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Perceptions of stress and ways of coping in people with non-epileptic attack disorder (NEAD)

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Award date:
1997

Awarding institution:
University of Wales, Bangor

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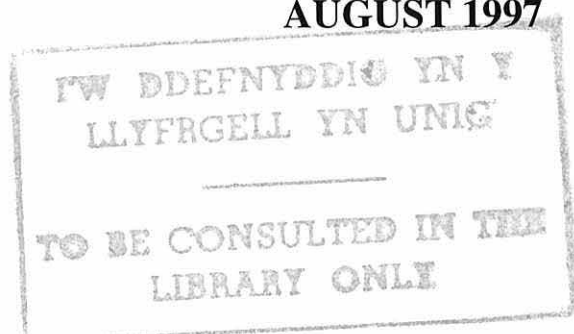
**PERCEPTION OF STRESS AND WAYS OF COPING IN
PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER
(NEAD)**

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**THESIS SUBMITTED FOR THE DEGREE OF
DOCTORATE IN CLINICAL PSYCHOLOGY**

UNIVERSITY OF WALES, BANGOR.

AUGUST 1997



ABSTRACT

Twenty women and ten men with Non-Epileptic Attack Disorder (NEAD) were matched by age and gender with an epilepsy- and a healthy-control group. In response to clinical and research evidence of a relationship between NEAD and the experience of stress, it was hypothesised that people with NEAD would perceive their ongoing lives as more stressful, and use more avoidant and distancing coping, and less problem focussed coping, than people in the two control groups. Using the Perceived Stress Scale (Cohen, Kamarck and Mermelstein, 1983) and the Ways of Coping -revised version (Folkman and Lazarus, 1988) the study found that people with NEAD (1) perceived their ongoing lives as significantly more stressful, (2) were significantly more likely to use escape-avoidant coping and (3) were significantly less likely to use planful problem solving coping than healthy controls. People with NEAD were similar in their level of use of distancing coping to epilepsy controls, who scored significantly higher on this variable than their healthy counterparts. The Hospital Anxiety and Depression (HAD) scale (Zigmond and Snaith, 1983) was intended as a control measure, and data revealed a significant elevation in depression and anxiety in the NEAD group over the healthy control group. However, because a statistical assumption was violated, HAD data were not used to covary. The study findings indicate that people with NEAD experience lives as stressful as do people with a debilitating neurological disorder, and are likely to employ maladaptive coping responses. Implications for diagnosis, intervention and future research are discussed.

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Acknowledgements

I am very grateful to my supervisors, Gus Baker and Peter Appleton, for their solid, ongoing and invaluable help and advice, and to all the study participants for their willingness to spend precious time and emotional effort answering awkward questions.

Thanks to Mike Startup for guidance with statistics, to Mark Williams for his feedback and encouragement, and to Rachel Blake for help with data management in the early stages.

Special thanks also to Kenny Midence for his tireless patience and generous support with the nitty gritty of statistics and computers; my partner, Nic, for helping bring clarity to many puzzles and for always having faith in me (especially when I didn't); and to my son, Charlie, for the light and proper perspective he brought to the whole business!

1 Introduction

This study assesses the perception of stress and employment of coping strategies in people with Non-Epileptic Attack Disorder. The introduction section of the study report begins with a description of NEAD in an historic and societal context. It then discusses the variety of terminology which has been applied to this psychophysiological phenomenon, before discussing epidemiology and associated methodological limitations. Diagnostic and classification issues related to NEAD in comparison to epilepsy are discussed (Section 1.2.1), and the problems of failure to recognise NEAD are outlined (1.1.5). Section 1.3 discusses aetiology. Section 1.4 describes processes involved in the experience of stress and coping, before proposing that the manifestation of NEAD is associated with the use of avoidant, emotion-focused coping strategies. Two hypotheses associated with this proposal are put forward as the basis of the current research study.

SECTION 1.1: NEAD

1.1.1 The problem of Non Epileptic Attack Disorder (NEAD).

People with Non Epileptic Attack Disorder (NEAD) present with episodes which bear clinical similarity to epileptic seizures, but which, in EEG analysis, are shown to be unaccompanied by the excessive electrical discharge of brain cells which indicates true epilepsy (Condler and Zasler, 1990).

NEAD is increasingly recognised as posing significant diagnostic and therapeutic challenges to general medical practitioners (Lowman and Richardson, 1987) and clinicians in neurological, psychological and psychiatric fields (Gates and Erdahl, 1993). Extensive medical resources and attention are allocated to a phenomenon which produces such dramatic symptomatology that, if the condition were organic, would reflect serious damage, and which is, by its very nature, intractable to medical intervention.

1.1.2 The nature of Non-Epileptic Attack Disorder: historic and societal context.

The phenomenon of NEAD has been documented in various guises across many cultures and in a variety of historical references. In Haitian communities a dissociative state known as "indisposition" (e.g. Philippe, Romain and Charles, 1979), or "falling-" or "blacking-out" (e.g. Lefley, 1979; e.g. Weidman, 1979) involves individuals collapsing, apparently unable to move, with open but unseeing eyes. Among Navajo Indians, fugue states and hand trembling occur without identifiable organic cause (Neutra, Levy, and Parker, 1977). A stone script in Babylonian times, dated between 718 and 616 BC refers to fits and falls which are due to emotional shock, or "the hand of Ishtar" (Ramsay, Cohen and Brown, 1993). In writings attributed to Hippocrates, hysterical epilepsy was described and attributed to the womb floating in the body and causing symptoms where it came to rest (Massey, 1982), while Aretaeus classified two varieties of epilepsy - ordinary and hysterical (Gates and Erdahl, 1993). In 19th century America,

cases were recorded among women of "hysterical fits" which mimicked epileptic seizures, and included symptoms such as sobbing, violent laughter, and a deathlike trance (Smith-Rosenburg, 1972). However, some of the earliest systematic descriptions of the phenomenon were made by Freud (1888/1966; 1928) and Breuer and Freud (1956).

In his Pre-Psychoanalytic Publications (Freud, 1888/1966) Freud described the symptoms of "hystero-epilepsy" or "major hysteria" based on the teachings of Charcot. Symptoms included convulsive attacks; "hysterogenic zones" (hypersensitive areas of the body, the stimulation of which leads to the generation of an aura); disturbances of sensibility such as hysterical anaesthesia of the skin; disturbances of sensory activity; paralysis; and, in extreme cases, contracture of the muscles.

1.1.3 Terminology and Definition

NEAD refers to recurring paroxysmal episodes which resemble epileptic attacks but lack characteristic clinical and electrographic features. There is a range of descriptive terminology describing this phenomenon which reflects a range of different models which have been used to make sense of the disorder. Labels including "hystero-epilepsy" (Freud, 1888/1966) and "hysterical-seizures" (e.g. Ramani, Quesney, Olson and Gumnit, 1980; Gross, 1979b) have their roots in psychodynamic literature. More recently the terms "psychogenic seizures" (e.g. Desai, Porter and Penry, 1982; Gross, 1982), "pseudo-seizures" (e.g. Ramchandani and Schindler, 1993; Gates and Erdahl, 1993), and "simulated epilepsy" (e.g. Roy,

1982) have been descriptive, while terms such as "functional seizures" (e.g. Gross, 1979a) have implied a more behavioural basis to the phenomenon. While "pseudoseizure" is probably the most popular term promoted in the literature (Gates and Erdahl, 1993) Betts and Boden (1991) suggest that it implies an intentionality that is inconsistent with the phenomenon - "Pseudoseizures are as real as epileptic seizures and only very rarely is the person who has the pseudoseizure trying to deceive" (Betts and Boden, 1991, p243). Because most pseudoseizures are mistaken for epilepsy, Betts and Boden (1991) propose the term Non Epileptic Attack Disorder as less pejorative and more definitive. On the basis of this reasoning "Non-Epileptic Attack Disorder (NEAD)" will be used in the current study, with the label "NEAD event" or "NEAD episode" describing paroxysmal episodes usually referred to as pseudoseizures.

On a cautionary note, there are a number of organic seizure types which are neither epileptic (i.e. involving abnormal neuronal discharge) nor functional. These include seizures involving the cardiovascular system, metabolic disorders (e.g. hypoglycaemia) sleep disorders, and so on. With this in mind, in this study, the label Non-Epileptic Attack Disorder refers to:

Definition

the occurrence of paroxysmal episodes which resemble epileptic and other organic attacks but which are devoid of clinical and EEG features associated with epilepsy and/or of other organic cause.

1.1.4 **Epidemiology**

While the epilepsies are regarded as a major health problem with estimated age-adjusted incidence rates ranging from 20 to 53 per 100 000 person years (Appleton, Baker, Chadwick and Smith, 1991; Hauser and Anagers, 1993), and an estimated prevalence rate of 3.5 per 1000 adults (Edeh, Toone and Corney, 1990), the epidemiology of non-epileptic attacks has not been the focus of systematic research (Lowman and Richardson, 1987). Rather estimates are made within the context of research into other aspects of NEAD. There are apparently no studies which assess the incidence and prevalence of the phenomenon in non-clinical populations (Lowman and Richardson, 1987), and information comes largely from specialist neurological settings. The literature concurs on two important points: (1) that patients with NEAD form a substantial proportion of people seen by neurological centres, and (2) that many people who have actual epileptic seizures also present with paroxysmal events which are not epileptic in nature. Estimates of the prevalence of NEAD come from a variety of locations and study designs and inevitably vary considerably. One American study found that 9% of 50 patients referred for intractable epilepsy had non-epileptic attacks while 1% had non-epileptic attacks as well as true epileptic events (Lesser, Lueders and Dinner, 1983). Also in America, Riley & Berndt (1980) surveyed 30 epilepsy referral centres, and found that 50% of inpatients and 20% of outpatients had solely non-epileptic attacks, or non-epileptic attacks in association with true seizures. In England, a study of 343 patients believed to have epilepsy found

that 63% of them had true epilepsy and 24% had NEAD (Betts and Boden, 1992). Regarding coincidence of non-epileptic and epileptic events Betts and Boden (1992) found that 13% of epilepsy patients had NEAD and either past or current genuine epilepsy. Ramani, Quesney, Olson and Gumnit (1980) found that 20% of 46 patients with true epilepsy admitted to an American epilepsy unit had concomitant nonepileptic attacks, while King, Gallagher, Murvin, and Smith (1982) found that 4 out of 60 people with diagnosed epilepsy had mixed attacks (with 12 of the 60 actually having non-epileptic attacks alone). Another perspective on the prevalence of NEAD seeks to discover what proportion of people with NEAD have concurrent epilepsy. Estimates from a number of studies range from 10% to 80% (Ramsay, Cohen and Brown, 1993).

Wide variation in estimates of NEAD indicates that establishing prevalence or incidence is problematic. Methodological issues which compound difficulties include inconsistency in definition and diagnosis of non-epileptic attacks, the relatively small sample sizes in most studies, and the selection biases in study populations (i.e. people with intractable seizures, attending specialist neurological centres), and different selection biases operating in different study centres.

Most of the NEAD literature points to a gender difference with the preponderance of people diagnosed with the disorder being female (Goodwin, 1989). In one group of over 100 NEAD patients, 83% were female (Betts and Boden, 1991). One explanation for the gender imbalance is the possible association between previous sexual abuse and development of NEAD. It is now widely

appreciated, however, that a greater number of males than was previously suspected, will have experienced some kind of sexual abuse in childhood (NSPCC, 1995). Another explanation for the greater number of females with NEAD than males, relates to the acceptability of emotional expression. Traditionally overt expression of anger, for instance, has been regarded as unfeminine and vulgar (Smith-Rosenburg, 1972), and the expression of emotions via symptoms and behaviours which carry with them an implication of weakness may provide an alternative which is more acceptable for women than men.

Data from the U.K., America and Canada show that the onset of NEAD usually occurs before the age of 40 (King, Gallagher, Mervin and Smith, 1982; Ramani, Quesney, Olson and Gumnit, 1980; Roy 1982). In an American study of 27 outpatients with NEAD the median age was 35 years and the mean age was 33.1 years (range = 12-48, with one 12 year old and one 16 year old) (Bowman, 1993).

There is some evidence that NEAD is more likely to occur in people with a history of neurological or other physical disease, including true seizure disorders (Lowman and Richardson, 1987). In a follow-up study of 41 discharged NEAD inpatients, 44% had coexisting neurological disorders (Krumholz and Niedermeyer, 1983).

People who present with NEAD have generally (a) directly experienced a seizure or seizures in infancy (febrile, epileptic, or related to some other organic cause); or (b) observed a family

member or friend who experienced epileptic seizures (Roy, 1982; Hopkins 1989).

In summary, while NEAD clearly poses an important challenge to neurological, medical and mental health services, its epidemiology is not well documented, and a number of methodological issues impede unequivocal interpretation of current data. Broadly speaking, about 10% to 50% of the people with "intractable epilepsy" who are referred to specialist neurological centres will also have NEAD. Most of them will be young adult women, with some prior experience of seizures, who may have associated neurological or physical disease.

1.1.5 Problems of failure to recognise NEAD

A failure to distinguish Non Epileptic Attacks from truly epileptic seizures often results in the inappropriate use of anti-epileptic drugs, with associated risks of toxicity and polypharmacy (Liske and Forster, 1964). The non-recognition of NEAD can also lead to the use of other hazardous and inappropriate interventions; demands on health and social services; and a neglect of psychological disorder (Baker, Moore and Appleton, 1995).

SECTION 1.2: DIAGNOSIS AND CLASSIFICATION

1.2.1 Diagnosing epilepsy

A comprehensive commentary on the diagnosis of epilepsy is within the remit of specialised neurology, and is beyond the scope of this paper. However, a basic understanding of the diagnostic issues regarding epilepsy is important in facilitating differential diagnosis of NEAD and true epilepsy.

Epilepsy is a chronic condition which is characterised by recurrent seizures which arise because of abnormal electrical discharges of cerebral neurones. Epileptic seizures are transient and discrete episodes (Porter, 1993). A person is therefore diagnosed with epilepsy if s/he is prone to recurrent epileptic seizures.

Investigation into epilepsy is initially clinical, and is based on detailed description of ictal and interictal events, both by the patient, and more importantly, by a reliable eye-witness (Appleton, Baker, Chadwick and Smith, 1991).

The diagnosis of epilepsy is made at three primary levels (Porter, 1993). At the first, aetiological level, epilepsy is caused either by brain pathology or neurological effects of systemic illness. Where the aetiology is known, epilepsy is referred to as "symptomatic". Where it is unknown, it is labelled "idiopathic". At the second level, involving classification of seizures, two main categories account for the vast majority of seizures. Seizures are categorised as either localised (partial) in origin, reflecting the presence of

specific cerebral abnormality and localised patterns of electrical discharge, or generalised in origin, reflecting diffuse and generalised electrical discharge. Table 1.1 shows a summary of the classification of epileptic seizure types. At the third level of diagnosis, syndromes are classified according to seizure types; the type of EEG abnormality and other neurological features; and the age of onset (Appleton et. al., 1991). As epilepsy can be caused by a wide range of diseases and disorders, including congenital defects, injury, infections, tumours, and vascular and degenerative diseases (Porter, 1993), it is also vital to establish a medical history.

Table 1.1
Classification of Epileptic Seizures According to
the International Classification System for
Epileptic Seizures

(Adapted from McIntosh, 1992)

Partial Seizures (seizures beginning locally)

Simple (consciousness not impaired)

With motor symptoms

With somatosensory or special sensory symptoms

With autonomic symptoms

With psychic symptoms

Complex (with impairment of consciousness)

Beginning as simple partial seizures, progressing to complex seizures

Impairment of consciousness at onset

1. Impairment of consciousness only

2. With automatisim

Partial seizures becoming secondary generalised

Generalised seizures

Absence seizures

Typical (petit mal)

Atypical

Myoclonic seizures

Clonic seizures

Tonic seizures

Tonic-clonic seizures

Atonic seizures

1.2.2 Diagnosis of NEAD

Diagnosis of NEAD is made as the result of the exclusion of epilepsy and other physiological disorders. Scrutiny of diagnostic processes and tools applied in the case of NEAD reveals that diagnosis here lacks the well defined levels of analysis applied to

epilepsy. Scrutiny of the literature reveals 5 main criteria which are usefully employed for establishing a NEAD diagnosis: (1) ineffectiveness of anti-convulsant drug treatment; (2) description of ictal behaviour which is not consistent with that of an epileptic event; (3) a normal EEG during and after seizures; (4) video-EEG telemetry yielding normal EEG recording during clinical episodes; (5) psychological aspects and psycho-social histories which are consistent with empirically established psychological profiles of people with NEAD. Less commonly, biological parameters such as tests for raised serum prolactin levels are used to aid diagnosis (Pritchard, 1993) although variability in patients with both epilepsy and NEAD limits the value of this procedure (Trimble, 1978; Mulder, 1990).

1.2.2.1 Ineffectiveness of anti-convulsant drug treatment

People presenting with epileptic seizures are typically seen initially by primary care physicians, who aim to control seizures with anti-convulsant medication (Lowman and Richardson, 1987). When seizures are not effected by anti-epileptic medication this would suggest either intractability of a genuine epilepsy to drug therapy (25 - 30% of people with epilepsy have seizures which do not respond to medication, Baker et. al, 1992) or NEAD.

1.2.2.2 Description of ictal behaviour

Clinical presentation of NEAD events is extremely diverse, and descriptions in the research literature are abundant, various and

largely inconsistent. Table 1.2 shows a summary of the features discussed in this section distinguishing NEAD events and epileptic seizures.

Table 1.2 Summary of differences between NEAD events and epileptic seizures.		
Feature	NEAD Event	Epileptic Seizure
Precipitated by trauma	Many (Betts and Boden, 1991)	Some (Betts and Boden, 1992a; Trimble, 1990)
Onset (Appleton et al., 1991)	Sudden	May be gradual
Duration (Appleton et al., 1991)	Seconds or minutes	Often many minutes
Retained consciousness in prolonged seizure (Appleton et al. 1991)	Common	Very rare
Clonic movements (Gates and Erdahl, 1993)	Out of phase	In phase
Side to side movement, pelvic thrusting (Gates et al., 1985)	Present	Absent
Cyanosis (Appleton et al., 1992)	Unusual	Common
Weeping (Ristanovic, 1993).	Present	Absent
Tongue biting and other injury (Appleton et al., 1992)	Less Common	Common
Post ictal drowsiness or confusion (Appleton et al., 1992)	Often absent	Usual

Appleton et al. (1991) outline a number of features which distinguish NEAD episodes from epileptic seizures (1991). In general, NEAD episodes have a gradual onset and prolonged duration compared to epileptic attacks which tend to occur suddenly and last only seconds or minutes. Consciousness is commonly retained in NEAD episodes but rarely retained in epileptic seizures, and while cyanosis, and tongue biting and other injury are common during epileptic seizures they are rare in NEAD episodes. Finally, there is often post ictal drowsiness and confusion in epilepsy and this is absent in NEAD (Appleton et al., 1992).

In epileptic seizures, clonic movements tend to be in-phase or stereotyped, while according to Gates and Erdahl (1993) NEAD clonic activity is out of phase with no apparent pattern. Some researchers have found that NEAD events include side to side movement, pelvic thrusting, non-verbal vocalisation and vocalisation at the onset of events (Gates, Ramani, Whalen, and Lowenson, 1985) whereas these are generally absent from true epileptic seizures. However other studies find most of these features to be uncommon: Scheepers, Budd, Curry, Gregory and Elson (1994) and Leis, Ross and Summers (1992) found the most frequently occurring presentation was verbal unresponsiveness, in their samples of 31 and 47 patients with NEAD (respectively), although no operational definition of "verbal unresponsiveness" is given for either study. Scheepers and colleagues suggest that the most consistent, clinically distinguishing feature of NEAD is normal pupil response during ictal events (although examination is not always possible because a common feature of episodes is rolling or

screwing up of eyes) (Scheepers et al., 1994). Other researchers report that weeping is a relatively common and specific feature of NEAD events. Although weeping is an extremely rare ictal phenomenon in true epilepsy, Bergen and Ristanovic (1993) found that it occurred in the 10 patients with NEAD whom they studied.

While most NEAD presentations are bizarre in comparison to epileptic seizures, making it relatively easy for the experienced observer to distinguish between the two, NEAD attacks may be most difficult to differentiate from unusual seizure types, particularly those of frontal lobe origin (Meierkord, Will, Fish and Shorvon, 1991). In addition, some epileptic seizures are known to be precipitated by anxiety and trauma (Betts and Boden, 1991), and for some patients there is a cycle of "seizures begetting anxiety begetting seizures" (Trimble, 1990, p489), which, in addition to posing the risk of medical emergency, can lead to a misdiagnosis of NEAD.

As well as endeavours to describe discrete NEAD events, attempts have been made at deriving systems of classification. Betts and Boden (1992a) suggest that there are three main types of non-epileptic attacks and make a classification of disorders based on clinical presentations in a psychodynamic context. Two typologies "the swoon" and "abreactive attacks" occur mostly in women who have been sexually abused in childhood, with "abreactive attacks" including jerking movements which bear a "superficial resemblance to sexual intercourse" (Betts and Boden, 1992a, p 23). "The tantrum" involves the person crying and thrashing about as

they fall and seems to be associated with "attention seeking" (Betts and Boden, 1992a, p24).

Reflecting on Betts and Boden's (1992a) classifications Scheepers et al (1994) found them generally unhelpful, although they recognised the association in some cases.

Porter (1993) suggests that a number of DSM classifications are useful in the description of NEAD. In DSM-IV, Conversion Disorder (300.11), Somatization Disorder (300.81), and Undifferentiated Somatoform Disorder (300.70) all include symptoms which suggest a physical disorder but for which there is no identifiable organic cause. Symptoms are related to underlying psychological factors but are not consciously controlled or intentional. In Conversion Disorders there is frequently a loss or alteration of physical functioning, temporally related to a psychological stressor, which is the manifestation of psychological conflict or need. In Somatoform Disorders, patients have a number of physical complaints, one of which may be non-epileptic attacks. Symptoms are often exaggerated and dramatic and medical histories are usually complicated. Undifferentiated Somatoform Disorder is applied to patients who have physical complaints with no organic basis, but fail to meet diagnostic criteria for Somatoform Disorder, *or* patients who have an actual physical problem and have resultant social impairment which is in excess of what would be expected.

While these and other DSM classifications may be relevant in that they reflect the heterogeneity of presentations of NEAD and

features associated with it, DSM classifications lack specificity to NEAD.

In attempting to make sense of the heterogeneity of this group, a nosology suggested by Gates (Gates and Erdahl,1993) provides a useful beginning. Gates categorises non-epileptic seizures as either physiologic or psychogenic. In the physiologic category are cardiac rhythm disorders, parasomnias, and paroxysmal dyskinesias. In the psychogenic category patients are either consciously aware of episodes, and would thus receive DSM diagnoses of malingering or factitious disorder, or unconsciously aware of their episodes and would probably be diagnosed with somatoform disorders, especially conversion disorder. According to Gates the unconsciously aware psychogenic group is the most significant to be referred to epilepsy centres. Within his psychogenic group he makes five subdivisions:

1. People with a diagnosis of true epilepsy who experience EEG verified epileptiform auras or partial motor events, and go on to present with non-epileptic attacks;
2. people with a diagnosis of true epilepsy who misinterpret normal physiological stimuli as auras of epileptic events, and go on to develop non-epileptic attacks;
3. people who unconsciously generate non-epileptic paroxysmal events as mechanisms for coping with stressors in their environments.
4. people with psychoses;
5. people with conversions disorders attributable to previous traumatic experiences such as sexual abuse (according to Gates this is the largest group, accounting for about 50% of psychogenic seizure patients).

In summary, the clinical presentation of NEAD is extremely diverse. Studies which have focused on identifying clinical characteristics of non-epileptic events, have failed to reach concordance regarding reliable clinical diagnostic criteria. Many of them use symptomatology which is derived from a psychoanalytic perspective of psychogenic events. Within this model movements such as pelvic thrusting are believed to simulate traumatic sexual contact. Others pinpoint certain ictal phenomena (e.g. weeping) as being specific to NEAD, while others suggest the presentation of "seizures" is idiosyncratic. Discrepancies arise because of definitional differences; the clear heterogeneity of the group; differences in theoretical approaches taken by researchers; and because of the small sample sizes employed in papers describing NEAD presentation phenomena. Scrutiny of the literature seems to reveal as the most common feature of non-epileptic events, their bizarre presentation in comparison to most seizures with an organic basis.

1.2.2.3 A normal EEG

The diagnosis of NEAD is greatly supported by the use of electroencephalography (EEG) which gives information about the presence or absence of ictal (during seizure) or interictal (between seizure) epileptiform activity (Mattson, 1993; Desai, Porter and Penry, 1982). However, while the diagnosis of NEAD is probably best supported by the absence of epilepsy correlates in EEG during a clinical episode, results must be considered in context with other evidence. The presence of EEG paroxysmal

abnormalities which would normally indicate epilepsy does not unequivocally rule out NEAD: epileptiform-like paroxysmal can be caused by anti-convulsant drug withdrawal, and spike and wave patterns found in epilepsy are also found in 3% of healthy people (Fenton, 1986). Conversely, a normal EEG does not rule out epilepsy or confirm a diagnosis of NEAD (Fenton, 1974).

1.2.2.4 Video-EEG telemetry

In addition to EEG monitoring, diagnosis of the absence of epileptiform activity during events is made using simultaneous EEG and video recording (Shen, Bowman and Omkar, 1990; Desai, 1983) or "video-EEG telemetry" (Meierkord, Will, Fish and Shorvon, 1991). Recordings are made over a number of hours (e.g. Luther, McNamara, Carwile, Miller, and Hope, 1982), or a day (e.g. Shen et al., 1990) or a number of weeks (e.g. Mattson, 1993). Events captured are then diagnosed according to criteria including typicality of patients' "seizures" as compared to their usual "seizures", the involvement of alteration of consciousness or bilateral motor/sensory phenomenon, and lack of EEG changes.

1.2.2.5 Psychological aspects and psycho-social history.

Just as a diagnosis of epilepsy must be made within the context of clinical course of illness, and individual and familial history, a diagnosis of NEAD will be indicated in association with psychopathology and/or a history of trauma (see section 1.3.1 for discussion of psychological correlates). The diagnosis of NEAD

must therefore be supported by a detailed psychological assessment interview which aims to identify psychological distress and/or the presence of other manifestations of psychological problems; and identify significant negative life events with a possible role in aetiology and precipitation of NEAD (Moore and Baker, 1997). (See Appendix for summary of psychological interview applied in a specialist neuropsychological clinic).

SECTION 1.3: AETIOLOGY

1.3.1 Empirical Aetiological Findings

When compared to people with epilepsy, people with NEAD have been found to be more likely to have family histories of psychiatric disorder, past personal history of psychiatric disorder, to have attempted suicide, and to be suffering current affective syndromes, (Roy, 1982; Stewart, Lovitt and Stewart, 1982). Estimates of affective disorders have been found to be as high as 85% in people with NEAD (Bowman, 1993). Compared to people with epilepsy, clinical depression is more common in people with NEAD but Ramchandani and Schindler (1993) point out that it is not clear whether affective disorders are causal, or a result of, NEAD. Current diagnosis of PTSD (Bowman and Markand, 1996), family problems (Moore, 1995; Lancman, Asconapé, Graves and Gibson, 1994) and family and marital problems (Roy, 1982) are also associated with NEAD. A number of studies find a high rate of conversion reactions (e.g. Meierkord et al 1991; Krumholz and Nierdermeyer, 1983), hysterical personality (e.g. Krumholz and

Nierdermeyer, 1983) and dissociative disorders (e.g. Bowman 1993; Ramchandani and Schindler, 1993) in people with NEAD.

Recently, Bowman and Markand (1996) found that of 45 patients with pseudoseizures, 84% reported having experienced some severe trauma, and 67% reported being sexually abused. Another study of 27 outpatients found that 88% had sustained significant trauma, including sexual abuse/rape (77%) and physical abuse (70%) (Bowman, 1993).

However, while the studies cited consider childhood sexual abuse to be a significant risk factor for NEAD, some reviews fail to mention it (e.g. Anderman, 1990; Mulder, 1990). Discrepancies in the literature may be because only some types of NEAD may be associated with childhood sexual abuse (Betts and Boden, 1991), and because of inconsistencies in definitions of NEAD, inconsistencies in definitions of abuse, limited knowledge of base rates of abuse in the general population, and the likelihood that available data provide an underestimate of prevalence, as disclosure may not be complete (Baker and Duncan, 1985).

Most importantly though, the consideration in isolation of childhood sexual abuse as a risk factor for a specific outcome (i.e. NEAD), is misleading. Children who have experienced chronic family-mediated sexual abuse are likely also to have experienced other physical abuse (British Psychological Society, 1995). In addition, other family members may also be victim to violence and abuse, and by witnessing such significant traumatic events children are vulnerable to severe problems with emotional and

social development (Carroll, 1994). The sexually abused child is likely to develop dysfunctional relationships in adulthood (Jehu, Gazan and Klassen, 1988). In addition, children who have been sexually abused are likely in adulthood to have problems with depression (e.g. Sedney and Brooks, 1984), and anxiety disorders (e.g. Beitchman, Zucker, Hood, DaCosta, Akman and Cassavia, 1992; Sedney and Brooks, 1984) which may include PTSD (e.g. Lindeberg and Distad, 1985). They are also likely to experience low self esteem and have increased vulnerability to suicide (Bagley and Young, 1990). Clearly there is a variety of psychopathology associated with sexual abuse in childhood, rather than a simple linear relationship between abuse and a single outcome such as NEAD. However evidence from the literature is consistent with elevated levels of affective disorders and psychopathology characteristic of people with a diagnosis of NEAD.

Given the numerous intrapersonal and interpersonal difficulties apparently associated with NEAD, some research has focused on the role of stress in precipitating seizures. Ramani, Quesney, Olson and Gumnit (1980) identified intrapersonal stressors including anxiety, and interpersonal stresses, such as conflicts in relationships, as immediate precipitants of seizures. Gumnit and Gates (1986) identified an "inadequate coping mechanism" subgroup in a study of people with NEAD. In their clinical classification of non-epileptic attacks, Betts and Boden (1992a) found that "tantrum" -type attacks were likely to occur following environmental challenges or demands that may be difficult for the person to cope with.

1.3.2 Theories of Aetiology

Psychological explanations for non-epileptic seizures have, until relatively recently, been predominantly psychoanalytic in orientation. In addition to symptomatic descriptions of non-epileptic phenomena, Freud theorised extensively about aetiology, proposing a correlation between hysterical personality traits and NEAD ("hysteroepilepsy") which has dominated explanations for the phenomenon and is regarded as credible by many later researchers (e.g. Freud 1888/1966; Greenson 1944; Parraga & Kashani, 1981).

In a case history of the Russian novelist Dostoevsky (Freud, 1928) Freud claimed that fits and loss of consciousness experienced by Dostoevsky, and diagnosed by doctors as epilepsy, were not due to organic disease but were neurotic symptoms. "Now it is highly probable that this so-called epilepsy was only a symptom of his neurosis and must accordingly be classified as hystero-epilepsy, that is, as severe hysteria" (Freud, 1928, p. 179).

From a psychoanalytical perspective, the underlying cause for neuroses which manifest as hysterical seizures, are traumas, frequently of a sexual nature. This association was extensively described by Freud, and is re-iterated in recent literature. For instance, Meir Gross (1986) writes of the relationship between adolescent incest and hysterical seizures and suggests that victims of incest may change their level of awareness (dissociation) and/or experience convulsions (conversion) in order to emotionally escape from threatful situations. Cartmill and Betts

(1992) suggest that a female rape-victim's paroxysmal behaviour was an "acting out" of intrusive and vivid memories of the rape. Lindner (1973) hypothesises that psychogenic seizure states are a defence mechanism employed in response to anxieties caused by unconscious incestuous desires, and that seizures are representative of repressed love-hate drives.

In response to the suggestion that NEAD events are symbolic representations of sexual trauma Slavney (1994) contends that the connection is purely hermeneutic in nature and that it is potentially dangerous to assume an association on the basis of seizure presentation.

In the psychodynamic tradition attempts have been made to align certain personality types with various diseases. During the 1950s, for instance, there was interest in identifying an "ulcer personality" and a "colitis personality" (Lazarus and Folkman, 1984). In a study of fainters, it was suggested that a syncopé-prone personality might be characterised by elevated MMPI scores for depression and hypochondriasis, as well as greater proneness to feelings of inadequacy (Vingerhouts and Schomaker, 1988). Following this line of research, some authors have investigated a possible relationship between scores on personality measures and NEAD. In a study of 16 individuals who had NEAD events which were frequent and prolonged enough to mimic status epilepticus, MMPI scores for hysteria and hypochondriasis were frequently elevated, but only in association with depression (Drake, Pakalnis and Phillips, 1991). However other studies have failed to identify a clear correlation between NEAD and hysterical

personality traits (e.g. Vanderzant, Giordini, Berent, Dreifuss, and Sackellares, 1986; Ramani, Quesney, Olson and Gurnit, 1980; Stewart, Lovitt and Stewart, 1992).

In the 1960s, the general focus of psychology shifted from intrapsychic psychodynamic explanations for behaviour, through behavioural explanations to finally encompass cognitive aspects and focus on thoughts, feelings and actions. However the preponderance of psychodynamic literature focusing on NEAD suggests that study in this area has lagged behind. While clinicians and researchers have begun to emphasise the predictive role of social, psychiatric and medical histories, and behavioural and psychological features associated with the disorder, little attention has been paid to psychological processes (beyond psychodynamic processes) involved in the manifestation of NEAD.

A relatively recent response to the phenomenon has been the application of behavioural explanations which regard NEAD as a learned pattern of behaviour which is developed to enable the person to deal with extreme stressors.

The suggestion that the behaviour is learned is supported by evidence that NEAD does not tend to occur in people with no experience of epilepsy, and that individuals with genuine epilepsy do not uncommonly also present with NEAD seizures.

SECTION 1.4: Stress, Coping and NEAD

1.4.1 The relationship between stress, coping and NEAD

Theoretical explanations about the apparent aetiological relationship between the experience of stress and NEAD suggest that NEAD constitutes a way of coping with stress. According to Ramani, Quesney, Olson and Gumnit (1980) NEAD events initially act as an anxiety reducing mechanism, and develop into a behaviour pattern which enables evasion of responsibility and escape from stressful situations. Thus NEAD episodes are initially precipitated by specific internal or external stressors, and then become part of a general behavioural repertoire. However the suggestion that NEAD serves as a strategy for coping with stress does not appear to have been empirically tested. Before discussing the possible influence of stress and the role of coping on the manifestation of NEAD, there are a number of conceptual and definitional issues regarding stress and coping which require review.

1.4.2 Transactional approaches to stress

Recent approaches to stress postulate that the way in which individuals cope with stress, rather than "stressful" events in themselves, influences psychological, physical and social well being (Folkman and Lazarus, 1988). Thus, contemporary approaches to stress are interactional in nature, focusing on the complex relationship between person and environment (Cox,

1978). Such approaches are distinct from earlier stimulus and response models which have been criticised as over-simplistic and circular (Lazarus, 1966; Lazarus and Folkman 1984).

Richard Lazarus (1966; Lazarus and Folkman, 1984) views psychological stress essentially as a product of two central processes which mediate between the person and the environment - cognitive appraisal and coping. "*Cognitive appraisal* is an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful. *Coping* is the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate" (Lazarus and Folkman, 1984, p19, italics added). There is nothing inherent about an event in itself which will precipitate outcome: a person will experience psychological stress if the demands of the environment are appraised as exceeding or taxing his or her resources and as threatening his/her well-being.

1.4.3 Coping

Because of its dynamic and changeable nature, and because trait approaches tend to underestimate the complexity of the processes involved in coping (e.g. Moos and Tsu, 1977), coping is conceptualised in Lazarus's model as a process rather than a trait (Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen, 1986). However while the construction of coping as a process argues against personality explanations for coping styles, there is a

theoretical link between appraisal, coping, somatic health status and psychological symptoms which would suggest that appraisal and coping must be at least moderately stable for particular individuals across diverse situations (Folkman et al, 1986).

Based on results of a field study of 100 middle aged people, who described over a thousand different episodes of coping with stressful encounters, Folkman and Lazarus (1980) initially identified two categories of coping - problem-focused or emotion focused. The study found the use of types of coping depended on appraisal. Where an encounter was appraised as requiring acceptance, emotion-focused coping tended to be used. Where an encounter was appraised as conducive to change through the person's actions, problem focused coping was used.

Later studies found these categories to be useful though inadequate, as it was evident that coping processes were far more diverse and complex, and many strategies could be both emotion or problem focused (Folkman and Lazarus, 1988).

Factor analysis of data from a community sample (Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen, 1986) and a sample of college students (Folkman and Lazarus, 1985) revealed 8 coping strategies: confrontive coping, where aggressive efforts were made to change a situation; distancing, where cognitive efforts were employed to minimise significance of the situation and achieve detachment; self controlling, where efforts were made to regulate feelings and actions; seeking social support, where informational, tangible and emotional support were sought;

accepting responsibility, along with efforts to put things right; escape-avoidance, where wishful thinking and behavioural efforts were used to escape and avoid; planful problem solving, where analysis and problem focused efforts were employed to alter the situation; and positive reappraisal, where efforts were made to create positive meanings (e.g. religious meanings or potential for personal growth) (Folkman and Lazarus, 1988).

Within a transactional/process model, coping strategies serve to alleviate specific stress experiences. Thus there are no intrinsically adaptive or preferable coping strategies, but rather strategies which are potentially adaptive in one context and maladaptive in another. For instance, denial is generally seen as a maladaptive response, but there are some circumstances, such as the time immediately following a trauma, where it has been shown to be adaptive (Horowitz, 1976). One study found that encouragement of denial or detachment coping resulted in substantially lower stress levels in experimental subjects recruited to watch disturbing motion pictures (Lazarus, Averill and Opton, 1970).

The influence of coping style on psychological adjustment has been explored in a number of studies, many of which use the "problem-focused coping"/"emotion-focused coping" distinction. Using a general measure of "Psychological Symptomatology" - the Hopkins Symptom Checklist (Lazarus et al., 1986) a study of 85 married couples in California found significant correlations between problem focused coping and psychological symptoms: confrontive coping was positively correlated with symptoms while

planful problem solving was negatively correlated. Depression has been positively related to escape-avoidance coping in non-clinical (e.g. Bruder-Mattson and Hovanitz, 1990; Folkman and Lazarus, 1986;) and clinical (e.g. Kuyken and Brewin, 1994) populations. Research focusing on adjustment to somatic illness has revealed comparable relationships. Generally, "emotion focused coping", including avoidance self-blame, and wishful thinking are positively associated with anxiety, depression, emotional distress and poor illness adjustment, while active and "problem focused" strategies correlate negatively (e.g. Wineman, Durand and Steiner, 1994; McCracken, Semenchuk and Goetsch, 1995; Bombadier, D'Amico and Jordan, 1990). In a British study of 139 people with intractable epilepsy there was a consistent relationship between poor emotional adjustment and a "wish-fulfilment" coping strategy (Upton and Thompson, 1992).

The behavioural manifestation of different coping strategies may be implicated in the development and maintenance of mental illness. It has been suggested, for instance, that the "abnormal behaviour" of people diagnosed with psychoses is a means of coping with life stress (Cox, 1978, p 132).

Most research in this area has looked at correlations between particular disorders and the use of coping strategies, rather than disorders as coping strategies in themselves. Here, people with panic disorders have been found to use proportionately more wishful thinking and less problem focused coping than people with "simple panic" or healthy controls (Vitaliano, Katon, Russo, Maiuro, Anderson and Jones, 1987). For people with a medical

diagnosis (rheumatoid arthritis, cancer, hypertension or diabetes mellitus), psychological adjustment has been shown to be far more predictive for types of coping than physical illness: people with negative affect, low self esteem and poor adjustment to illness use more avoidance, blame and emotional ventilation, while people with positive affect use information seeking coping styles (Felton and Revenson, 1984). Women with eating disorders have been found to use more avoidant and passive coping strategies than active and problem focused strategies compared to control subjects (Troop, Holbrey, Trowler and Treasure, 1994).

The recurrent use of certain coping strategies has also been shown to have an effect on somatic health. A model which accounts for this relationship, the *specificity model* (Selye, 1976, cited in Cox, 1978), postulates that each somatic complaint is associated with a distinctive pattern of physiological response, which may in turn be associated with specific patterns of appraisal and coping (Wright and Sweeney, 1989). In a study which hypothesised that diastolic blood pressure (DBP) is a product of how an individual copes with stress, participants with higher DBP were found to use more wishful thinking, avoidance, and minimisation of threat than participants with lower DBP (Wright and Sweeney, 1989).

1.4.4 NEAD as coping

Given the relationship between styles of coping, psychological ill-health, and physiological response, and the suggestion that manifestations of psychological disorders may in themselves constitute coping processes, it is feasible that NEAD events

represent an avoidant coping strategy. This notion has intuitive appeal in that a NEAD event certainly achieves avoidance of a situation. In the context of Lazarus's model, where every day events interact with the perception of stress and the employment of coping strategies, a disorder with recurrent episodes, such as NEAD, could be accommodated.

If a NEAD event is a way of avoiding responsibility and escaping from stressful situations (following Ramani et al., 1980), people with NEAD might be expected to (1) appraise every day and life events as more stressful than people who don't have NEAD, and (2) employ avoidant and distancing coping strategies rather than planful, problem-focused strategies. The current study will therefore use Lazarus' and Folkman's Ways of Coping questionnaire (WOC) (1988), and the Perceived Stress Scale (Cohen Kamarck and , 1983) to address these research questions.

1.5 Hypotheses

(1) people with NEAD are more likely to appraise their ongoing life situations as stressful than people with genuine epilepsy and people who do not have epilepsy or NEAD.

(2) people with NEAD are more likely to use escape-avoidant and distancing coping strategies and less likely to use planful-problem solving coping strategies than people with genuine epilepsy and people who do not have epilepsy or NEAD.

PART TWO

Method

2.1 Study Design

The research presented in this paper hypothesises that there is a relationship between the way in which people perceive stress and cope, and the manifestation of Non-Epileptic Attack Disorder. The between groups matched control design involved the administration of two well standardised questionnaires which measure perceived stress and coping strategies respectively to a group of people with NEAD and two control groups (people with genuine epilepsy and healthy controls). Initially, anxiety and depression were regarded as possible confounding variables, and were measured in this study using a scale which does not confound physical illness symptomatology with psychological symptoms.

2.2 Participants

A total of 90 participants between the ages of 17 and 71 years were allocated to the three groups. Participants in the NEAD group were 20 female patients (aged 18 to 59, mean = 35 *SD* = 12.8) and 10 male patients (aged 17 to 71, mean = 40.8, *SD* = 15.4) attending the neuropsychology outpatients clinic at the Walton Centre for Neurology and Neurosurgery for assessment and treatment. Participants had a diagnosis of NEAD made by (1) an experienced neurologist on the basis of clinical history and the results of EEG and/or ambulatory or telemetered EEG; and (2) one of two clinical

psychologists working in neuropsychology, with particular expertise in NEAD, on the basis of a comprehensive assessment interview (see appendix for content of assessment interview). The age of onset of NEAD seizures ranged between 6 and 70 (median = 29).

Exclusion from the study occurred if (1) results of psychological assessment were regarded as ambiguous ($n = 1$), (2) there was any evidence of frank epilepsy ($n = 6$, 3 via video telemetry and 3 via ictal EEG), (3) they also had a confirmed diagnosis of epilepsy, or (4) were unable to read questionnaires (because of cognitive rather than physical difficulties) and understand the concepts being studied ($n = 1$).

Participants in the epilepsy control group were 20 female patients (aged 18 to 58, mean = 34.5, $SD = 12.2$) and 10 male patients (aged 16 to 65, mean = 39.7, $SD = 14.1$) attending the specialised epilepsy clinic at the Walton Centre. All participants had a diagnosis of intractable epilepsy made by a consultant neurologist on the basis of EEG and clinical evidence. The age of onset of epileptic seizures ranged between 3 months and 49 (median = 14). People in the epilepsy control group were matched in terms of age, gender, and years of education with the experimental group.

Epilepsy control subjects were excluded from the study if they also presented with non-epileptic attacks, or had previously presented with NEAD. This information was gained from medical records prior to data collection. They were also excluded if they were unable to read questionnaires (because of cognitive rather

than physical difficulties) and understand the concepts being studied. There were no exclusions from the epilepsy control group post data collection, although where medical records indicated that patients would not meet criteria, these people were not asked to participate.

The healthy control group consisted of 20 women (aged 18 to 61, mean = 34.9, $SD = 13.0$) and 10 men (aged 19 to 71, mean = 42.1, $SD = 14.9$). Healthy controls were excluded from the study if they had a history of fits of any kind (i.e. infantile febrile seizures, epileptic seizures or other seizures of known or unknown aetiology), or if they were unable to read questionnaires (because of cognitive rather than physical difficulties) and understand the concepts being studied. There were no exclusions from the healthy control group.

Participants in the healthy control group were matched with the other two groups for age, gender and years in full time education. Participants were recruited on an informal and voluntary basis from hospital staff, and a local voluntary organisation.

2.3 Measures

2.3.1 Ways of Coping - Revised Version (Folkman and Lazarus, 1988).

The Ways of Coping questionnaire (Appendix A.1) assesses categories of coping described in Lazarus and Folkman's theory of stress and coping (e.g. Lazarus and Folkman 1984). It consists of 66 items measuring 8 coping strategies (see Table 2.1 for definitions of scales). Three of the eight scales are relevant to hypotheses in this study. The *distancing scale* describes cognitive efforts towards personal detachment (e.g. "tried to forget the whole thing") which includes attempts at minimising the significance of the situation and creating a positive outlook (e.g. "made light of the situation - refused to get too serious about it") (Lazarus and Folkman, 1988; Folkman, Lazarus et al, 1986). The *escape-avoidance scale* describes behavioural efforts to avoid or escape (e.g. "avoided being with people in general", "slept more than usual", "tried to make myself feel better by eating, drinking, smoking, using drugs or medications, etc.") and wishful thinking (e.g. "wished the situation would go away or somehow be over with") (Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen, 1986). The *planful problem-solving scale* describes purposeful problem-focused efforts towards changing the situation (e.g. "I knew what had to be done so I doubled my efforts to make things work") and an analytical approach to the problem (e.g. "came up with a couple of different solutions to the problem") (Folkman, Lazarus et al, 1986).

Table 2.1 Description of Coping Scales from the Ways of Coping (After Lazarus and Folkman, 1988)	
Confrontive Coping (6 items)	Describes aggressive efforts to alter the situation and suggests some degree of risk-taking.
Distancing (6 items)	Describes cognitive efforts to detach oneself and to minimise the significance of the situation.
Self-Controlling (7 items)	Describes efforts to regulate one's feelings and actions.
Seeking Social Support (6 items)	Describes efforts to seek informational support, tangible support, and emotional support.
Accepting Responsibility (4 items)	Acknowledges one's own role in the problem with a concomitant theme of trying to put things right.
Escape-Avoidance (8 items)	Describes wishful thinking and behavioural efforts to escape or avoid the problem. Items on this scale contrast with those on the Distancing Scale, which suggest detachment.
Planful Problem Solving (6 items)	Describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem.
Positive Reappraisal (7 items)	Describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension.

Individuals are asked to think of a specific event which occurred in the past week and which they found stressful, and indicate the extent to which they used each strategy to cope with it. Responses are entered on a four point scale. For example, item 2 measures Problem Focused Coping:

I tried to analyse the problem in order to understand it better.

does not apply or not used

used somewhat

used quite a bit

used a great deal.

It usually takes about 10 minutes to complete (Folkman and Lazarus, 1988).

Test-retest measures for reliability in using the Ways of Coping are considered inappropriate because of the variable nature of coping processes (Folkman and Lazarus, 1988). In a review of the scales averaged over five occasions, estimates of internal consistency for the three coping scales relevant to this study, using Cronbach's alpha coefficient, were 0.61 for the Distancing scale, 0.72 for Escape-Avoidance, and 0.68 for Planful Problem Solving (Folkman and Lazarus, 1988).

Construct validity has been assessed in a number of studies which compare their results with the theoretical predictions of Lazarus's and Folkman's model of stress. Relationships between appraisal, coping strategies, the experience of distress and the demands and constraints of contexts, have been found to support the model (e.g. Folkman and Lazarus, 1980, 1985; Vitaliano et. al., 1985). Further, significant positive and negative correlations between the individual coping scales and anxiety and depression have been

established in a number of different groups (Vitaliano et. al, 1985).

In order to control for the different numbers of items within scales, total raw scores are obtained by calculating means of total raw scores for each coping scale (Folkman and Lazarus, 1988). Higher scores indicate greater use of the coping strategy being measured.

2.3.2 Perceived Stress Scale (PSS) (Cohen, Kamarck, and Mermelstein, 1983).

The Perceived Stress Scale (Appendix A.2) is a global measure which focuses on the extent to which respondents find their lives unpredictable, uncontrollable, and overloaded (Cohen and Williamson, 1988). The scale measures the degree to which situations in one's life are appraised as stressful. It consists of 14 items referring to subjective appraisal of events occurring within the previous month. Responses are made according to a 5 point scale. It takes five to ten minutes to complete (Cohen et. al, 1983).

Scores for items range from 0 to 4. The total score is the sum of all items, and the highest possible score is 56.

While the authors do not suggest cut off points, higher scores indicate more stress. A telephone study of 2,387 randomly selected people found a mean score of 19.62 ($SD = 7.49$, range 0 to 45, Cohen and Williamson, 1988).

Internal consistency, assessed using Cronbach's alpha coefficient, was .75 in Cohen and Williamson's telephone study (1988) and .84 in a study of 456 college students and 64 participants in a smoking cessation programme (Cohen, Kamarck and Mermelstein, 1983).

In support of the theoretical prediction that the perception of stress is mediated by psychological variables, a study which partialled out variance associated with life events, found that PSS scores were still significantly correlated with affective and physical symptoms (Pbert, Doerfler and DeCosimo, 1992).

2.3.3 Hospital Anxiety and Depression (HAD) Scale (Zigmond and Snaith, 1983).

The HAD (Appendix A.3) was developed in response to the problem that questionnaires that deal with mood disorders are often confounded by the symptoms of patients with physical illnesses (Zigmond and Snaith, 1983). The scale consists of 14 items, 7 of which measure depression while seven measure anxiety. Complaints of a somatic nature (e.g. tiredness) are not included in the scale because they may be attributable to physical disease and not just mood disturbance (Zigmond and Snaith, 1983; Aylard, Gooding, McKenna and Snaith, 1987). Responses are made on a 4 point scale. It takes five minutes to complete.

Total scores for each subscale are calculated. In clinical settings, scores of 0 - 7 are categorised as "mild" anxiety or depression,

scores of 8 - 10 are categorised as "moderate" and scores of 11 and above are categorised as "severe" (Snaith and Zigmond, 1994).

Correlations between the anxiety and depression subscales have been found to be $r = -0.04$ $n = 41$ NS (Aylard et al, 1987) and $r = 0.08$ $n = 17$ (Zigmond and Snaith, 1983) indicating that they assess different dimensions of mood disorder . The scale has been found to be reliable across a number of different groups of non-psychiatric hospital patients (Zigmond and Snaith, 1983). Validity has been established by correlating the HAD depression subscale with the Montgomery Åsberg Depression Rating Scale ($r = 0.77$, $p < 0.01$) and HAD anxiety subscale with the Clinical Anxiety Scale ($r = 0.67$, $p < 0.01$) (Aylard et al, 1987). Scoring categories (Mild, Moderate and Severe) have been correlated with ratings from psychiatric interviews using Spearman's r , with $r = 0.70$ for depression ($p < 0.001$) and $r = 0.74$ for anxiety ($p < 0.001$), indicating that both subscales accurately measure severity (Zigmond and Snaith, 1983).

2.4 Ethical Approval and Pilot Stage

Following approval from university and Health Authority ethics committees (see Appendix B for ethics committee applications), a pilot stage was conducted with three patients attending the NEAD clinic for first appointments. The study procedure was adapted based on the outcome of the pilot stage.

2.4.1 Procedure

Participants in the NEAD group were approached by letter prior to scheduled appointments and asked whether they would attend appointments 15 minutes early to participate in the project. Participants in the epilepsy control group were approached by the researcher in person as they waited for scheduled appointments with neurologists. The study was outlined in brief, and participants who agreed to take part signed a consent form (see Appendix C for Information Sheet and Appendix D for Informed Consent Document). Socio-demographic details were taken, and instructions about completing the HAD scale and Perceived Stress Scale were given. Participants then completed the first two questionnaires, with the researcher present for guidance as required. Before completing the Ways of Coping Checklist participants were asked to call to mind the most stressful experience they had dealt with in the previous week, and to describe it briefly to the researcher.

2.5 Statistical Analysis

Data were analysed using the Statistical Package for the Social Sciences, Release 6.1 (SPSS 6.1).

Descriptive analysis of sample characteristics used both parametric and non-parametric statistical procedures. One way analysis of variance was used to compare mean age of the groups, Mann Whitney U test for comparison of median age of onset in the

two clinical groups, and Kruskal Wallis for comparison of median years in full time education.

Between groups multivariate analysis of variance (MANOVA) was used to explore differences between all three groups in perception of stress, and in coping strategies. Multiple comparisons between means were made using one way analysis of variance, and Tukey's Honestly Significant Difference (HSD) post hoc test was applied to establish the direction of any significant results.

Based on previous research findings (e.g. Bowman, 1993) people in the NEAD group were expected to present with more severe affective symptomatology, reflected in higher scores on the H.A.D. scale, than people in the two control groups. It was therefore considered appropriate to statistically control for the effect of anxiety and depression on the dependent variables by using Multiple Analysis of Covariance (MANCOVA). The expectation of increased affective symptomatology was tested using one way analysis of variance. To test an assumption of MANCOVA that regression coefficients are equal across treatment ("assumption of homogeneity of regression", Howell, 1992), correlation analysis using Spearman's r was applied.

Finally, where results failed to reach statistical significance, power analysis, using a power analysis computer package (Borenstein and Cohen, 1988) was applied. The analysis was conducted to establish the size of the sample which would have been required to show significant differences with obtained results. In the absence of relevant data from previous research, and in the

absence of theory regarding anticipated effect sizes for perceived stress and coping styles in NEAD, the analysis was conducted post hoc and used obtained effect sizes. The significance level was 0.05 and the statistical power was 0.8.

PART THREE

Results

3.1 Sample Characteristics

Participants were aged 17 to 71 years and consisted of 60 females and 30 males. Groups were matched for age and years of full-time education (Table 1), with one way analysis of variance showing that regarding age the groups were well matched with no significant differences (age $F(2, 87) = 0.05$, NS). There was however, a significant difference in years in full time education in favour of the epilepsy control group ($F(2, 86) = 4.40$, $p = 0.02$). Data regarding age of onset were collected for the NEAD and epilepsy groups (Table 3.1) and a significant difference between the two groups was found ($X^2 16.17$ (df,1) $p = 0.0001$). Figure 3.1 shows distribution of age of onset for the NEAD and epilepsy groups.

Table 3.1
Distribution of age, years in full time education and age of onset of seizure disorder for the three groups.

	Mean Age and <i>SD</i>	Mean Years in Full-Time Education and <i>SD</i>	Median Age of Onset and <i>Inter-quartile Range</i>
NEAD group	36.9 (13.7)	11.03 (0.9)	29 (18.75 - 36.5)
Epilepsy control group	36.2 (12.9)	14.5 (1.1)	14 (12 - 20)
Healthy control group	37.3 (13.8)	12.2 (1.8)	<i>Not Applicable</i>

3.1.1 Selection and categorisation of stressful situations for the Ways of Coping

Following Folkman and Lazarus (1980) the stressful events described by respondents when completing the Ways of Coping questionnaire were categorised into four basic contexts - family, health, work and other (Appendix F). Figures 3.1.1, 3.1.2, and 3.1.3 show the distribution of contexts for each group. More than half of the NEAD group selected situations involving family ($n = 16$), while 6 chose situations relating to health, 3 to work, and 5 to "other". In the epilepsy control group, 12 participants chose situations relating to family, 9 to health, 5 to work, and 4 to other. In the healthy control group, 15 participants chose situations relating to family, 8 to work and 7 to other. Notably, no-one in the healthy control group chose a situation relating to their health.

Figure 3.1.1
Proportion of stressful contexts selected for the Ways of Coping questionnaire by the NEAD group:

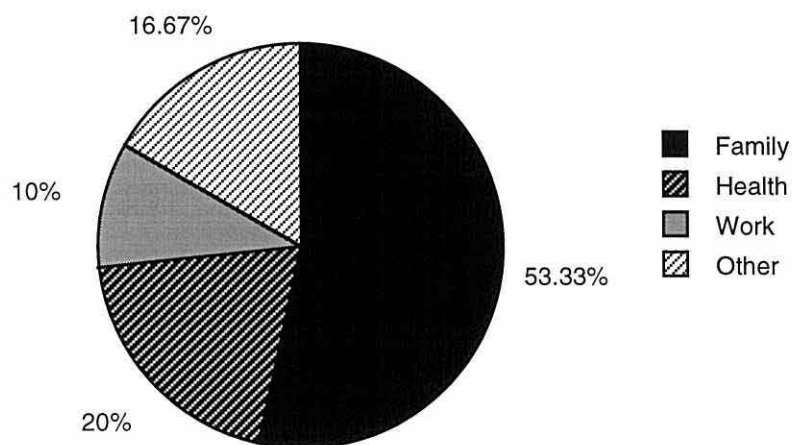


Figure 3.1.2
Proportion of stressful contexts for the Ways of Coping
questionnaire by the epilepsy control group

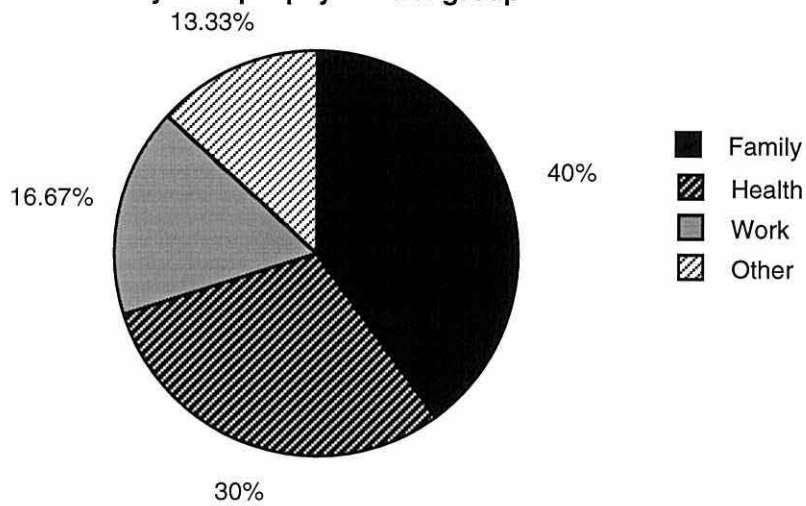
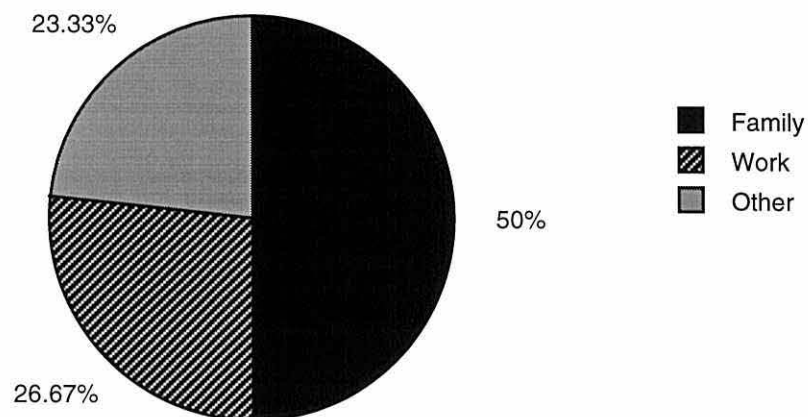


Figure 3.1.3
Proportion of stressful contexts selected for the Ways of Coping
questionnaire by the healthy control group



3.2 Comparing perception of stress in the NEAD group, and the Epilepsy- and Healthy-Control groups.

Data were analysed to test the hypothesis that people with NEAD would perceive their ongoing lives to be more stressful than people with epilepsy or people who do not have NEAD or epilepsy.

Examination of mean scores from the Perceived Stress Scale showed that the trend in results was in the anticipated direction, with the NEAD group scoring highest for perceived stress, and the healthy controls scoring lowest. One way analysis of variance showed a significant difference between the three groups ($F(2,87) 3.01 p = 0.05$). A post hoc Tukey's HSD test indicated a significant difference in mean scores between the NEAD and healthy control groups at the 0.05 level. Post hoc power analysis indicated that the size of the difference in scores obtained for the NEAD and epilepsy control groups (i.e. 2.27) would have been significant at the .05 level if 262 subjects had been used.

	Mean Score	Standard deviation	Range (0 - 56)
NEAD group	29.37	10.06	9 - 51
Epilepsy group	27.07	8.65	6 - 43
Healthy controls	23.9	7.0	12 - 45

3.3 Comparing the use of "escape-avoidance", "distancing" and "planful problem-solving" coping strategies by the NEAD group, the Epilepsy Control group, and the Healthy Control group.

Preliminary analysis was conducted to test the hypothesis that people with NEAD would be more likely to use escape-avoidant and distancing coping strategies, and less likely to use planful problem-focused strategies than people with epilepsy or people who do not have epilepsy or NEAD.

Table 3.3
Mean scores and standard deviation for the eight Ways of Coping questionnaire coping strategies for all three groups.

Coping Strategy	NEAD group		Epilepsy Control Group		Healthy Control Group	
	Mean	<i>SD</i>	Mean	<i>SD</i>	Mean	<i>SD</i>
Confrontive Coping	0.80	0.66	1.15	0.61	0.89	0.50
Distancing*	1.33	0.77	1.35	0.58	0.92	0.65
Self-Controlling	1.18	0.76	1.36	0.64	1.19	0.64
Seeking Social Support	1.17	0.81	1.60	0.80	1.22	0.84
Accepting Responsibility	1.09	0.88	1.14	0.90	0.93	0.75
Escape-Avoidance*	1.36	0.61	1.11	0.62	0.76	0.56
Planful Problem Solving*	0.89	0.60	1.25	0.68	1.54	0.74
Positive Reappraisal	0.77	0.74	0.97	0.68	1.00	0.71

* = Sig. F , .05

Mean scores for Ways of Coping Checklist coping strategies are shown in Table 3.3. Of the three subscales included in the study hypotheses, the mean **"escape-avoidance"** score was highest for the NEAD group (mean = 1.36, $SD = 0.61$), the mean **"distancing"** score was highest for the epilepsy control group (mean = 1.35, $SD = 0.58$), and the mean **"planful problem solving"** score was highest for the healthy control group (mean = 1.54, $SD = 0.74$).

MANOVA tested differences between the groups regarding application of coping strategies. The overall F using Pillais trace was significant ($F(16,160) = 3.71$ $p = .0005$). Univariate tests for significance using one way analysis of variance confirmed significant differences only in the three subscales relevant to the study hypotheses (**"escape-avoidance"**, $F(2,87) = 7.58$ $p = .001$); **"distancing"**, $F(2,87) = 3.88$ $p = 0.024$; and **"planful problem solving"** $F(2,87) = 7.10$ $p = 0.001$). Post hoc Tukey's HSD tests revealed that, in partial support of the hypothesis, mean **"escape-avoidance"** scores for the NEAD group were significantly higher than for the healthy control group, while mean **"planful problem solving"** scores were significantly higher for the healthy control group than for the NEAD group. Mean **"distancing"** scores were significantly higher in the epilepsy control group compared to the healthy control group, and almost identical for the epilepsy control group and the NEAD group. There were no significant differences between the NEAD group and the epilepsy control group in level of use of any of the three hypothesised coping strategies. Post hoc power analysis indicated that for the obtained results to have been significantly

different between the two clinical groups, at least 51 subjects would be required for "**planful problem solving**", and at least 91 for "**escape-avoidance**".

3.4 Comparing levels of depression and anxiety between the NEAD group, the Epilepsy Control Group and the Healthy Control group.

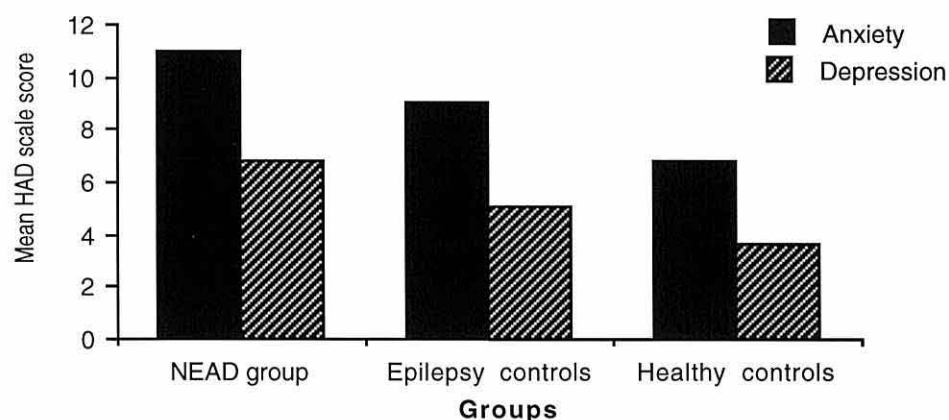
Descriptive statistics and one way analysis of variance were used to test Hospital Anxiety and Depression Scale scores for the three groups. One case in the Epilepsy Control group was not included in the analysis because of missing data. Table 3.4 and Figure 3.2 show distribution of mean **anxiety** and **depression** scores for the three groups. The mean **anxiety** score for the NEAD group was 11.00 ($SD = 5.81$) which falls into the "severe anxiety" clinical category (Snaith and Zigmond, 1994). The mean score for the epilepsy control group (9.07, $SD = 4.45$) fell into the "moderate anxiety" category, and the mean score for the healthy control group (6.77, $SD = 4.50$) fell into the "mild anxiety" category (Snaith and Zigmond, 1994).

One way analysis of variance showed a significant difference in **anxiety** between the three groups ($F(2,86) = 5.47, p = 0.006$), and a post hoc Tukey's HSD test, using a 0.05 significance level, showed a significant difference in anxiety between the NEAD and Healthy Control groups.

Table 3.4
Anxiety and Depression scores from the H.A.D. scale for the three groups

		Mean	Standard deviation	Range (0-21)
NEAD group (n = 30)	Anxiety	11.00	5.81	1 - 21
	Depression	6.83	5.13	2 - 19
Epilepsy group (n = 29)	Anxiety	9.07	4.45	3 - 18
	Depression	5.10	3.89	3 - 15
Healthy controls (n = 30)	Anxiety	6.77	4.50	2 - 19
	Depression	3.63	3.34	0 - 11

Figure 3.2
Mean HAD scale anxiety and depression scores by group



For **depression**, the mean score for the NEAD group was 6.83 ($SD = 5.13$). For the epilepsy control group the mean **depression** score was 5.10 ($SD = 3.90$), and for the healthy control group the mean **depression** score was 3.63 ($SD = 3.34$). **Depression** scores for all three groups fell within the "mild" score category. One way analysis of variance showed a significant difference in

depression between the three groups ($F(2,86) = 4.38, p = 0.016$), and a post hoc Tukey's HSD test indicated the significant difference lay between the NEAD and Healthy Control groups.

3.5 Correlation Analysis

Spearman's r was applied to test the assumption of homogeneity of regression. Correlations for the three groups for anxiety, depression, perceived stress, escape-avoidance coping, distancing coping and planful problem solving coping are shown tables 3.5.1 (NEAD group), 3.5.2 (epilepsy control group) and 3.5.3 (healthy control group).

Tables 3.5.1, 3.5.2 and 3.5.3

Correlation matrices showing H.A.D. scale (anxiety and depression), Perceived Stress Scale, and the 3 coping scale scores for the three groups.

* = Sig. F , 0.05

** = Sig. F , 0.001

Table 3.5.1: NEAD Group

	Anxiety	Depression	Perceived Stress	Distancing	Escape Avoidance
Depression	$r = 0.75^{**}$ $n = 30$				
Perceived Stress	$r = 0.85^{**}$ $n = 30$	$r = 0.77^{**}$ $n = 30$			
Distancing	$r = -0.14$ $n = 30$	$r = 0.06$ $n = 30$	$r = -0.16$ $n = 30$		
Escape-Avoidance	$r = 0.49^*$ $n = 30$	$r = 0.52^*$ $n = 30$	$r = 0.53^*$ $n = 30$	$r = 0.16$ $n = 30$	
Planful Problem Solving	$r = 0.06$ $n = 30$	$r = 0.18$ $n = 30$	$r = -0.07$ $n = 30$	$r = 0.64^{**}$ $n = 30$	$r = 0.18$ $n = 30$

Table 3.5.2: Epilepsy Control Group

	Anxiety	Depression	Perceived Stress	Distancing	Escape Avoidance
Depression	$r = 0.64^{**}$ $n = 29$				
Perceived Stress	$r = 0.65^{**}$ $n = 29$	$r = 0.72^{**}$ $n = 29$			
Distancing	$r = 0.34$ $n = 29$	$r = 0.18$ $n = 29$	$r = 0.03$ $n = 30$		
Escape-Avoidance	$r = 0.41^*$ $n = 29$	$r = 0.60^*$ $n = 29$	$r = 0.46^*$ $n = 30$	$r = 0.04$ $n = 30$	
Planful Problem Solving	$r = 0.19$ $n = 29$	$r = 0.14$ $n = 29$	$r = -0.09$ $n = 30$	$r = 0.21$ $n = 30$	$r = 0.28$ $n = 30$

Table 3.5.3: Healthy Control Group

	Anxiety	Depression	Perceived Stress	Distancing	Escape Avoidance
Depression	$r = 0.45^*$ $n = 30$				
Perceived Stress	$r = 0.56^*$ $p = n = 30$	$r = 0.55^*$ $n = 30$			
Distancing	$r = 0.17$ $n = 30$	$r = -0.10$ $n = 30$	$r = -0.09$ $n = 30$		
Escape-Avoidance	$r = 0.33$ $p = n = 30$	$r = 0.10$ $n = 30$	$r = 0.23$ $n = 30$	$r = 0.25$ $n = 30$	
Planful Problem Solving	$r = 0.15$ $n = 30$	$r = 0.18$ $n = 30$	$r = 0.25$ $n = 30$	$r = 0.33$ $n = 30$	$r = 0.25$ $n = 30$

There were no significant correlations for any of the 3 groups between **distancing** coping, and the variables **perceived stress, anxiety** or **depression**. However both clinical groups showed significant positive correlations between **escape-avoidance** coping and **perceived stress, anxiety** and **depression**. In the healthy control group the pattern was different, with no significant correlations between **escape-avoidance** coping and **perceived stress, anxiety** or **depression**. There were no significant correlations in any group between "**planful problem solving**" and **anxiety, depression, or perceived stress**.

Because the difference in correlational pattern in the groups violated the assumption of homogeneity of regression (Howell, 1994), analysis of covariance was not conducted.

SECTION FOUR: DISCUSSION

Within the context of Lazarus and Folkman's transactional model of stress, and on the basis of empirically established relationships between styles of coping, psychological ill-health, and somatic outcomes, this research study sought to explore the questions of whether the presentation of Non Epileptic Attack Disorder was associated with high levels of perceived stress and was symptomatic of the employment of particular coping strategies. Specifically, the current study hypothesised that people with NEAD would perceive their ongoing life situations as more stressful than people with epilepsy and people with neither epilepsy or NEAD, and that people with NEAD would be more likely to employ escape-avoidant and distancing coping strategies, and less likely to employ planful problem focused strategies, than people in the other two groups.

4.1 Comparing perception of stress in the NEAD group, the epilepsy control group, and the healthy control groups.

Of participants in the current study, people with NEAD were slightly more likely to appraise their ongoing lives as stressful than people with genuine epilepsy, and significantly more likely to do so than people who did not have epilepsy or NEAD. According to Cohen and Williamson (1988) higher PSS scores indicate that people experience their lives as more unpredictable, uncontrollable, and overloaded. To some extent therefore, Perceived Stress Scale scores in both the NEAD and epilepsy

control groups may reflect reality. The recurrent experience of unpredictable paroxysmal events clearly might provoke the experience of stress (e.g. Trimble, 1990). However the fact that people with NEAD perceive their ongoing lives to be equally, or possibly more, stressful than do people with epilepsy, who actually do have a debilitating neurological disorder, suggests the involvement of other factors. Within the transactional model, where the experience of stress depends on appraisal of threat and of a person's ability to manage the threat, this difference in perceived stress would be mediated by appraisal.

Appraisal can be inappropriate and unrealistic, as is most clearly seen in extreme cases such as paranoia, where unrealistically elevated appraisals of danger are made. If people with NEAD perceive their ongoing lives as equally stressful as do people with epilepsy, this might suggest that people with NEAD have a vulnerability to unrealistically appraise situations as threatening, and to underestimate their resources for coping. Evidence of unrealistic appraisal in people with NEAD compared to people with epilepsy comes from a study of perception of family support (Moore, Baker, McDade, Chadwick and Brown, 1994). Although both people with epilepsy and people with NEAD had families who were actively involved in the management of their conditions, people with NEAD perceived their families to be significantly less supportive and lacking in commitment towards them.

The experience of stress is the product of a complicated relationship between environment or stimulus, appraisal and coping, and it is possible that while the structure of this equation

may be different for people with epilepsy compared to people with NEAD, the final level of perceived stress could be the same. For people with epilepsy, threat appraisals may be realistic based on the constraints of the condition. People with NEAD, however, do not face the same objective dangers and limitations, and yet their estimation of threat seems to be elevated.

4.2 Comparing the use of escape-avoidance, distancing and planful problem solving coping strategies by the three groups.

4.2.1 Comparing the use of escape-avoidance coping

In partial support of the hypothesis, people with NEAD were found to use significantly more escape-avoidance (wishful thinking and behavioural efforts to avoid or escape from situations) than people in the healthy control group. This result concurs with other research using the Ways of Coping questionnaire, which finds a strong association between psychopathology and avoidance (e.g. Troop et al., 1994; Folkman and Lazarus, 1986). People with NEAD were also found to be slightly more likely to use escape avoidant coping than people in the epilepsy control group, although this difference was not statistically significant.

The hypothesis that people with NEAD would be most likely to use escape avoidant coping was developed in response to the conceptualisation of NEAD as part of a generally avoidant behavioural repertoire, aimed at avoiding responsibility and

escaping from stress (Ramani, et al., 1980). Results regarding escape-avoidance coping in the current study support this conceptualisation, particularly when seen in the context of evidence that NEAD develops after periods of stress (Ramani et al., 1980) and that NEAD events occur in response to difficult situations (Betts and Boden, 1992). In addition, avoidant coping lends itself to unconscious processes including self-deception and distortion of reality (Lazarus and Folkman, 1984), and researchers and clinicians working with people with NEAD consistently reiterate the subconscious nature of the disorder (e.g. Betts and Boden, 1991; Bowman, 1993).

If NEAD is an escape-avoidant mechanism, then this could help to explain the recurrent nature of NEAD episodes. A recurrent use of escape avoidant coping is likely to maintain anxiety, because the person will not have the opportunity to learn that a feared stimuli is not dangerous, or is less dangerous than anticipated (*cf.* phobic anxiety, Butler, 1988). In addition, escape-avoidant coping can be ineffective because a person fails to engage in problem focused coping where this is appropriate, and is therefore unprepared to deal with possibly exacerbated difficulties (Lazarus and Folkman, 1984). While no coping strategy is maladaptive by nature, escape-avoidance and NEAD coping may be both ineffective and self-perpetuating.

It should be noted that while a significant difference was only found between the NEAD and healthy control groups, the trend in the data suggests that a larger sample size may produce significant differences between each of the three groups.

4.2.2 Comparing the use of distancing coping

Contrary to expectation, people with NEAD did not use more distancing coping than people with epilepsy, although both clinical groups used more distancing coping than their healthy counterparts. People with NEAD and people with epilepsy were almost identical in their level of use of distancing coping, while people with epilepsy were significantly more likely to use distancing coping than their healthy counterparts. Scrutiny of Ways of Coping literature reveals a diversity in findings regarding distancing. For instance, the coping strategy has been positively associated with psychological distress in patients with rheumatoid arthritis (Parker, McRae, Smarr, Beck, Frank Anderson and Walker, 1988) and negatively associated with depression and positively associated with activity levels in patients with osteoarthritis (Regan, Lorig and Thoresen, 1988). In non-clinical populations higher levels of distancing coping are associated with "unsatisfactory outcome" (Folkman, Lazarus, Gruen and De Longis, 1986). This diversity in outcome gives support to a dynamic model of stress in which no particular coping strategy is preferable to, or more adaptive than, another. As Horowitz (1976) and Lazarus and colleagues (1970) showed, coping which utilises denial or detachment can lead to lower stress levels and be more adaptive in some circumstances. For someone with an intractable and severe neurological disorder such as epilepsy, problem focused coping efforts are likely to be ineffective and even maladaptive. Alternatively, cognitive efforts towards personal detachment, minimisation of the significance of a situation, and

creating a positive outlook may indeed be more appropriate and adaptive. For a person whose seizures are psychogenic in origin, however, attempts to detach oneself and minimise situational significance could result in a failure to apply problem focused strategies where appropriate.

4.2.3 Comparing the use of planful problem solving coping

The pattern for using planful problem solving coping strategies was the reverse of the pattern for escape-avoidance. Healthy controls were most likely to use planful problem solving, followed by epilepsy controls, with participants in the NEAD group being least likely to use planful problem solving (with a significant difference between the NEAD and healthy-control groups). Research in non-clinical populations has found a negative correlation between planful problem solving and psychological symptoms (Folkman and Lazarus et al., 1986) and an association between higher levels of planful problem solving and subjectively rated "satisfactory outcome" (Folkman and Lazarus et al., 1986). In light of these results it could be concluded that the healthy control group is likely to employ more adaptive coping than the other two groups. While it must be remembered that coping is contextual, and that no process is, of itself, better than another, it does seem likely that when healthy control subjects employ their most frequently used coping strategy, their behaviour will be positively reinforced. This would suggest that there is a reciprocal effect of coping on psychological well being, which may provide

some protection against psychopathology for people employing planful problem solving coping.

While not statistically significant, the trend in the data suggests that people with NEAD may be less likely to use problem solving coping than people with epilepsy, even though their problems are more likely to be amenable to change via these approaches than are the difficulties faced by people with epilepsy. Regardless of whether there is an actual difference in the use of planful problem solving between people with NEAD and people with epilepsy, people with NEAD are significantly less likely than their healthy counterparts to use planful problem solving, and almost certainly less likely to experience "satisfactory outcomes".

4.2.4 Context and differences in coping

One reason for differences in coping between groups may relate to context. Research which has focused on the effect of context on appraisal and coping has found that work contexts are associated with higher levels of problem-focused coping while health contexts are associated with higher levels of emotion focused coping (which includes distancing and avoidance) (Folkman and Lazarus, 1980). In the current study, 27% of stressful situations used for the Ways of Coping questionnaire by the healthy control group related to work, compared to 17% in the epilepsy control group and only 10% in the NEAD group. At the same time, health contexts, which have been associated with higher levels of emotion-focused coping (Folkman and Lazarus, 1980) were not referred to at all by the healthy control group, but constituted the

second largest categories for both clinical groups. However, family contexts, which have been found to have a varied and inconclusive association with coping strategies (Folkman and Lazarus, 1980; Troop et al., 1994), constituted the largest proportion of stressful situations for all three groups, and while this effect was not analysed statistically, the current findings suggest that there is likely to be a difference in preference for coping strategies used in family contexts between the groups.

Regardless of the influence of context, results of the current study find a clear association between stress, coping and NEAD. Based on current results, somebody with NEAD would be likely to experience high levels of stress and employ escape-avoidant and distancing coping, largely in health and family contexts. They would also be unlikely to employ planful problem focused coping.

4.3 Anxiety and Depression

The measurement of anxiety and depression, and the correlational analysis, were not conducted to test hypotheses, but rather as preliminary analyses for multiple analysis of covariance which was found to be contra indicated (see section 4.7.2 for discussion of methodological issues). However, the results merit some discussion because of their relevance to the current study.

Anxiety and depression scores were highest in the NEAD group, next highest in the epilepsy control group, and lowest in the healthy control group. There were significant differences between the NEAD and healthy control groups. This pattern of results is

consonant with research literature which reveals elevated occurrence of affective disorders in epilepsy and NEAD patients (Betts, 1988; Lowman and Richardson, 1987) and similar levels of depression in people with epilepsy and people with NEAD (Moore et al., 1994; Eisendrath and Valan, 1994).

The correlation analysis highlights a differential association between anxiety, depression perceived stress and escape-avoidant coping, when comparing the study groups. Neither planful problem solving nor distancing coping showed significant correlations with affective variables for any of the three groups. However, while escape-avoidance coping was significantly and positively correlated with affective symptoms and perceived stress in the NEAD group and epilepsy control group, there were no significant correlations between escape-avoidance coping and these variables in the healthy control group. Although the data are correlational and do not imply a direction or cause, these results may suggest that both people with NEAD and people with epilepsy are more likely than their healthy counterparts to use escape-avoidant coping in response to psychological distress. Results of the correlation analysis also suggest that, of all three groups, the healthy controls were employing coping strategies which were most appropriate to the stressful situations they encountered, and therefore more adaptive, than coping strategies employed by the other two groups. Apparently anxiety, depression and psychological distress are integral to the experience of both people with NEAD and epilepsy, in a way that they are not integral to the experience of their healthy counterparts.

4.4 Integration of findings

In the current study, people with NEAD and people with epilepsy perceived higher levels of stress in their ongoing lives than their healthy counterparts. People with NEAD were significantly more likely to employ escape-avoidant coping, and less likely to use planful problem focused coping, than healthy controls. People with NEAD were similar in their use of distancing coping to people with epilepsy, who were significantly more likely to use this form of coping than healthy controls. Healthy controls perceived lower levels of stress than the two clinical groups, and were most likely to employ planful problem-solving coping.

Consideration of perceived stress is important as it will influence utilisation of coping strategies and outcome. Central to an experience of stress is an appraisal of uncontrollability (Williamson and Cohen, 1988). Coping processes are directed towards gaining control and alleviating distress either by managing or changing the stressful "person - environment relationship", or through regulating one's stressful emotions, or both (Folkman and Lazarus, 1980, p223). If a situation is objectively uncontrollable then the application of distancing or even avoidance coping has been found to be appropriate, while problem focused coping efforts have been found to be limited in utility, and even maladaptive. If a situation is objectively amenable to change, planful problem solving has been found frequently to be adaptive. However, where there is a mis-match between perceived controllability, and objective controllability, so

that a situation which is amenable to change is appraised as unchangeable, then the application of *non* problem-focused strategies may be inappropriate and maladaptive. If people with NEAD in the current study have an elevated perception of stress because of unrealistic appraisal of threat, then they are at risk of making maladaptive coping responses. Furthermore, the use of escape avoidance carries with it a risk of increased avoidance (as the person fails to experience a successful encounter with the feared situation), and is likely to impede problem focused efforts, and create further distress.

In fact there is evidence that coping is less successful for people with NEAD than for people with epilepsy and healthy controls: people with NEAD reported higher levels of stress, depression and anxiety than people in the other two groups. Thus the distancing coping employed by people with epilepsy, and the planful problem solving coping employed by healthy controls, seem to be relatively more adaptive for these two groups, than is escape-avoidant coping for people with NEAD.

The current findings suggest that a possible function of NEAD events is the reduction of emotional distress, in response to perceived stress. Thus there might be a negative reinforcement schedule in operation, where behaviour is reinforced by the absence of aversive stimuli, and the individual with NEAD experiences as sense of control through successful avoidance. NEAD events have been plausibly conceptualised elsewhere as a means of gaining control, with support for this notion being found in an association between high internal locus of control scores and

NEAD (Moore et al., 1994). People with NEAD have been found to report a belief that they exercise control over their lives, despite living with a serious "seizure" disorder (Moore et al., 1994). Unfortunately though, both escape-avoidant coping and NEAD carry with them great costs. Firstly, by employing such strategies, a person fails to experience success via other approaches, or to find evidence to decrease perceived aversiveness of the feared stimuli. Secondly, while causality cannot be inferred, the association between escape-avoidant coping and a subjective sense of unsatisfactory outcome (Folkman and Lazarus, 1986) is likely to lead to feelings of helplessness and lack of control, which are likely to (1) develop into generalised clinical symptoms of anxiety, depression, and an exacerbated experience of stress, and (2) lead to the use of further escape-avoidant coping, possibly including Non Epileptic Attacks. People with NEAD may therefore be caught in an habitual pattern of response from which the possibility of escape is obscured.

4.5 Implications for Diagnosis

The results of this study highlight patterns of appraised stress and styles of coping which should prompt further enquiry for (1) people for whom an unequivocal diagnosis of epilepsy cannot be made, or (2) people with a confirmed diagnosis of epilepsy who are experiencing psychological difficulties. Elevated patterns of perceived stress and a tendency to use avoidant coping strategies may be usefully viewed as factors suggestive of Non-Epileptic Attack Disorder. Thus, in assessment, evidence that a person's perception of stress is out of proportion with what would be

expected in response to a given situation, should prompt further investigation, and would support a diagnosis of NEAD. It may therefore be appropriate to compliment the use of a scale assessing subjective stress (based within a transactional model of stress), with a scale devised within the context of stimulus response models which would provide norms for expected responses to life events.

In addition, the study results have implications for the presentation of diagnosis. If people are inclined to avoid realities because they may be overwhelming if confronted (Lazarus and Folkman, 1984), people with NEAD may find acknowledging the reality of their problem extremely challenging. A sensitive presentation of the diagnosis is therefore of paramount importance.

4.6 Implications for Interventions

In light of the current findings, a therapeutic response to NEAD would be effectively aimed at increasing the likelihood of effective coping, and should include interventions aimed at bolstering coping resources

Given that negative beliefs about a person's ability to control a situation, or the potential threat of a situation, have been associated with the perception of stress and with maladaptive coping (Lazarus and Folkman, 1984) cognitive therapy would be an appropriate treatment response for someone with NEAD.

Based on evidence that one of the functions of NEAD escape-avoidant coping is to reduce the experience of distress, the management of negative feelings must be a central theme of therapy for people with NEAD. Effective coping does not mean freedom from negative feelings. In fact, the experience of negative feelings is an unavoidable and appropriate response to the ambiguity of many, if not most, life situations. Even when a problem is effectively solved, as it may be with the placement into residential care of a severely disabled relative, there is likely to be emotional distress associated with the solution. If people with NEAD were able to deal with difficult emotions, the necessity for avoidant coping may be diminished.

Lazarus and Folkman (1984) describe a number of resources upon which people draw "to cope with the myriad demands of living" (Lazarus and Folkman, 1984, p 159). Of the resources they include, positive beliefs, problem solving skills, and social skills would be amenable to incorporation into a therapeutic schedule for NEAD. Positive beliefs are associated with a sense of hope and active problem solving (Lazarus and Folkman, 1984) and could be promoted in a cognitive therapeutic framework. Problem solving skills are important resources for coping in that they enhance ability to identify problems, look for information, generate appropriate responses and implement plans of action (Janis, 1977, cited in Lazarus and Folkman, 1984). Social skills facilitate social interactions and communication and increase the opportunity for effective coping via the enlistment of support of others.

4.7 Critical Review

4.7.1 Diagnostic issues

Inconsistencies in diagnostic criteria and methodology have made epidemiological estimates, and interpretation of much of the past research into NEAD, extremely difficult. The current study, therefore, endeavoured to use well defined diagnostic criteria to exclude epilepsy sufferers from the NEAD group and NEAD sufferers from the epilepsy group. However, diagnosis in both groups proved problematic. Six patients initially recruited into the NEAD group had shown no epileptiform activity during inter-ictal EEG analysis. Of these, two patients who had later been admitted to hospital for video telemetry analysis of ictal events, were found to be having true epileptic seizures. Two patients were having frontal lobe seizures which were initially not picked up using scalp electrode EEG. Two patients were regarded as having epilepsy by eminently experienced consultant neurologists, despite inconclusive results from EEG analysis. This experience parallels that of Betts and Boden (1991) where 6% of patients suspected of having NEAD were impossible to diagnose either because seizure activity disappeared or because epileptic origins became apparent.

Of the patients with epilepsy from whom participants were selected, many were experiencing such severe psychopathology that the concurrence of NEAD was considered highly probable. Frequently recorded in patients notes were instances of alcohol,

prescription and non-prescription drug abuse; depression; panic and generalised anxiety.

Psychopathology (Baker, Smith, Dewey, Jacoby and Chadwick, 1993) and immense social disadvantage (Betts, 1988) in association with epilepsy is well documented. For example, people with epilepsy commonly experience agoraphobia, phobic anxiety (Betts, 1988), and depression (Robertson, Trimble and Townsend, 1987). They are also likely to have difficulties developing and maintaining relationships and often become socially isolated (Baker et al., 1993). Difficulties arise because these kinds of affective and social problems are a main focus of psychological assessment for NEAD. If EEG fails to identify epileptiform activity in a person with frank epilepsy, who is also exhibiting psychopathology, then there is a risk of misdiagnosis. It is clearly vital to err on the side of caution in such cases, as a failure to respond to epileptic seizures with appropriate treatment could be life-threatening.

Thus NEAD research is fraught with difficulties associated with diagnosis, In the current study, and in NEAD research generally, the homogeneity of groups may be impossible to ensure.

4.7.2 Methodological issues

The present study used a global measure of perceived stress to indicate the extent to which individuals perceive their ongoing lives to be stressful. Within Lazarus and Folkman's model appraisal concerns both the perceived threat of a specific situation

or stimulus ("primary appraisal") and the persons perception of the resources they have to deal with it ("secondary appraisal"). Thus the interaction between appraisal and coping is likely to be more complex than is implied in the current study.

The current study employed a procedure normally used when administering the Ways of Coping questionnaire (Folkman and Lazarus, 1988), which requires subjects to respond by thinking of the most stressful situation they have experienced in the past week. However, data were not analysed separately according to categories of situations. While this approach was regarded as appropriate in response to a recurrent and non-specific condition like NEAD, the differential influence of context and other factors on coping were not taken into account. While inclusion of these factors is recommended, it would require a far larger sample size than was feasible in the current study.

A decision was made to statistically control for anxiety and depression because of the expectation of high levels of affective disorder in both of the clinical groups in the study. It was regarded as important to establish that dependent variables (stress and coping) were affected by the independent variable "group" (i.e. NEAD, epilepsy control or healthy control), rather than by confounding variables. However, it was also recognised that because of the known relationship between the clinical groups and anxiety and depression, partialling out the affective variables may have created a false profile. Ultimately, on the basis of the questionable validity of controlling statistically, and the found

violation of the assumption of homogeneity of variance, covariation was regarded as contra indicated.

4.8 Future research

Diagnostic issues, and the similarities between people with epilepsy and people with NEAD have implications for future research. It may be that similarities between people with epilepsy and people with NEAD render a definitive distinction between them false. Rather the conceptualisation of NEAD and epilepsy as extremes of a continuum may be more appropriate, and cases may be best studied on an individual basis.

This approach would also be consonant with research into intra-individual coping processes in NEAD. Coping is known to change in different contexts, but also across time within a single encounter (Folkman and Lazarus, 1985). More research is needed into the influence of context and intra-individual coping processes across time in people with NEAD. In order to study changes in coping and the factors that contribute to them, future research should ideally utilise single case designs where the same person can be observed over a number of occasions and contexts. An understanding of process and context specific coping in NEAD would support the development of the most appropriate interventions.

4.9 Conclusion

This research project provides substantive evidence for a relationship between NEAD and avoidant coping which has been

postulated, but not tested, in previous research. It also shows that ongoing life for a person with NEAD is experienced as stressful, possibly even more so than for a person with severe, intractable epilepsy. While much previous research has focused on differential diagnosis between NEAD and epilepsy, the current study finds a number of similarities between the two groups which highlight the necessity to consider cases separately rather than relying on diagnostic and treatment tools developed on the assumption that NEAD and epilepsy are separate and homogenous entities. Given the burden on tertiary health resources created by the problem of NEAD, and the cycles of psychological distress associated with the disorder, research such as this which illuminates operational mechanisms, and future paths for intervention, is vital.

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Appendix A
Measures

Appendix A.1

Ways of Coping - revised version (Folkman and Lazarus, 1988)

Please provide the following information:

Name: _____ Date: _____
Month / Day / Year

Identification Number (optional): _____ Gender (Circle): M F Age: _____

Marital Status (check): Single Married Widowed Separate/Divorced

TO THE COUNSELOR

Fill out your Institutional Address below:

Name/ Institution:

Address

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week*.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate, by circling 0, 1, 2 or 3, to what extent you used it in the situation.

Key: 0 = Does not apply or not used 1 = Used somewhat
 2 = Used quite a bit 3 = Used a great deal

Please try to respond to every question.

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I just concentrated on what I had to do next – the next step. 0 1 2 3
2. I tried to analyze the problem in order to understand it better. 0 1 2 3
3. I turned to work or another activity to take my mind off things. 0 1 2 3
4. I felt that time would make a difference- the only thing was to wait. . 0 1 2 3
5. I bargained or compromised to get something positive
from the situation. 0 1 2 3
6. I did something that I didn't think would work,
but at least I was doing something. 0 1 2 3
7. I tried to get the person responsible to change his or her mood. 0 1 2 3 *cc*
8. I talked to someone to find out more about the situation. 0 1 2 3
9. I criticized or lectured myself. 0 1 2 3
10. I tried not to burn my bridges, but leave things open somewhat. 0 1 2 3
11. I hoped for a miracle. 0 1 2 3
12. I went along with fate; sometimes I just have bad luck. 0 1 2 3
13. I went on as if nothing had happened. 0 1 2 3
14. I tried to keep my feelings to myself. 0 1 2 3
15. I looked for the silver lining, so to speak;
I tried to look on the bright side of things. 0 1 2 3
16. I slept more than usual. 0 1 2 3
17. I expressed anger to the person(s) who caused the problem. 0 1 2 3 *cc*
18. I accepted sympathy and understanding from someone. 0 1 2 3
19. I told myself things that helped me feel better. 0 1 2 3
20. I was inspired to do something creative about the problem. 0 1 2 3
21. I tried to forget the whole thing. 0 1 2 3
22. I got professional help. 0 1 2 3

Go on to next page

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

- | | | | | |
|--|---|---|---|---|
| 23. I changed or grew as a person. | 0 | 1 | 2 | 3 |
| 24. I waited to see what would happen before doing anything. | 0 | 1 | 2 | 3 |
| 25. I apologized or did something to make up. | 0 | 1 | 2 | 3 |
| 26. I made a plan of action and followed it. | 0 | 1 | 2 | 3 |
| 27. I accepted the next best thing to what I wanted. | 0 | 1 | 2 | 3 |
| 28. I let my feelings out somehow. | 0 | 1 | 2 | 3 |
| 29. I realized that I had brought the problem on myself. | 0 | 1 | 2 | 3 |
| 30. I came out of the experience better than when I went in. | 0 | 1 | 2 | 3 |
| 31. I talked to someone who could do something concrete
about the problem. | 0 | 1 | 2 | 3 |
| 32. I tried to get away from it for a while by resting or taking a vacation. | 0 | 1 | 2 | 3 |
| 33. I tried to make myself feel better by eating, drinking,
smoking, using drugs, or medications, etc. | 0 | 1 | 2 | 3 |
| 34. I took a big chance or did something very risky
to solve the problem. | 0 | 1 | 2 | 3 |
| 35. I tried not to act too hastily or follow my first hunch. | 0 | 1 | 2 | 3 |
| 36. I found new faith. | 0 | 1 | 2 | 3 |
| 37. I maintained my pride and kept a stiff upper lip. | 0 | 1 | 2 | 3 |
| 38. I rediscovered what is important in life. | 0 | 1 | 2 | 3 |
| 39. I changed something so things would turn out all right. | 0 | 1 | 2 | 3 |
| 40. I generally avoided being with people. | 0 | 1 | 2 | 3 |
| 41. I didn't let it get to me; I refused to think too much about it. | 0 | 1 | 2 | 3 |
| 42. I asked advice from a relative or friend I respected. | 0 | 1 | 2 | 3 |
| 43. I kept others from knowing how bad things were. | 0 | 1 | 2 | 3 |
| 44. I made light of the situation; I refused to get too serious about it. | 0 | 1 | 2 | 3 |

Go on to next page

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

- | | | | | |
|--|---|---|---|-------------|
| 45. I talked to someone about how I was feeling..... | 0 | 1 | 2 | 3 |
| 46. I stood my ground and fought for what I wanted..... | 0 | 1 | 2 | 3 <i>cc</i> |
| 47. I took it out on other people..... | 0 | 1 | 2 | 3 |
| 48. I drew on my past experiences; I was in a similar situation before... .. | 0 | 1 | 2 | 3 |
| 49. I knew what had to be done, so I doubled my efforts
to make things work..... | 0 | 1 | 2 | 3 |
| 50. I refused to believe that it had happened..... | 0 | 1 | 2 | 3 |
| 51. I promised myself that things would be different next time. | 0 | 1 | 2 | 3 |
| 52. I came up with a couple of different solutions to the problem..... | 0 | 1 | 2 | 3 |
| 53. I accepted the situation, since nothing could be done..... | 0 | 1 | 2 | 3 |
| 54. I tried to keep my feeling about the problem from interfering
with other things..... | 0 | 1 | 2 | 3 |
| 55. I wished that I could change what had happened or how I felt..... | 0 | 1 | 2 | 3 |
| 56. I changed something about myself..... | 0 | 1 | 2 | 3 |
| 57. I daydreamed or imagined a better time or place
than the one I was in..... | 0 | 1 | 2 | 3 |
| 58. I wished that the situation would go away or somehow
be over with..... | 0 | 1 | 2 | 3 |
| 59. I had fantasies or wishes about how things might turn out..... | 0 | 1 | 2 | 3 |
| 60. I prayed..... | 0 | 1 | 2 | 3 |
| 61. I prepared myself for the worst..... | 0 | 1 | 2 | 3 |
| 62. I went over in my mind what I would say or do..... | 0 | 1 | 2 | 3 |
| 63. I thought about how a person I admire would handle
this situation and used that as a model..... | 0 | 1 | 2 | 3 |
| 64. I tried to see things from the other person's point of view..... | 0 | 1 | 2 | 3 |
| 65. I reminded myself how much worse things could be..... | 0 | 1 | 2 | 3 |
| 66. I jogged or exercised..... | 0 | 1 | 2 | 3 |

Stop Here.

Appendix A.2
Perceived Stress Scale (PSS)
(Cohen, Kamarck, and Mermelstein, 1983)

PERCEIVED STRESS SCALE

Name:.....

Date:..... Record Number:.....

Instructions

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you have felt a particular way, but rather indicate the alternative that sounds like a reasonable estimate.

	never never	almost times	some- times	fairly often	very often
1. In the last month, how often have you been upset because of something that happened unexpectedly?					
2. In the last month, how often have you felt that you were unable to control the important things in your life?					
3. In the last month, how often have you felt nervous and stressed?					
4. In the last month how often have you dealt with irritating life hassles?					
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?					
6. In the last month, how often have you felt confident about your ability to handle your personal problems?					
7. In the last month, how often have you felt that things were going your way?					
8. In the last month, how often have you found that you could not cope with all the things you had to do?					
9. In the last month, how often have you been able to control irritations in your life?					
10. In the last month, how often have you felt that you were on top of things?					
11. In the last month, how often have you been angered because things that happened were outside of your control?					
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?					
13. In the last month, how often have you been able to control the way you spend your time?					
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?					

Appendix A.3
Hospital Anxiety and Depression (HAD) scale
(Zigmond and Snaith, 1983)

Hospital Anxiety and Depression Scale



Name Date

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

fold along dashed line

A

3

2

1

0

D

0

1

2

3

A

3

2

1

0

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)



HOSPITAL ANXIETY AND DEPRESSION SCALE

D	
0	
1	
2	
3	
	A
	3
	2
	1
	0
D	
3	
2	
1	
0	
	A
	0
	1
	2
	3
D	
3	
2	
1	
0	
	A
	0
	1
	2
	3

fold along dashed line

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

(continued overleaf)



HOSPITAL ANXIETY AND DEPRESSION SCALE

D	fold along dashed line
3	
2	
1	
0	
A	
3	
2	
1	
0	
D	
0	
1	
2	
3	
A	
3	
2	
1	
0	
D	
0	
1	
2	
3	
D	A

I have lost interest in my appearance:

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things:

- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Now check that you have answered all the questions

For office use only:

D : Borderline 8-10

A : Borderline 8-10

© Zigmond and Snaith, 1983. From 'The Hospital Anxiety and Depression Scale,' *Acta Psychiatrica Scandinavica* 67, 361-70. Reproduced by kind permission of Munksgaard International Publishers Ltd, Copenhagen.

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Appendix B
Ethics Committee Applications

University of Wales, Bangor

School of Psychology

Ethics Committee
Proposal cover sheet

Chief investigator/Supervisor: Dr. Gus. A. Baker, Clinical Lecturer in
Neuropsychology

Associate investigator/Student: PHILIPPA FRANCES
TRAINEE CLINICAL PSYCHOLOGIST.

Brief project title: NON EPILEPTIC ATTACK DISORDER

Date of submission: 8/10/86

Form used to prepare submission:

School ethics committee outline

Gwynedd Health Authority

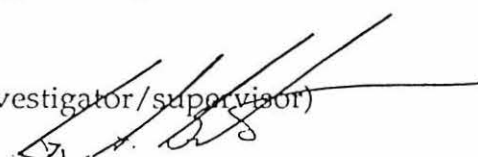
Other (please give details) Sefton Health
Authority (Guidelines attached)

NB. All relevant paperwork (including consent forms and any translations) must be completed before submission to the School Ethics Committee.

Declaration of ethical compliance

This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research.

(Chief investigator/supervisor)

Signed: 

Date: 8/10/86

(Associate investigator/student)

Signed: 

Date: 8/10/86

For School Use Only

Reviewer 1 M. STARTUP Approved MSS (Initials) 24/10/91 (Date)

Reviewer 2 _____ Proposal No. _____



Ysgol Seicoleg
Prifysgol Cymru Bangor
Bangor, Gwynedd LL57 2DG
Ffôn: Bangor (01248) 382211
Ffôn Rhyngwladol: +44 1248 382211
Ffacs: (01248) 382599
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International Fax: +44 1248 382599

e-mail: ps1029@bangor.ac.uk
<http://www.psych.bangor.ac.uk/>

October 24, 1996

Philippa Frances
12 Prince Alfred Road
Wavertree
Liverpool
L15 5BG

Dear Colleague,

Your research proposal (referred to on the attached sheet) has been reviewed by the School of Psychology Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines. If you wish to make any substantial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research.

Good luck with your research.

Kath Chitty
Coordinator - School of Psychology Ethics Committee

SOUTH SEFTON RESEARCH ETHICS COMMITTEE APPLICATION FORM

Revised Sept 1994

Ref: E.C.

1.0 PROJECT TITLE

PERCEIVED STRESS AND COPING STYLES
IN PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER.

2.0 THE INVESTIGATORS

2.1 State the name, profession, grade and place of work of ALL the investigators involved in the study.

**For staff in training, the name of the SUPERVISOR of the research project is required
(e.g. consultant in the case of junior medical staff - see SSREC Revised Guidelines, Sept 1994).

***Any subsequent change should be notified to the Ethics Committee.

PHILIPPA FRANCES, TRAINEE CLINICAL PSYCHOLOGIST,
UNIVERSITY OF WALES, BANGOR.

SUPERVISOR: DR. GUS A. BAKER PH.D., LECTURER IN
CLINICAL NEUROPSYCHOLOGY.

2.2 State briefly the personal experience of the investigator(s) in the field of the investigation concerned.

THE SUPERVISOR (DR. BAKER) HAS EXTENSIVE EXPERIENCE OF THE FIELD, INCLUDING
OVER 100 PUBLICATIONS ON EPILEPSY AND OTHERS ABOUT NON-EPILEPTIC
ATTACK DISORDER (NEAD).

2.3 Person to be contacted if further discussion required.

PHILIPPA FRANCES

Tel No. 0151 529 4146 Ext.

Fax No. 529 4703

2.4 Location of proposed study.

WALTON CENTRE FOR NEUROLOGY AND NEUROSURGERY.

[YES/NO: delete whichever is not applicable.]

3.0 THE RESEARCH SUBJECTS

3.1 Does this research involve patient volunteers who may not benefit from participating in it? YES/~~NO~~
 If YES, have the senior clinicians responsible for the overall care of the patients given approval for the proposed research? YES/~~NO~~

3.2 Does the study involve research on healthy, non-patient volunteers? YES/~~NO~~

3.3 Number of subjects 120 (40 in each of three groups)

3.4 Source of subjects. How will they be recruited? EXPERIMENTAL GROUP (PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER) RECRUITED FROM WALTON-CENTRE HEAD CLINIC, EPILEPSY CONTROL GROUP FROM EPILEPSY CLINIC. SUBJECTS FROM BOTH GROUPS WILL BE ASKED TO MEET WITH THE RESEARCHER FOR 30-40 MINUTES PRIOR TO OUTPATIENT APPOINTMENTS.

HEALTHY CONTROLS RECRUITED FROM HOSPITAL STAFF AT THE WALTON CENTRE, AND GENERAL PUBLIC

3.5 Will the study involve any -

Minors	YES /NO
Unconscious Patients	YES/NO
Pregnant Subjects	YES/NO
Elderly Patients	YES/NO
Mentally ill/ mentally handicapped patients	YES/NO
Other vulnerable groups (specify)	YES/NO

4.0 THE STUDY

4.1 Please summarise the AIMS of the study (these should be stated fully in the protocol). What HYPOTHESES are to be tested?

THIS STUDY AIMS TO

1. IDENTIFY ATTRIBUTIONS MADE ABOUT STRESSFUL SITUATIONS BY PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER;
2. IDENTIFY COPING STRATEGIES USED BY PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER;
3. EXAMINE THE PROCESSES INVOLVED IN REMEMBERING EXPERIENCES OF SUCCESSFUL COPING IN PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER (NEAD)

HYPOTHESES: PEOPLE WITH NEAD ARE MORE LIKELY TO APPRAISE NORMALLY CHALLENGING SITUATIONS AS STRESSFUL THAN PEOPLE WITH GENUINE EPILEPSY OR HEALTHY CONTROLS; ① PEOPLE WITH NEAD ARE MORE LIKELY TO USE INEFFICIENT COPING STRATEGIES THAN PEOPLE WITH GENUINE EPILEPSY OR HEALTHY CONTROLS; ② PEOPLE WITH NEAD WILL TAKE LONGER TO RECALL EXAMPLES OF SUCCESSFUL COPING, AND BE LESS LIKELY TO RECALL SPECIFIC EXAMPLES OF SUCCESSFUL COPING, THAN PEOPLE WITH EPILEPSY OR HEALTHY CONTROLS.

4.2 Summary of proposed research (ie the overall plan)

MID-LATE NOVEMBER 1996: PILOT STAGE. 6 SUBJECTS.

NOVEMBER 1996 - MARCH 1997: DATA COLLECTION

MARCH/APRIL 1997 : DATA ANALYSIS

MAY/JUNE 1997 : WRITE UP

JUNE/JULY 1997 : FEEDBACK/MODIFICATIONS TO WRITE-UP

AUGUST 1997 : COMPLETION.

4.3 Is study PILOT STUDY ~~YES~~/NO DEFINITIVE STUDY YES/NO
 Is study SINGLE-CENTRE YES/~~NO~~ MULTI-CENTRE YES/NO
 If multi-centre, who is responsible for co-ordinating the project?

4.4 List all procedures to be done for the purpose of this study which are NOT part of the ordinary care of the subject.

1. SUBJECTS WILL BE ASKED TO COMPLETE THREE QUESTIONNAIRES (SEE 6.1)
2. GUIDED MEMORY SCHEDULE: SUBJECTS WILL BE ASKED TO RECALL AN EVENT THEY REGARD AS STRESSFUL, AND WITH WHICH THEY COPE WELL. RESPONSE LATENCY TIME WILL BE MEASURED.

4.5 Please outline ALL THE RISKS to the subject in the study AND indicate the potential benefits that justify the risks.

NO RISKS.

THE STUDY WILL POTENTIAL LEAD TO A GREATER UNDERSTANDING OF FACTORS INVOLVED IN NON-EPILEPTIC ATTACK DISORDER, AND HAVE IMPLICATIONS FOR THE DESIGN AND APPLICATION OF THERAPEUTIC TREATMENTS.

4.6 Describe the discomfort, incapacity or inconvenience incident to the proposed study.

SUBJECTS WILL BE ASKED TO GIVE 30 - 40 MINUTES OF THEIR TIME. FOR PATIENT GROUPS THIS WILL BE IMMEDIATELY PRIOR TO OUTPATIENT APPOINTMENTS.

4.7 Are the procedures in the study customarily used for diagnostic and/or therapeutic purpose? YES/NO
If NO, please clarify

ONE QUESTIONNAIRE (HOSPITAL ANXIETY AND DEPRESSION SCALE) IS A WIDELY USED DIAGNOSTIC TOOL, AND WILL BE USED AS A CONTROL MEASURE IN THIS STUDY. OTHER QUESTIONNAIRES + PROCEDURES WILL HIGHLIGHT PSYCHOLOGICAL FACTORS ASSOCIATED WITH NEAD, HELPING WITH FUTURE DIAGNOSIS AND INTERVENTION.

4.8 Are any standard therapies or diagnostic procedures to be withheld for the purpose of the study? YES/NO
If so, discuss the balance between risk and possible benefit.

4.9 State the likely duration of the project.

8 MONTHS

4.10 Does the project involve the use of a drug? YES/NO

If YES, which of the following are available?:

Clinical trial certificate	YES/NO
Clinical exception certificate	YES/NO
Product Licence	YES/NO
Other (specify)	

5.3 If the research is supported by payment or gifts, please state

a) the sources of the support

N | A

b) the value of the payments/gifts

N | A

c) who will receive them?

N | A

d) how will they be used?

N | A

5.4 Are payments to be made on a "fee- per-patient" basis?

YES/NO

Are payments to be made on a pro-rata basis, for extra procedures?

YES/NO

6.0 PATIENT LITERATURE ****Please include copies of the questionnaire(s) with the application**

*****See SSREC Revised Guidelines, Sept 1994 regarding recorded and semi-structured interviews.**

6.1 Are Patient Questionnaires to be used in this study?

YES/NO

Have they been validated previously?

YES/NO

If YES state by whom and give references.

PERCEIVED STRESS SCALE (COHEN, KAMARCK + MERMELSTEIN, 1983). VALIDATED BY COHEN ET. AL (1983, A GLOBAL MEASURE OF PERCEIVED STRESS, JOURNAL OF HEALTH & SOCIAL BEHAVIOR, 24, 385-96).

COPE (CARVER, SCHEIER + WEINTRAUB, 1989, "ASSESSING COPING STRATEGIES" JN OF PERSONALITY AND SOCIAL PSYCHOLOGY, 56, 2, 267 -82. (OR, IF AVAILABLE, "WAYS OF COPING CHECKLIST", LAZARUS, L + FOLKMAN, S. 1984))

HOSPITAL ANXIETY AND DEPRESSION SCALE (ZIGMOND + SNAITH, 1983, ACTA PSYCHIATRICA, SCANDINAVICA, 67, 361-70.

6.2 Are patients to be approached by letter?

YES/NO

If YES please include specimen copies of ALL proposed correspondence with the application form.

SEE ENCLOSED INFORMATION SHEETS AND INFORMED CONSENT DOCUMENTS.

7.0 COMPENSATION FOR RESEARCH SUBJECTS (See SSREC Revised Guidelines, Sept 1994)

7.1 Please state the indemnity arrangements for this research

N | A

Signature of Applicant *Philip James*

Date 28/10/96

SOUTH SEFTON RESEARCH ETHICS COMMITTEE
c/o Clinical Trials Unit
W.C.N.N.
Walton Hospital
Liverpool L9 1AE

[Please quote our reference in reply]

Chairman: Dr.P.Charters] Fax: 0151-529-4854
Deputy Chairman: Dr.I.F.M.Graham]
Secretary: Mrs.L.Adamson] Tel: 0151-529-4452

LA/EC.170.96/AWP

21st November 1996

Ms.P.Frances,
c/o Dr.Gus Baker,
Walton Centre for Neurology & Neurosurgery
Rice Lane,
Liverpool L9 1AE

Dear Ms.Frances,

EC.170.96: PERCEIVED STRESS AND COPING STYLES IN PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER

Thank you for submitting the protocol and other documents relating to the above study which was considered at the meeting of our Ethics Committee yesterday. I am pleased to tell you that there were no problems from an ethical point of view and APPROVAL to commence the study was granted. However, a number of comments were made about the Patient Information Sheet and Consent Form and the Committee has requested that these documents should be modified, as follows:

Patient Information Sheet: We considered that the final paragraph about the complaints procedure was not necessary and recommend that it should be deleted.

Consent Form: This document should have a heading, similar to that of the Patient Information Sheet.

For our records, would you please let me have copies of the amended documents?

APPROVAL is given for a period up to eighteen months, which should be sufficient for the purposes of your project. If, in the meantime, the study is terminated or there are any changes in personnel or amendments to the documents approved by the Committee, please let me know.

Yours sincerely,



Dr.P.Charters
Chairman
South Sefton Research Ethics Committee

SOUTH SEFTON RESEARCH ETHICS COMMITTEE
c/o Clinical Trials Unit
W.C.N.N.
Walton Hospital
Liverpool L9 1AE

[Please quote our reference in reply]

Chairman: Dr.I.F.M.Grahams] Fax: 0151-529-4854
Deputy Chairman: Dr.K.Mutton]
Secretary: Mrs.L.Adamson] Tel: 0151-529-4452

LA/EC.170.96/A

27th February 1997

Ms.P.Frances,
c/o Dr.Gus Baker,
Walton Centre for Neurology & Neurosurgery
Rice Lane,
Liverpool L9 1AE

Dear Ms.Frances,

EC.170.96: PERCEIVED STRESS AND COPING STYLES IN PEOPLE WITH NON-EPILEPTIC ATTACK DISORDER

Many thanks for your letter of 20th February 1997 in which you enclosed amended Consent Form and Patient Information Sheet (versions undated). I am pleased to note that these will meet with the requirements of the Ethics Committee and will be kept with the other records for the above mentioned study.

Yours sincerely,



Dr.I.F.M.Graham
Chairman
South Sefton Research Ethics Committee

Appendix C
Informed Consent Document

Informed Consent Document

Research Project on Stress In People who have Seizures

The nature and purpose of the study have been described to me by _____ . I have also read the information sheet about the study. I understand that I will be asked to complete three questionnaires and answer some questions. I understand that my participation in this research project is entirely voluntary, and that I am free to withdraw from the project at any time without penalty and without affecting my future medical care.

Signed _____

Date _____

Sex MALE/FEMALE

Please indicate whether you now experience, or have ever experienced, seizures or fits of any kind YES/NO

Appendix D
Information Sheets for the Three Groups

Appendix D.1
Information Sheet for the NEAD group

Information Sheet

Research Project on Experiencing Stress with Attacks and Seizures

We are trying to find out whether people who have attacks or seizures experience problems with stress related to their condition. In order to measure this we need to have first hand information from people who suffer with attacks or seizures. People who are attending the neuropsychology clinic at the Walton Centre for Neurology and Neurosurgery are being asked to assist us in the study. We would therefore be grateful if you could complete three short questionnaires and answer some questions about the stress you may have experienced. It will take about 20 minutes.

Everything you tell us will be treated as strictly confidential. Information will not be given to your G.P. or seen by anyone other than staff involved with the research project.

Please feel free to ask any questions you may have before starting. After you have completed the questionnaires and interview we will be happy to discuss the results with you if you wish. Should any questions arise afterwards please contact either Philippa Frances or Dr. Gus Baker, study investigators, at the Walton Centre for Neurology and Neurosurgery on 529 4146.

THANKYOU

Appendix D.2
Information Sheet for the Epilepsy Control Group

Information Sheet

Research Project on Stress in People who have Seizures

We are trying to find out whether people with epileptic and other seizures experience problems with stress related to their condition. In order to measure this we need to have first hand information from people who suffer from epileptic seizures and are asking people who attend the epilepsy outpatients clinic at the Walton Centre for Neurology and Neurosurgery to assist us in finding this information. We would therefore be grateful if you could complete three short questionnaires and answer some questions about the stress you may have experienced. It will take about 20 minutes.

Everything you tell us will be treated as strictly confidential. Information will not be given to your G.P. or seen by anyone other than staff involved with the research project.

Please feel free to ask any questions you may have before starting. After you have completed the questionnaires and interview we will be happy to discuss the results with you if you wish. Should any questions arise afterwards please contact either Philippa Frances or Dr. Gus Baker, study investigators, at the Walton Centre for Neurology and Neurosurgery on 529 4146.

THANKYOU

Appendix D.3
Information Sheet for the Healthy Control Group

Information Sheet

Research Project on Stress in People who have Seizures

We are trying to find out whether people who have epileptic and other seizures experience problems with stress related to their condition. In order to measure this we need to an understanding of the experience of stress in people who do not suffer from seizures. People who do not have seizures are being asked to assist us in this study. We would therefore be grateful if you could complete three short questionnaires and answer some questions about the stress you may have experienced. It will take about 20 minutes.

Everything you tell us will be treated as strictly confidential. Information will not be given to your G.P. or seen by anyone other than staff involved with the research project.

Please feel free to ask any questions you may have before starting. After you have completed the questionnaires and interview we will be happy to discuss the results with you if you wish. Should any questions arise afterwards please contact either Philippa Frances or Dr. Gus Baker, study investigators, at the Walton Centre for Neurology and Neurosurgery on 529 4146.

THANKYOU

Appendix E
Summary of Psychological Assessment Interview
for NEAD used in the Neuropsychology Department
at Walton Centre for Neurology and Neurosurgery

**Summary of Psychological Assessment Interview for
NEAD used at the Neuropsychology Department, Walton
Centre for Neurology and Neurosciences**
(After Moore, 1995)

- | | |
|---------------------------------------|--|
| 1. Personal background history | where born and raised, number of siblings, position within family, whether they had a happy childhood, nature of relationships within the family, which schools attended, enjoyment at school, evidence of any emotional or behavioural difficulties, age on leaving school, formal qualifications; |
| 2. Occupational history | further training once left school, vocational or academic qualifications, past positions of employment held, duration of present employment, if retired - on what grounds; |
| 3. Psychological factors | possibility of abuse (sexual, physical, verbal), neglect or mistreatment in childhood or subsequently, whether view self as "a worrier", reactions to past bereavements/separations etc., previous contact with counselling, psychological, or psychiatric services; |
| 4. Medical history | past serious childhood illnesses, illnesses in the family during childhood, family reaction to illness when growing up, current health status of parents and siblings, relative or acquaintance with epilepsy, previous medical treatment and hospitalisations, current medical conditions, current medications; |
| 5. Marital history | whether in a long-term relationship, past marriages / separations / divorces, reasons for past relationship failures, number of ages of children; |
| 6. Current circumstances | where living, who with, whether employed or in receipt of any state benefits; |

7. History of attacks

Onset - when, what happened, what life was like at time.

Description - what, where, when, who with, precipitating / aggravating / alleviating factors, others' reactions, frequency / intensity, can they be prevented?

Course - development over time, Any changes, periods of remission, periods when worse;

8. Effects of attacks

restrictions on life, unemployment, benefits, being cared for, avoidance, frustration, depression, contentment with life, previous personality changed?, what they think causes the attacks;

9. Current emotional status

current stresses or worries, administer BDI and BAI (Beck Depression Inventory and Beck Anxiety Inventory).

NOTE:- This information is corroborated and added to by interviewing the spouse or relative of the patient concerned.

Appendix F
Categorisation of Contexts Selected by the Three
Groups for the Ways of Coping

APPENDIX F.1
Categorised Stressful situations chosen by the NEAD group

Family	Health	Work	Other
<ul style="list-style-type: none"> • Argument with wife. • Family argument. • Family argument. • Family argument. • Family argument. • Looking after mother who is unwell. • Her son and son's ex-girl-friend had argument. • Argument with boyfriend in front of children. • Family argument about her not having a job. • Teenage daughter giving her cheek. • Niece thrown out of home by niece's husband. • Wife starting IVF treatment. • Family argument. • Jealous and suspicious because wife changed hair. • Funeral of distant uncle last week. • Family argument. 	<ul style="list-style-type: none"> • Psychology appointment re NEAD diagnosis. • Appointment with doctor re unknown cause for dizziness. • Worried about coming into hospital. • Couldn't go shopping because of "do". • Attack (NEAD) last week at home. • Hospital test. 	<ul style="list-style-type: none"> • University interview. • Said something "foolish" at work, got very embarrassed. • Looking for job. 	<ul style="list-style-type: none"> • Argument with housing people. • Car broke down late at night in unsafe area. • Family friend collapsed while she was there. • Put something down at home and couldn't find it. • Getting ready to go to friend's wedding - got so wound up couldn't go.

APPENDIX F.2
Categorised stressful situations chosen by the Healthy Control Group

Family	Health	Work	Other
<ul style="list-style-type: none"> • New baby.- partner not helping enough. • Grandson left son's home to go and live with son's ex- wife. • Mother ill. • Argument with partner. • 6 year old son had epileptic seizure on bus. • Argument with sister during shopping trip. • Mother ill in nursing home. unable, because of work, to make 3 hour drive to get to her. 		<ul style="list-style-type: none"> • Applied for own job - interviewed but didn't get it. • Court case - suing for compensation for work injury. • Dispute at work involving someone she line manages. • Exams. • Incident at work - felt manager didn't listen. • Trying to meet deadline with piece of college work. 	<ul style="list-style-type: none"> • Playing rugby - referee wrongly decided against her. • Vicar left church. • 14 year old daughter of friend ran away from home to respondent's home - negotiations with family. • Good friend (ex girl-friend) gone to hospital for operation.

<ul style="list-style-type: none"> • 4 year old son sick through night. • Argument with girlfriend • Mother unwell - psychiatric illness. • Ex-partner coming to take children out. • Teenage daughter had temper tantrum. • "Copped off with" ex-boyfriend when currently in long term relationship with different boyfriend. • Try to comfort wife who is upset because dog has operation. • Father in very bad mood -shouting at everyone. 		<ul style="list-style-type: none"> • Argument with work colleague (someone he line-manages). • Argument with supervisor at work. 	<ul style="list-style-type: none"> • Argument with airport official re passport • Long drive from Switzerland with drunk passenger. • Dog injured, needed operation.
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APPENDIX F.3
Categorised Stressful Situations chosen by the Epilepsy
Control Group

Family	Health	Work	Other
<ul style="list-style-type: none"> • Family argument. • Argument with son. • Daughter left for Australia. • Husband away - coping with children on own. • Argument with partner. • Family argument • Parents worried about him. • Baby had pneumonia. • Found out daughter has chronic illness. • Wife doing shopping on her own - he cant go because of condition. • New born baby crying. • Sitting in car with husband learning to drive. 	<ul style="list-style-type: none"> • Hospital appointment re tinutus. • Seizures. • Seizures. • Seizures. • Unidentified pain in stomach - pregnant. • Recent two hour black-out. • Seizure on leaving a pub out with friends. • 3 seizures in one day - 2 in public. • Hospital appointment. 	<ul style="list-style-type: none"> • Works in shop - kids causing trouble. • Passed over for job. • Working to deadline for piece of college work. • Too much to do at work - cut backs. • Boss on my back at work. 	<ul style="list-style-type: none"> • Drove from London with vociferous back seat driver. • Saw woman punch young child in the head. • Carer split up with boyfriend and keeps on about it. • Just given up smoking.