1980) presents coping as a process, with coping efforts changing in response to ongoing stress appraisals. The present data support this dynamic conceptualisation of coping by identifying meaningful group differences. Chronic (clinic) patients, the group with the smallest number of patients in remission, were characterised by higher utilisation of wishful thinking and avoidance coping. Evidence suggests that avoidance can be an adaptive strategy early in the process of coping with illness (Suls and Fletcher, 1985) but typically becomes a maladaptive strategy (Sarafino, 1994).

Psychosocial adjustment to epilepsy: The most important issue from the epilepsy - psychopathology perspective are the data on psychosocial adjustment relative to normal comparisons and within sample differences in adjustment measures. Contrasting epilepsy patients with normative data on the 8 Mental Health Inventory (MHI) scales revealed unequivocal results. The combined epilepsy patients displayed significantly poorer mental health on all 8 scales. This result supports the generally accepted concept of epilepsy as a high psychosocial risk disorder. However, recent work highlighting the influence of selection bias in many studies has led researchers to review the epilepsy - psychopathology literature. It is suggested that data obtained largely from specialist centres for epilepsy care has biased findings in a pathological direction (Zielinski, 1986; Hermann and Whitman, 1992). No previous work has contrasted chronic patients attending hospital clinics with recently diagnosed patients and patients cared for in the community. If the selection bias hypothesis is correct, then significant group differences should exist in the present study. Relative to chronic (GP) patients, chronic (clinic) patients exhibited significantly poorer psychological adjustment on 7 of the 8 MHI scales; anxiety, depression, loss of emotional control, affect, distress, wellbeing and the overall mental health index. Additionally, chronic patients attending the clinic had lower self-esteem and higher social anxiety / distress than chronic (GP) patients. In terms of mental health outcomes then, there was a good level of distinction between the two chronic epilepsy groups, with clinic patients showing the poorest psychosocial adjustment.

There is evidence, that irrespective of diagnosis, psychological disturbance is greatest in the early stages of illness (Meyercwitz, 1980; Cassileth et al, 1984). The present data were further analysed to contrast recent onset patients and combined chronic patients on the mental health outcome measures. Recently diagnosed patients had significantly reduced mental health on 2 of the 8 MHI scales (affect and wellbeing). However, these difference were due to the relatively good mental health status of the GP group rather than differences between the recent and chronic (clinic) patients. All other contrasts between recent onset and combined chronic patients failed to attain significance. It is important to note the pattern of outcome results. Whilst GP patients exhibited better psychosocial adjustment when compared to chronic (clinic) patients, relative to the latter group recent onset patients had 5 outcome scores in a negative direction and 5 in a positive direction. However, these represented small fluctuations with all but 2 differences washing out in statistical analysis.

In sum, among chronic epilepsy patients, clinic attendees displayed poorer adjustment on 9 of the 10 outcome measures. The outcome profile of the recently diagnosed group more closely resembled the chronic (clinic) group than the chronic (GP) group. Relative to all chronic patients, recent onset patients had poorer mental health on 2 of the 10 scales (affect and wellbeing). These differences resulting from comparison with well adjusted GP patients. Therefore, of the 3 groups, chronic (GP) patients could clearly be delineated on the basis of good psychosocial adjustment. There was a less clear distinction between recently diagnosed and combined chronic patients, due to a high degree of parity in outcome scores between recent onset and chronic (clinic) patients.

The present data support recent findings by Edeh et al (1990); Trostle et al (1989) and Jacoby (1992) that epilepsy patients do not form a homogenous group. Patients cared for in hospital clinics and the community could be distinguished in terms of their; neuroepileptic status; illness representations and morbidity. Whilst chronic (clinic) patients display significant psychosocial adjustment problems, chronic patients cared for in the community appear relatively well adjusted. It is important to characterise clinic and community patients in future mental health research. The scant evidence available on recently diagnosed epilepsy patients suggests mild psychosocial effects from which, adjustment problems may develop as the condition becomes chronic (Chaplin et al, 1992). However, in the Chaplin et al study cut-off for recent onset was 36 months with patients recruited via general practitioners. The number of patients discharged from neurology back to their GP for management is not cited. The present data point to more severe adjustment problems among recently diagnosed patients, with greater congruity in mental health scores between recent onset and chronic (clinic) patients than between recent onset and chronic (GP) patients.

Relationships between illness representations, coping and adjustment: Having identified meaningful group differences in the variables studied, the research aimed to investigate associations between illness representations and coping and determine the mediating role of neuroepileptic, illness representation and coping factors in adjustment to epilepsy.

There were a number of strong and cogent associations between illness representation components and coping strategies. Both epilepsy and non-epilepsy symptoms were positively associated with wishful thinking and avoidance coping.

However, a strong belief in the applicability of an epilepsy diagnosis was negatively related to avoidance coping. It appears that breaking the identity component down to symptoms and label reveals important relationships. Symptom frequency was associated with escape coping. Patients who had belief in their epilepsy label, also endorsed a chronic time perception, reported a negative association with avoidance coping. The consequences scales (physical, stigma and discrimination) were also positively related to wishful thinking and avoidance coping. In their study of chronic fatigue patients (Moss-Morris et al, 1996) reported similar positive relationships between illness representation components of identity and consequences and emotion-focused coping strategies. On the self-illness relationship scale, perceptions of containment were negatively associated with wishful thinking and avoidance whilst role contamination was positively related to these escape strategies. Coping by seeking social support was positively related to belief in an epilepsy label and negatively relayed to; personal responsibility, stress and fatalistic control beliefs. Problem-focused coping was positively related to personal control beliefs and perceived stigma. The latter finding was unexpected and could possible reflect differences in perceived stigma between the two chronic patient groups.

Overall, the data provide support for the theory that illness representations and coping are related to psychosocial adaptation to disease. After controlling for neuroepilepsy factors, illness representations accounted for; 28 per cent of the variance in mental health, 20 per cent of the variance in psychological wellbeing, 33 per cent of the variance in psychological distress, 25 per cent of the variance in self-esteem and 19 per cent of the variance in social anxiety / distress. Neuroepileptic and illness representations combined explained; 41 per cent of the variance in mental health, 34 per cent of the variance in psychological wellbeing, 42 per cent of the variance in psychological distress, 35 per cent of the variance in self-esteem and 24 per cent of the variance in social anxiety / distress. Using their multietiological model, Hermann and Whitman (1990) accounted for 34 per cent of the variance in depression scores. In the final equation only illness representation variables retained predictive power. Consistent significant predictors were; identity, containment of disability effects and external control. In the context of illness representation research, the association between identity and adjustment was supportive of work by Moss-Morris et al (1996) on chronic fatigue patients. Additional studies (Earll et al, 1993; Goldstein et al, 1990 and Williams, 1995) have reported strong associations between perceived consequences and psychosocial adjustment. This relationship was not evident in the present study. Of particular relevance in the present data was the strong and consistent association between containment and adjustment,

with perceptions of containment predictive of good psychosocial adjustment. Patients gave both qualitative and quantitative responses indicating the impact of epilepsy on their self perceptions. Perhaps the central issue in chronic illness is how the representation of the illness is related to the underlying self-system (Leventhal and Nerenz, 1983). The current data support this position. It is possible that the self-illness relationship variables of containment and role contamination acted as super ordinate variables, subsuming the explanatory power of variables in the consequences domain such as; physical, stigma and discrimination.

Patients in the present study most strongly endorsed an external locus of control. This is in keeping with existing studies in the epilepsy literature (Matthews and Barabas, 1986; Arntson et al, 1986). However, the data revealed a positive association between perceptions of external control and adjustment. This finding is consistent with the theory that surrendering control to significant others is adaptive in situations where there are few opportunities for control (Burish, Carey, Wallston and Stein, 1984; Affleck et al, 1987). Patients recruited to the study did not receive guidance on cognitive-behavioural methods of seizure control as part of their epilepsy management. The lack of association between causal attributions and adjustment was in keeping with work by Taylor et al, (1984) and Earll et al (1993). In a review of the literature, Turnquist et al (1988) concluded that while patients who report explicit attributions are better adjusted than patients who fail to report attributions, associations between attribution content and adjustment is less clear. However, there is some consensus that blaming others is associated with poorer outcomes (Tennen and Affleck, 1990). This relationship was not supported by the present data.

These findings contribute to the current literature. Firstly, by providing support for the position that biomedical factors explain small amounts of variance in psychosocial adjustment to epilepsy. Secondly, by connecting variables with known etiological significance to a health psychology oriented theoretical framework and demonstrating good explanatory power and significant interrelationships.

The same hierarchical regression procedure was conducted for the coping variables, with neuroepilepsy factors controlled for. The coping scales accounted for; 23 per cent of the variance in mental health, 18 per cent of the variance in psychological wellbeing, 21 per cent of the variance in psychological distress, 24 per cent of the variance in self-esteem and 17 per cent of the variance in social anxiety / distress. On all five outcome variables, coping demonstrated weaker explanatory power compared to the illness representation components.

Among the coping scales, wishful thinking and avoidance were predictive of poor psychosocial adjustment whilst problem-focused coping was associated with good adjustment. Seeking social support did not attain significance in the final equation. The pattern of findings supports previous work in documenting the beneficial effects of problem-focused coping and the deleterious effects of emotion strategies (wishful thinking and avoidance) on adjustment and psychological wellbeing (Felton et al, 1984; Vitaliano et al, 1985; Bombardier et al, 1990 and Upton and Thompson, 1992). In line with suggestions made by Bombardier et al (1990), the present data suggest interventions aimed at promoting adjustment should consider both improving problem-focused strategies and interrupting the utilisation of maladaptive emotion-focused strategies (wishful thinking and avoidance).

According to self-regulation theory the impact of illness representations is mediated by coping. The present data do not support this part of the model. Although there were several significant associations between illness representations and coping, illness representation components were more strongly predictive of adjustment than were coping variables. Illness representations components retained significant predictive power having firstly controlled for both neuroepileptic variables and coping. Together these three block variables explained; 50 per cent of the variance in mental health, 42 per cent of the variance in psychological wellbeing and 51 per cent of the variance in psychological distress. The data indicate that illness representations both influence coping and have direct effects on adjustment. Other researchers using the illness representation paradigm have reported similar findings; Johnston et al (1996) in a study of stroke patients; Earll et al (1993) in a study of motor neurone disease and multiple sclerosis and Moss-Morris et al (1996) in their work with chronic fatigue patients.

Methodological considerations

Given the cross-sectional design of the study and correlational nature of the data, direct causal interpretations cannot be made. Self-regulation theory proposes reciprocal relationships between its elements, with coping efficacy appraised and fed-back to influence illness representations and future coping efforts. Only longitudinal prospective designs can clarify the nature of these relationships. Given that the study developed a new measure of patients` cognitive representations of epilepsy, all resultant variables were entered into the correlational analyses for exploratory purposes. Liberal alpha values were employed. Correlations attaining significance at the $P < .05$ level should be interpreted with caution.

The present work could have been limited by clinic non-attendance and response rates. Among the recently diagnosed clinic patients, 38 (49 per cent) failed to attend for appointment. Of those 40 patients invited to participate, 19 (47 per cent) declined the invitation. The non-attendance and non-response rates were substantially lower among chronic (clinic) patients, with just 26 per cent failing to attend and 31 per cent declining to participate. Of the 70 GP patients contacted by letter, 63 per cent declined to participate. Questions therefore remain, regarding the representativeness of the sample, particularly the recent onset and GP patient groups.

One of the strengths of the study was that it contrasted recently diagnosed patients with chronic patients cared for both in hospital clinics and the community. Further, within each patient group, data was obtained from multiple sources including three hospital sites and five GP surgeries. All patients participating in the study had received a diagnosis of epilepsy from a neurologist.

Theoretical and clinical implications

The study comprised the development of an instrument for the measurement of cognitive representations of epilepsy and the use of this measure together with a coping scale to investigate psychosocial adaptation to epilepsy. The work was based on the self-regulation model. The instrument was designed to assess the components of illness representations proposed by Leventhal and colleagues (1984) with each domain expanded to incorporate variables with relevance to coping with epilepsy. Initial data suggest the scales have satisfactory internal consistency. The interview format, with each scale preceded by an open-ended question was agreeable and engaging for patients. There is debate in the literature regarding the relative merits of qualitative versus quantitative approaches to the measurement of illness cognitions. The current combined approach has advantages over exclusive interview or questionnaire methods. These include, improved rapport with patients and a possible `priming effect` with open-ended questions serving to activate the associated illness schemata. The current instrument holds potential to be further developed for use with epilepsy and other patient populations.

The authors of self-regulation theory, Leventhal and colleagues propound their work as a model or framework to guide thinking and from which, to derive specific theories. The model makes no specific predictions and was not intended to be testable in its entirety. Recent interest in illness representation research among British health psychologists has involved an explicit operationalization of the proposed coping process, in which coping mediates the health impact of illness cognitions. The resultant studies do not support this position. As a result, Johnston (1996) has sought to elaborate current explanatory models by combining relevant variables from disparate theories. Future illness representation research should proceed with the knowledge that illness cognitions influence coping and have direct effects on psychosocial adaptation. Both the latter approach and one of theoretical reformulation are congruent with the illness representation paradigm. The general point to emerge from the literature, is support for the validity and health impact of the distinct domains comprising illness representations.

The present work contributes to the growing recognition that illness representations play a significant role in understanding the psychosocial impact of disease. The self-regulation model incorporates both illness cognitions and coping behaviours. The study therefore, carries the clinical implication of developing interventions with a cognitive-behavioural focus aimed at promoting adjustment. One, as yet unpublished study, has taken this approach with rheumatoid arthritis patients (Pimm, Byron and Curson, 1995). Evidence that cognitive-behavioural variables explain significant outcome variance in adjustment coupled with the emerging literature on the role of psychological factors in seizure control (Fenwick, 1992) provide a sound rationale for intervention work with epilepsy populations. Further, given that the model has demonstrated a satisfactory level of predictive utility, there is potential for using the representational approach to identify individuals who are `at risk` of poor psychosocial adjustment following a diagnosis of epilepsy.

The present data indicated a 49 per cent clinic non-attendance rate among recently diagnosed patients. Recently diagnosed patients were characterised by; reduced belief in the applicability of their diagnosis, an acute time perception and perceptions of less severe consequences. Clinic non-attendance creates inefficiency in care provision and more importantly may militate against a good prognosis. The role of illness cognitions in care seeking and adherence to epilepsy treatment regimens is a further area open to future investigation.

Conclusion

Epilepsy has long been associated with significant interictal psychopathology. However, inaccuracies exist in the current literature. Firstly, the majority of studies have recruited samples from special centres for epilepsy care. Such centres treat a high proportion of patients presenting intractable epilepsy. The high rates of psychopathology found have been generalised to the population of epilepsy patients. Secondly, most attempts to account for the variance in psychosocial adjustment have relied exclusively on a biomedical research paradigm. Neuroepileptic factors have demonstrated only modest explanatory power. There is now growing recognition of the need to consider multiple biomedical and psychological variables in order to understand the complex associations between epilepsy and adjustment. Although health-oriented psychological theory and methodology provides a framework for such inquiry, research on the non-neurological factors associated with psychosocial outcome in epilepsy and other neurological conditions has been little influenced by the discipline of health psychology. The present work represents a first step in evaluating adjustment among different groups of epilepsy patients, with both neurological and psychological predictor variables integrated within a clear theoretical framework. The main theme of the self-regulation framework (Leventhal et al, 1984) is that patients are active in construing a cognitive representation of illness which, has coping and adjustment implications.

The study made several contributions to the current literature. First, support for the position, that in terms of psychosocial adaptation epilepsy patients do not form a homogenous group. The present data point to more severe adjustment problems among chronic patients attending hospital clinics and recently diagnosed patients, relative to chronic patients cared for in the community. Second, the development of an instrument to assess patients cognitive representations of epilepsy. Third, the study has demonstrated the value of the self-regulation model in identifying relationships between neuroepileptic, illness representation, coping and psychosocial adjustment variables. Both illness representations and coping were significantly related to adjustment after controlling for the modest effects of neuroepileptic variables. Illness representations had the strongest overall association with adjustment. Finally, the work has implications for interpreting the self-regulation model and for developing clinical interventions with patient populations.

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APPENDIX 1:

ILLNESS REPRESENTATIONS MEASURE

RESEARCH INTERVIEW - D. CLIN. PSYCHOL - STEVEN KEMP

Firstly, I would like to ask some questions about yourself and your attacks. These are to do with age, education, employment and the number of attacks you have.

DEMOGRAPHIC VARIABLES

1) Age / Dob

2) Gender

3) Years education since age 16

4) Financial status - annual household income:
A) >40k
B) 30k - 40k
C) 20k - 30k
D) 10k - 20k
E) <10k

5) Occupation:

6) Marital status

7) Number of dependants

NEUROLOGICAL VARIABLES

1) Age at onset:

2) Time since last seizure:

3) Seizure frequency - A) > once per day
B) > once per week
C) > once per month
D) 1 - 6 mths
E) 6 mths or less

4) Duration of disorder:

*5) Aetiology - symptomatic

location of lesion

idiopathic

history of surgery

*6) Seizure type: partial seizures - simple / complex

presence of secondarily generalised seizures

primary generalised seizures

*7) Number of different seizure types:

*8) Currently treated by - GP

Outpatient neurological clinic

MEDICATION VARIABLES

*1) Number of AED`s being taken:

*2) Medication type: Phenytoin
Carbamazepine
Phenobarbitone / Methylphenobarbitone
Primidone
Sodium valproate
Vigabatrin
Clonazepam
Clobazam / Benzodiazepines (adjunct anxiolytics)

* Obtained from medical notes

INTERVIEW TO ELICIT ILLNESS REPRESENTATION IN ADULT EPILEPSY PATIENTS

For this part of the interview I will be asking you two types of question. Firstly, questions which I would like you to answer in your own words. Secondly, questions which you should answer on the scale in front of you.

For all questions it is important to say what you think is true for **you**, not what maybe true for most people who have attacks.

On some questions I may move you on so we don't fall behind time.

DIMENSION 1 - IDENTITY

1a) SYMPTOMS - EXPERIENCED OVER THE LAST 6 MTHS

Can you describe to me some of the symptoms that you have experienced in the last 6 months (Open question). Rate each for severity and frequency.

Severity:

1	2	3	4	5
Very mild	Mild	Moderate	Severe	Very severe

Frequency:

1	2	3	4	5
< 3 mthly	2-3 mthly	Mthly	Weekly	Daily

Specific Probes: (Partial - Simple)

Unwanted limb or facial movement / twitching:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Loss of speech or difficulty speaking:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Spots or flashes before eyes:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Dizziness:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Unpleasant or unusual smells or tastes:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Buzzing, whistling or hissing sounds in ears:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Sensations of familiarity or memory flashbacks:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Feeling dreamy:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Seeing or hearing things in an unusual way:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Nausea / butterflies or sweating:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Numbness of some parts of your body
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

<u>Specific probes (Partial - complex)</u>

An aura or strange feeling or sensation that may tell you are about to have an attack:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Change in your level of consciousness - this may include: suddenly falling to the floor or loosing the ability to fully understand what is going on around you:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Loss of ability to move your limbs or body:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Unwanted or repetitive movements or activity like shaking or twitching:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Repeated movements like lip-smacking, chewing, swallowing, scratching or picking:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Feeling confused following an attack:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Specific probes (Generalised seizures)

A temporary loss of attention or a strange sensation of being mesmerised:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Rapid jerky muscle movement:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

A big attack involving violent muscle contractions and temporary loss of consciousness:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Other concrete signs of epilepsy

In your own words, do you experience any other signs of symptoms associated with the attacks or seizures.(Open question)
(Rate each for severity and frequency)

Specific probes:

Enlarged gums:
Severity

1 2 3 4 5 ☐

Scars or a skin condition:
Severity

1 2 3 4 5 ☐

Tremor or shaking of the hands:
Severity

1 2 3 4 5 ☐

Rashes:
Severity

1 2 3 4 5 ☐

Slurring of speech:
Severity

1 2 3 4 5 ☐

Are you aware that you are having an attack or do you only learn about it afterwards from other people or by how you feel or look.

☐

1b) IDENTITY - LABEL

In your own words, have the symptoms / attacks that you have experienced been given a name or diagnosis. (Open question)

Response Scale:

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Agree	Strongly Agree

Specific probes

* I believe I have an illness that looks like epilepsy, but is not epilepsy ☐

* I don't think that I have epilepsy or any such illness ☐

Specific probes (non-epileptic)

Tiredness / fatigue:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Loss of appetite:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Weakness:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Weight loss:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Minor infections such as colds, ear or eye infections:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

Breathlessness:
Severity

1 2 3 4 5 ☐

Frequency

1 2 3 4 5 ☐

DIMENSION 2 CAUSAL ATTRIBUTIONS

In your own words, what do you believe caused epilepsy in your case (open question)

What do you believe sets off an attack for you (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

PERSONAL RESPONSIBILITY

The epilepsy was caused by my behaviour ☐

The presence of the epilepsy relates to something I did ☐

The disease was caused by my diet ☐

The disease was caused by lack of rest ☐

The epilepsy resulted from something in my life like my job or home situation ☐

The epilepsy was caused by something that I did not do ☐

BLAMING OTHERS

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

I believe that my epilepsy was caused by something that somebody else did ☐

My illness was caused by carelessness or mistakes made by other people ☐

Doctors or other medical people caused my illness ☐

People other than myself must take some responsibility for the onset of my epilepsy ☐

I think that my family are the cause of my epilepsy ☐

ENVIRONMENT

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

My illness was caused by something that I came into contact with ☐

Something in the environment like chemicals or pollution is responsible for my illness ☐

STRESS

My epilepsy resulted from stress ☐

My epilepsy was caused by work ☐

GENETIC

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

I think my epilepsy is genetic ☐

CHANCE

I think my epilepsy is the result of bad luck ☐

DIMENSION 3 - CONSEQUENCES

PHYSICAL

In your own words, what are the possible consequences for your present and future health of having attacks (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

Having an attack could cause me to swallow my tongue ☐

An attack could cause me to have an accident ☐

The attacks I have leave me vulnerable to other illnesses ☐

Having attacks reduces my life expectancy ☐

In the long run my attacks could result in some loss of memory or loss of ability to think clearly ☐

SOCIO-ECONOMIC (PERCEIVED DISCRIMINATION)

In your own words, do you think that your epilepsy has any effect on your social life of your ability to earn a living (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

It is more difficulty to get a job if you suffer with attacks ☐

There are certain places that I can't go to because of my epilepsy ☐

My attacks mean it is more difficult for me to get married ☐

My illness reduces the quality of my social life ☐

I have had difficulty obtaining a driving licence ☐

There are certain sporting activities that I would not do because of my epilepsy ☐

I do not drink alcohol because of my attacks ☐

EMOTIONAL / PERCEIVED STIGMA

In your own words, do you think that in any way your epilepsy makes you different to other people
(open question)

Specific probes

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Employers treat people who get attacks unfairly	☐
People put unreasonable limits on what I can do	☐
People who know I have attacks treat me differently	☐
The legal system is unfair on people with epilepsy	☐
I always feel I have to prove myself	☐
People who suffer epileptic attacks are less valued by society	☐

EXPERIENCE OF STIGMA

In your own words, can you think of any examples where people have actually treated you unfairly because of your attacks (open question)

Specific probes

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

I have lost friends because of my attacks ☐

I have lost a job because of my attacks ☐

People have treated me differently or rejected me because I get attacks ☐

DIMENSION 4 -TEMPORAL COURSE

In your own words, how long do you think that you will suffer from epileptic attacks (open question)

How long do you think that you will need to be on treatment (open question)

Will the cause of your attacks ever go away or become cured (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

* Now I have seen a doctor about my attacks I expect that they will stop quite quickly ☐

* Given a couple of months, whatever caused my attacks will have gone for good ☐

My attacks will tend to come and go, rather than go away for good ☐

I think what causes my attacks is an illness / condition that will last for a lifetime ☐

I will need to take medication to control my attacks for a very long time ☐

DIMENSION 5 - CONTROLLABILITY

PERSONAL CONTROL OVER SYMPTOMS AND DISEASE COURSE

In your own words, do you think that you have any control over the severity or frequency of your attacks or what causes them (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

Things that I do influence how severe my attacks are ☐

The number of attacks that I have depends on what I do ☐

I believe that I can control my attacks ☐

The course of my illness (whether the attacks stop or continue) is under my control ☐

In the long run whether my epilepsy goes away completely or keeps recurring is down to me ☐

EXTERNAL CONTROL

In your own words, do you think that other people such as medical staff have control over your attacks or what causes them (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

I think the doctors I have seen have the know- how to control my attacks ☐

Whether my epilepsy improves or not is determined by what the doctors and other staff can do for me ☐

The frequency of my attacks depends on others ☐

CHANCE / FATALISM

In your own words, do you think the control of your attacks has more to do with luck or chance than what you or your doctor do (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

Staying free of attacks is mainly due to good luck ☐

Whether in the future I am free of attacks depends more on good fortune than my treatment ☐

DIMENSION 6 SELF - ILLNESS RELATIONSHIP

In your own words, how big a part does epilepsy play in your life- e.g. you as an employee, a husband/wife, a parent, a friend, a sports person etc. (open question)

Specific probes

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

ROLE CONTAMINATION

My attacks cause problems for me as a husband / wife / partner ☐

My attacks have a bad effect on me as a parent ☐

My attacks have a bad effect on my friendships with people ☐

My attacks cause problems for me as an employee ☐

The attacks have a bad effect on my social life ☐

There are many sports that I am unable to do because of my attacks ☐

CONTAINMENT OF DISABILITY EFFECTS

* In some way or other my epilepsy affects all aspects of my life ☐

I can ignore the problems of my epilepsy by looking at the good things in my life ☐

* Almost all areas of life are closed to me because of my epilepsy ☐

* My attacks effect the areas of my life that I care about most ☐

I can often forget that I have attacks and get on with things ☐

SEVERITY

1	2	3	4	5
Very Mild	Mild	Moderate	Severe	Very Severe

FREQUENCY

1	2	3	4	5
Less than every 3 months	2-3 monthly	Monthly	Weekly	Daily

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neither Agree or Disagree	Slightly Agree	Agree	Strongly Agree

APPENDIX 2:

PATIENT INFORMATION SHEET

DOCTORAL RESEARCH PROJECT - STEVEN KEMP

INFORMATION SHEET

My name is Steven Kemp and I am a psychologist from the University of Leeds. I am conducting a research project on how people with epilepsy view themselves.

My specific interest is in the relationship between the beliefs that people have about their attacks and how they cope with / manage them.

This work is important because it should help NHS staff to better understand how people cope with attacks. This will help staff improve their service to people.

The study has been granted ethical approval by the local Research Ethics Committee. All involved with the project would greatly appreciate your help with this, but please note that there is no obligation to take part.

If you do take part, then I will interview you and ask you to fill in some short questionnaires about the attacks. This should take about 40-45 minutes.

Please note that all information you provide is strictly anonymous and confidential.

At the end of the project I will prepare a brief summary of what I have found. If you would like this or any other information about the project then please contact me at the address below.

Your time and assistance is greatly appreciated.

Steven Kemp
Research Psychologist

APPENDIX 3:

GP PATIENT RECRUITMENT LETTER

10 September 1995

I am a Research Psychologist conducting a study about epilepsy. The study aims to improve our understanding of how people cope with epileptic attacks. This is important in helping staff to provide better advice and support to people diagnosed with epilepsy.

The study has been granted ethical approval by the local Research Ethics Committee. Your GP (Dr and partners) agreed to contact you on my behalf to seek your permission for your name to be given to the project. If you would like to disclose your name and help with this work, then please return the slip below in the SAE provided and I will contact you. I have enclosed an information sheet, which tells you more about the project.

If you would like to be included in the project, then I will briefly interview you and ask you to fill in some short questionnaires. This would take about 40 Minutes and I could see you at home or arrange to meet at your GPs surgery.

Please note that there is no obligation to take part.

Thank you

Yours Sincerely

Steven Kemp
Research Psychologist

✂

Name:.....

Tel:.....