

**PSYCHOLOGICALLY DERIVED NON-EPILEPTIC ATTACK
DISORDER (PNEAD): PSYCHOSOCIAL INFLUENCES AND
PSYCHOSOCIAL EFFECTS**

Thesis submitted in accordance with the requirements of

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by

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To

Beloved mother

And

Father's soul

**I was wishing that he were still alive at this moment
so he can see the result of his warm support to me.**

May God rest his soul in peace.

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ABSTRACT

Some of the most pressing problems of health care involve the presentation of physical pathology in the absence of physical disease. Psychogenic non-epileptic attack disorder (PNEAD) accounts for a small but significant proportion of referrals to neurologists. Management of this condition is difficult because little is known about what factors are important in understanding its development and maintenance. Mismanagement of PNEAD can result in inappropriate use of anti-epileptic drugs and neglect of psychological needs.

This thesis contains 3 studies. Study 1 examined the psychosocial factors that are important in understanding the development and maintenance of PNEAD. Assessments included childhood and adulthood abuse, anxiety and depression, somatisation, parental overprotection, hypochondriacal concerns and family dysfunction. One hundred and sixty two patients took part in this study matched for age and sex between PNEAD and epilepsy groups. PNEAD patients recalled more childhood and adulthood abuse than epilepsy patients and were more emotionally distressed. Findings from this study suggest that abuse and family of origin are involved in the development of PNEAD.

In study 2, 30 patients with PNEAD were matched by age and gender with an epilepsy control group. They completed questionnaires at the time of diagnosis and 3 months later measuring impact of condition, illness and symptom beliefs, family and psychosocial functioning, and satisfaction with consultation. This study compared PNEAD and epilepsy patients' reaction to the diagnosis of their condition.

Before diagnosis there were few significant differences between PNEAD and epilepsy patients. After diagnosis significant differences emerged between the two groups. The diagnosis of PNEAD patients, compared with epilepsy patients, was associated with a greater negative psychological impact. Such findings may reflect for PNEAD patients the fact that they are not provided with an adequate explanation for their symptoms and behaviour.

In study 3, 194 patients were matched between PNEAD and epilepsy groups by age and gender. They had been diagnosed 12-36 months previously. This study examined factors that may contribute to differences in impact of PNEAD vs epilepsy by measuring family and psychosocial function, beliefs regarding illness, clinical characteristics of attacks and satisfaction with the consultation process. Impact of the condition was greater for PNEAD than epilepsy patients. Factors that helped to explain such differences included the perceived psychological and physical impairment.

Ethical approval

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PREFACE

In my own country, the United Arab Emirates (UAE), I met with a number of young women presenting with eating disorders, depression, and somatisation disorder. As a result, my interest in women's health problems grew over time. In particular I was keen to explore factors that contributed to the causation of somatisation disorders. Because of the role of women in UAE society, I was particularly interested in the effects of abuse. The opportunity to study non-epileptic attack disorder at the University of Liverpool represented a unique opportunity to follow these ideas.

This thesis will therefore address the following issues. 1. The contribution of abuse to understanding the development and maintenance of non-epileptic attack disorder. 2. The immediate impact of a diagnosis of non-epileptic attack disorder. 3. The long-term impact of non-epileptic attack disorder on quality of life.

My aim was, and remains, to help those who suffer from psychological problems underlying non-epileptic attack disorder, and to help develop a successful treatment approach. The knowledge gained from my thesis will help me as a researcher and a clinician in my own country to work with women who experience non-epileptic attack disorder and related problems.

CHAPTER 1: PSYCHOGENIC NON-EPILEPTIC ATTACK DISORDER (PNEAD): A COMPREHENSIVE REVIEW

1.1 Histories and Background

The distinction between non-epileptic seizures and epilepsy has been understood within different cultures for a long time. In the Kahan and Ebers Papyrus (1900 and 1600 B.C.) non-epileptic attacks according to ancient Egyptian doctors resulted from abnormal positioning of the womb (Devinsky, 1998). A stone script from Babylonian times dated between 718 and 618 B.C. refers to non-epileptic attacks as fits and falls as noted by Ramsay et al (1993): 'If before he fits he suffers from frontal headaches and is emotionally upset, and afterward his hands and feet roll from side to side without deviation or foaming, it is a fall due to emotional shock, or 'hand of Ishtar'; he will recover. Hippocrates, one of the firsts to challenge primitive ideas about epilepsy and non-epileptic attacks (Massey 1982) described hysterical epilepsy. While Alerates a fellow Greek philosopher classified epilepsy into two varieties: ordinary epilepsy and hysterical epilepsy (Gates and Erdahl, 1993). Both Greek writers posited an abdominal genesis of attacks especially uterine, creating a feminine connection to hysteria, where the paroxysms reminiscent of epilepsy form part of the clinical pattern of the disorder (Gates, 2000). Non-epileptic attacks had also been reported among Navajo Indians, where the cause was considered to be incest (Neutra et al, 1979).

During the 18th and 19th centuries, neurological interest in non-epileptic disorders grew immensely and included major contributions from neurologists, such as

Robert Carter in 1853, who suggested three etiologic factors within hysteria: (1) temperament, (2) circumstances that trigger the initial attacks, and (3) concealment linked to sexual passion especially in female patients. Charcot in the early 20th century argued for the relation of hysterical seizures to the female reproductive system. He further considered the role of anxiety and depression in the genesis of hysterical symptoms. During his tenure at the Salpetriere Charcot attempted to distinguish between the convulsions of female subjects who had seizures and those of hysterics. Gowers discussed the differences between hysterical seizures and epileptic seizures earlier in 1881 (Lesser and Krauss 1993), as reported by Trimble in 1986:

'In practice, most authors have attempted to emphasize differences between the seizures of epilepsy and those of hysteria, many drawing up tables for differential diagnosis of the condition. In clinical practice, this has been enhanced by the fact that the treatment of epilepsy has gradually fallen almost entirely into the province of neurology and the treatment of hysteria into that of psychiatry, the reverse of the position of 100 years ago. However, the potential lack of experience of psychiatrists in the diagnosis and management of epilepsy, and in neurologists the diagnosis of hysteria, has led to many practical difficulties. One of these is that the assessment of many of these difficult cases evolves at the borderline between the two specialties.'

Breure and Freud (1842-1925) started to collaborate with 'hysteria' patients, especially Anna O., who presented with severe with hysterical symptoms. Freud and Breure revealed Anna O's unconscious, unpleasant, repressed memories under

hypnosis, and noticed such forbidden desires affected her physical symptoms, which seemed to be relieved following hypnosis and catharsis. Charcot (1825-1893), a French physician, gained fame in Europe for his innovative, radical attempts to treat emotional and behavioural abnormalities. He was interested in the effects of hypnotism (with female hysterics), a therapeutic tool that purportedly explored underlying emotional problems, which the patient could not consciously express or confront verbally. Later in 1885 Freud observed Charcot's method of hypnosis and so learnt about the importance of unresolved repressed sexual problems within the underlying causality of hysterical seizures (Chordof and Lyons, 1958). In time Freud rejected the hypnosis hypothesis and so favoured catharsis as the key therapeutic tool, that would, within a psychotherapeutic relationship expose unconscious desires, conflicts and so weaken elaborated defence mechanisms. Pierre Janet, (1859-1947) a student of Charcot, again used hypnotism to change the hysteric presentation. Again it was assumed that hysterical seizures were symbolic symptom metaphors, expressed via the body to communicate or disguise unresolved, unconscious trauma (Showalter 1997).

Freud in the 20th century described the symptoms of 'hystero-epilepsy' linked to his study of female patients. Freud proposed that internal unconscious sexual conflict if brought to consciousness led to physical symptoms, for example paralysis and contraction of the muscles (Francis and Baker 1999). Freud initially emphasized the role of unconscious motivation, active repression, conversion and trauma, within hysteria. In later writings Freud would argue that fantasy and the unsuccessful resolution of the Oedipal complex lay at the cornerstone of hysteria (Goodwin 1993).

1.2 Terminology and Definition

Diverse terminology for describing the term Non-epileptic attack disorder (NEAD) has in turn led to some confusion regarding the phenomenology and meaning. Both Charcot and Freud used the term 'hysteroepilepsy' or grand hysteric to describe these attacks, to be later replaced (by Freud) with the term 'hysterical fits' (Freud, 1888/1966). Liske and Forster (1964) put forward the term 'pseudoseizure' as a preferred alternative to hysterical seizures. It has also been referred to as 'emotional seizures', 'psychogenic seizures', 'fictitious seizures', and 'hysterical seizures' (Wood et al, 1998).

Non-epileptic attack disorder 'NEAD' represents a new term for pseudo-epileptic seizures. King et al (1982), for example, in their study of non-epileptic attack seizures, provide definitions of NEAD as 'behavioural events that mimic epileptic seizures but do not have an epileptic mechanism', or a 'psychogenic events that superficially resemble generalised tonic-clonic seizures'.

Early definitions of NEAD have been provided. Reynolds in 1861 (Porter 1993) defined NEAD patients as:

'Hysterical patients frequently deceive themselves and others; but they are sometimes very clever in their attempts and practices upon their medical advisors and their friends.'

Liske and Forster (1964), later extended the definition of NEAD as:

'Paroxysmal episodes of altered behaviour resembling epileptic attacks, but devoid of characteristic epileptic clinical and electrographic features'

Recent definitions have proposed that NEAD are assumed to be a symptom of emotional conflict; in contrast, epileptic seizures are the manifestation of sudden abnormal changes in brain function, accompanied by excessive electrical discharge of brain cells (Alber et. al, 1997). As a result of further research, Trimble (1978) defined the condition of NEAD as:

'Different from those of epilepsy, but... the patient has a sudden paroxysmal experience that an observer interprets as being epileptic-like'.

Likewise, Ramani and Gumnit (1982) have defined NEAD as episodes that superficially resemble epileptic seizures but are neither caused nor accompanied by abnormal paroxysmal discharges.

More recently Betts and Boden (1992) (see page 243) have defined non-epileptic attack disorder as:

'A sudden disruptive change in a person's behaviour, which is usually time limited, and resembles, or is mistaken for epilepsy, but which does not have the characteristic Electro-physiological ictal changes in the brain detectable by electroencephalography which accompanies a true epileptic seizure'.

What these definitions have in common is that psychogenic seizures imply a sudden episode of change in behaviour or psychic state that is not associated with an identifiable process, either vasculogenic or neurogenic. During such episodes there is an absence of characteristic epileptiform changes on the electroencephalogram (Conder and Zasler, 1990).

Non-epileptic attack disorder is used to describe the phenomenon of 'psychogenic events that resemble generalised tonic-clonic or partial seizures' (Riaz et. al, 1998). The term 'psychogenic non-epileptic attack disorder' generally refers to episodes of emotional origin that resemble epilepsy but for which no underlying epileptic cause can be determined. The term 'Psychogenic Non-Epileptic Attack Disorders (PNEAD)' will be used in the current thesis because there are other non-epileptic disorders that are confused with epilepsy, but which have clear physical causes e.g. febrile seizure, syncope, cardiovascular events.

1.3 Epidemiology of Psychogenic Non-Epileptic Attack Disorder (PNEAD)

Epilepsy is regarded as a major health problem with an estimated incidence rate between 20 and 70 per 100, 000 persons, and a prevalence of 4 to 10 per 1000 children and adults (Appleton et. al 1991). Non-epileptic attacks however have not been the focus of systematic research. Most of the data on the prevalence of PNEAD are estimates based on findings from neurology clinical populations (Edeh et al 1990)). A number of the epilepsy clinics report that up to 20% of seizure patients have PNEAD or non-epileptic attacks in association with true seizures (Carmant et. al, 1995, McDade and Brown, 1992). Of the estimated 250, 000

patients in the USA who experience different kind of seizures including epilepsy, a reported 5 to 20 % may be experiencing PNEAD (Shen et. al 1990; Drake et. al 1992). Recently, Benbadis and Hauser (2000) proposed an estimate based on a calculation. Results indicated that their estimated prevalence of PNEAD is 1/50,000 to 1/3000 population, or 2 to 33 percentages 100,000.

Most of the literature here indicates that female patients constitute 75% to 80% of those diagnosed with PNEAD (Barry et al 1990; Shen et al 1990). In a study by Limpert and Schmidt (1990) 32 (64%) of their sample (n=50) were female while 18 (36%) were male. In one group of 56 PNEAD patients, 71% were female (Ettinger et. al 1999). In a study by Bowman (1993), 92% of the subjects diagnosed with PNEAD were female. In a further study by Bowman and Markand (1996), 78% were female. Moore and Baker (1997) found 74% of patients were female (n =185). In contrast with the usually quoted female bias, McDade and Brown (1992) found that 62% of their patients with PNEAD were male. Kristensen and Alving (1992) reported in his case-control study that the sex ratio once again confirmed the majority of patients as female (86%). In Betts and Boden study (1992), of over 100 patients admitted and assessed with non-epileptic seizures, 96 were female. Among the male patients in this study the diagnosis was invariably one of anxiety. Panic attacks, tantrums, swoon and abreactive attacks were not seen.

1.4 Incidences and Prevalence

Annually, 5-25% of 2 million patients in the USA who were treated for epilepsy were later diagnosed as suffering from PNEAD (Martin et al 1998; Kuyk et al 1995; French, 1995). Furthermore 15% of patients from within the UK assessed at the National Hospital for Neurology and Neurosurgery and the National Society of Epilepsy at Chalfont were later diagnosed with PNEAD (Betts and Boden 1992; Samuel and Duncan, 1994).

Studies indicate that up to 35% of patients with seizures have PNEAD. Driefuss et al (1981) report in 10% of patients with seizures the presence of PNEAD. Scott (1982) found a prevalence of PNEAD (in an outpatient population visiting an epilepsy clinic) of 5%. Other literature has estimated prevalence rates in the range of 5-35%. For example, King et al (1982) estimated that 36% of their highly selected group had PNEAD.

Betts and Boden (1992) reported that 343 patients with “seizures” identified as epilepsy were admitted for assessment to a neuropsychiatry ward in a small English Mental Hospital over a 5-year period. Analysis revealed that 63% (n=215) of these patients had epilepsy, and 37% (n=113) had non-epileptic attack disorder. Forty-six patients had a history of past or present epilepsy and 24% of the total patients had psychogenic non-epileptic attack disorder only. In a previous survey of thirty university students at the department of neurology, Riley (1980) found that 10% of inpatients and 10-20% of outpatients met diagnostic criteria for PNEAD. Other studies note that PNEAD is common among patients who are

diagnosed with epilepsy-as high as 50% in certain populations (Kristensen and Alving 1992). The following table provided a summary of the published studies that have documented the prevalence of PNEAD. More recently, Smith et al (1999) reported that 324 patients were referred to a single consultant at the epilepsy clinic in The Walton Centre during a 12-month period. Patients were divided into two groups, 140 patients who had not been treated for epilepsy and were not subsequently given such a diagnosis, and 184 patients who had been exposed to AED treatment. Results indicated that the diagnosis of epilepsy was confirmed in 138 patients, the remaining 46 (26.1%) had been misdiagnosed, of which 19 patients were given a diagnosis of PNEAD.

Table 1.1:**Summary of References which Relating to Prevalence 1983-1999.**

Author	Year	Patients	Diagnosed with	Male	Female
		N	PNEAD N	N	N
Krummholz and Niedermeyer	1983	NS	41	12	29
Lempert and Schmidt	1990	NS	50	18	32
Betts and Boden (Part 1)	1992	343	82	NS	NS
Betts and Boden (Part 11)	1992	128	113	17	96
Cohen et. al	1992	32	19	12	20
Kristensen and Alving	1992	NS	28	4	24
Lancman et al	1993	NS	93	80	13
Blumer et. al	1994	117	97	57	40
Moore et. al	1994	57	19	6	13
Scheepers et. al	1994	31	27	7	20
Kuyk et. al	1995	13	6	3	3
Slater et. al	1995	101	22	NS	NS
Bowman and Markend	1996	77	45	25	75
Aldenkamp and Mulder	1997	48	24	15	9
Krahn et. al	1997	571	108	21	50
Van Merode et. al	1997	NS	62	15	47
Riaz et. al	1998	91	25	5	20
Frances et. al	1999	90	30	10	20
Parra et. al	1999	100	39	75	75
Smith et. al	1999	324	19	NS	NS

NS= Not Stated

1.5 Diagnoses and Classification

Important diagnostic procedures that clinicians now employ to establish a PNEAD diagnosis include the following key relevant factors (Pritchard 1993; Francis and Baker 1999):

- Ineffectiveness of anti-epileptic drug treatment.
- Description of ictal behaviour
- A normal EEG during and after seizures.
- Video-EEG telemetry yielding a normal EEG recording during clinical episodes.
- Complex psychological presentations and psychosocial histories which are consistent with empirically- established psychological profiles of people presenting with PNEAD.

1.5.1 Anti-epileptic drugs

Incorrect diagnosis can have severe, harmful effects for patients, negative psychosocial consequences, and so lead to wrongful prescription of anti-epileptic medication (Pritchard 1993). Rodin and his colleagues (1982) studied 194 patients with seizures who were admitted to an intensive treatment unit and treated with

anti-epileptic medications. Seizures could not be controlled in 33.7% who presented with PNEAD. Meierkord et al (1991) reported that a majority of PNEAD patients (n=110) had been on anti-epileptic drugs for many years before a diagnosis was made. Attacks typically do not cease when anti-epileptic medication is employed further stressing the difficulty in establishing a correct diagnosis.

1.5.2 A normal EEG before, during, and after seizures

The diagnosis of non-epileptic attack disorder can be greatly supported by use of electrographic (EEG), which in turn provides important information concerning the presence or absence of epileptiform inter-ictal or ictal activity (Mattson, 1993; Lesser, 1996; Gumnit and Gates, 1986). However, in some cases a normal EEG recorded before, during and after tonic-clonic attacks does not rule out epilepsy, nor does it confirm the diagnosis of PNEAD, if the clinical seizure phenomenology is complex or simple partial. Abnormal EEG scan can be observed in some PNEAD cases. (Chabolla et al 1996, and Gumnit and Gates 1986).

Epileptiform abnormalities can be caused by anti-epileptic drug withdrawal, which increases the probability of seizure occurrences accompanying such a state. However, in 90% of cases clinically diagnosed with epilepsy, EEG activity would still be present. Also it should be noted that EEGs with epileptiform activity could also occur in healthy people (Kuyk et al, 1995). Berkhoff et al (1998) presented results on 10 of 20 patients with PNEAD by EEG results that showed the absence of post-ictal during attacks.

1.5.3 Video-EEG monitoring

The use of video-EEG monitoring has revolutionized the diagnosis of PNEAD. Video EEG permits the correlation of behavioral and EEG activity. Video monitoring enables clinical behaviour, seizure frequency and attack classification to be quantified (Desia et al 1982; Meierkord et al 1991; Connolly et al 1994; and Gilmore and Ellen 1994). Long-term video-EEG telemetry has allowed the diagnosis and distinction of PNEAD with epilepsy to be significantly enhanced (Devinsky, 1998). Video-EEG monitoring may be useful for patients with frequent events. However, the majority of patients will require inpatient monitoring, in order to record their attack events during sleep, and withdrawal from anticonvulsant drugs (French, 1995). Video EEG monitoring typically captures sufficient episodes to enable correlation of clinical and EEG data. Recording times range from 2-10 hours (Connolly et al 1994). Leis et al (1992) reported that 47 (18%) of 254 patients were diagnosed with psychogenic attacks using video-EEG recordings. Video-EEG recording was carried out with 60 patients, 12 (36%) patients were diagnosed with PNEAD (King et al 1982). In a study by Gulick et al (1982) 71 patients were diagnosed with PNEAD by video-EEG recording. In a more recent study by Samuel and Duncan (1994) video-EEG assisted the diagnosis of PNEAD in 10 (46%) of 22 patients. Ozkara and Dreifuss (1993) however have concluded that distinguishing PNEAD by video EEG telemetry is complex, less than satisfactory and frequently not informative even when recorded ictally.

1.5.4 The Ictal behaviour description

Clinical presentation and past medical history constitute a necessary starting point to describe the boundary between epileptic and non-epileptic attacks. Table (1) shows a summary of the features distinguishing PNEAD events and epileptic seizures. The onset of individual episodes is often gradual. One might expect that non-epileptic attacks would only occur when the patient is awake. PNEAD episodes also have prolonged duration compared to epileptic attacks, which tend to occur suddenly and last only seconds or minutes. In a study by Meierkord et al (1991) 8 of 110 PNEAD patients had episodes lasting more than 30 minutes, and 5 of 110 had episodes lasting less than minutes, while 87 patients had episodes lasting between 1-30 minutes. Betts and Boden (1991) note that some patients have sudden disruptive behavior, which can resemble so called childish tantrums. According to Gates and Erdahl (1993) PNEAD clonic activity is out of phase associated with no apparent pattern, while clonic movements tend to be in phase and stereotyped.

Betts and Boden (1992) put forward hypothetical mechanisms linking PNEAD with psychiatric psychopathology. They note that there are three main types of non-epileptic attacks and form classifications of PNEAD disorder based on clinical presentation, associated with underlying psychodynamic processes. Within the first type-‘swoon’, the patient closes his eyes suddenly collapses, and slides slowly unconscious onto the floor without injury. Abreactive attacks often occur at night, although they may occur during the daytime, in which case falling initiates attacks. A ‘swoon’ reportedly occurs mostly in women who have been sexually abused in

childhood. There may be initial over breathing, followed by stiffening of the body, followed by thrashing of the limbs, breath-holding, pelvic thrusting; incoordinate jerking of the body, and gasping that looks a little like sexual activity. These attacks the authors claim resemble the symptoms of post-traumatic stress disorder. 'Swoon' and 'Abreactive' attacks were presented in a clinical study by Betts and Boden (1992). Results indicated that previous sexual abuse (see below) was a particularly common factor among patients with swooning or abreactive attacks. The third type of non-epileptic attacks was 'Tantrums' which are not like epilepsy although often mistaken for it. The patient emits a cry then thrashes about kicking and screaming, often biting himself or onlookers. Injury is common with such attacks, caused by falling, biting the lips, the hands or arms. Reflecting upon Betts and Boden's (1992) classification, Scheeper et al (1994) were unable to associate ictal characteristics with possible psychopathology, though they recognized the association in some instances, and noted in conclusion that ictal characterization was unhelpful with the diagnosis of PNEAD.

Leis and his colleagues (1992) found that 7 (15%) of a sample of PNEAD patients showed side to side head movements, 7 (15%) patients show side to side movements, 4 (9%) patients demonstrate out of phase limb jerking, and 2 (4%) show forward pelvic thrusting. However, Scheepers et al (1994) found the most common ictal presentation in 31 (76%) of 47 patients was verbal unresponsiveness. Scheepers and his colleagues concluded that the most consistent, clinically distinguishing feature of PNEAD is pupil response during or after ictal events. Examination is not always possible because a common feature of such episodes is ictal deviation or the screwing up of eyes. Another study by

Gates et al (1985) reported that 25 patients with PNEAD presented with predominant motor phenomena including side-to-side head movements. Meierkord et al (1991) reported prominent features e. g. pseudo-convulsions, and thrashing, in 73 of 110 patients and emphasized that the sequence and rhythmicity of events during attacks differed from patients that were observed during generalized tonic-clonic seizures due to epilepsy.

Weeping has been reported as a common feature of PNEAD and is viewed as a helpful diagnostic feature (Gulick et al 1982). Bergen and Ristanovic (1993) found that 10 patients (5 male and 5 female) wept during their attacks. Weeping is more commonly seen in patients with grand mal-like attacks. In another study Walczak et al (1995) found 10 of 36 patients who were diagnosed with PNEAD wept during their events. Walczak and his colleagues suggested that weeping could be viewed as a dissociative response caused by unpleasant emotions. Other researchers report that ictal weeping is a specific feature of PNEAD events, and may help distinguish non-epileptic attacks from epileptic attacks (Francis and Baker, 1999). Bergen and Ristanovic (1993) found that weeping occurred with 10 PNEAD patients, of whom five were female and five were male, their ages ranging from 14-40 years. Patients wept in convulsive like episodes, cried quietly; no-one sobbed aloud, no-one tried to hide weeping, and they were responsive, while crying. Walczak and Bagolioubov (1996) in a similar study describe the results of patients with a final diagnosis of PNEAD or epilepsy. The authors reviewed 31 patients who had PNEAD only and five patients with both PNEAD and Epilepsy. Those who wept constituted 10 of 31 (32%) patients with PNEAD, 1 of 5(20%) patients with both PNEAD and epilepsy, and none of 48 (0%) patients with

epilepsy alone. Overall the authors suggested concluded that weeping could be viewed as a dissociative response caused by negative memories and unpleasant emotions.

In addition further common events reported during non-epileptic attacks include eyes deviating outward, and the patient may resist eye opening. Other clinically distinguishing features of epilepsy from PNEAD during ictal events include ictal injuries and tongue biting (Boon and Williamson 1993; Lesser 1996; Frances and Baker 1999). In Meierkord et al's (1991) study, physical injury occurred in 19 of 110 patients with PNEAD, while Scheepers et al (1994) found that 10 out of 27 (37%) sustained injuries during attacks. Most injuries were minor e.g. bruises. In another study, Peguero and his colleagues (1995) interviewed 73 patients with PNEAD by telephone; 29 patients reported injuries, and 32 reported biting their tongues. Urinary incontinence is often associated with epileptic seizures but not PNEAD. Scheepers et al (1994) found that 7 of 27 PNEAD patients had urinary incontinence. Peguero et al (1995) reported 5 of 32 patients with urinary incontinence, but 0 of 41 patients with epilepsy.

Recently, Gates and Erdahl (1993) suggest that certain psychiatric classifications are useful in the description and distinction of PNEAD from epilepsy. In DSM-IV (1994) somatisation disorder (300.81), conversion disorder (300.11), and undifferentiated somatoform disorder (300.70) all include symptoms suggesting a physical disorder for which there is no identifiable organic cause. Symptoms are related to underlying psychological factors but are not intentionally produced or consciously controlled. Within somatisation disorder, patients present a number of

physical complaints. PNEAD characteristics can mimic somatisation disorder. Symptoms are often presented as exaggerated, dramatic, and vague; in addition a long history of medical consultations, which are usually complicated, is cited.

Undifferentiated somatoform disorders is typically applied to patients who have one or more physical complaints with no organic basis, but fail to meet diagnostic criteria for somatisation disorder. Whilst these and other DSM-IV classifications may be relevant in the description of PNEAD, they reflect the heterogeneity of PNEAD presentations indicating that such diagnostic systems lack the specificity necessary for accurate diagnosis. Table 1.2 provides a summary of features distinguishing PNEAD events from epileptic seizures.

Table 1.2:

Summary of Features Distinguishing PNEAD Events and Epileptic Seizures.

Characteristics	Epileptic seizures	Psychogenic non epileptic seizures
Duration	Seconds	Minutes
Frequency	Rarely more than one a day, except petit mal	Often, frequent many a day
Onset	May be gradual	Sudden
EEG during seizure	Abnormal and change from pre-ictal	Usually normal and unchanged from pre-ictal
EEG immediately after seizure	Almost always abnormal and change from pre-ictal	Usually normal an unchanged from pre-ictal
Weeping	Absent	Present
Age	Any past infancy	Usually older child or adult
Sex	F = M	F > M
Tongue biting	Frequent	Rare
Urinary	Common	Uncommon
Talking during attack	Never	Frequent
Abnormal neurologic signs during seizure	May be present	None
Injuries sustained as a result of event	Common	Rare
Stereotypy of attacks	Relatively little variation	Attacks may or may not be varied; patterns may occasionally be widely divergent

Gates R and Erdhal P, 1993; Guberman, 1982; and Roy, 1989.

1.5.5. Psychological histories and psychological aspects

The diagnosis and description of PNEAD is typically associated with psychiatric and psychological findings. Krahn et al (1997) in a recent study has suggested that most of the patients with PNEAD had a psychiatric disorder e.g. anxiety disorder and most of them were advised to obtain psychiatric care. The importance of obtaining a psychosocial history has been identified by a number of researchers in the identification of PNEAD (Nash and Tenn 1993; Betts and Boden 1992; Francis and Baker 1999). Identifying psychological problems and significant negative life events in part supports the diagnosis of PNEAD. For example, Betts and Boden (1992) found that patients with PNEAD were more likely than patients with epilepsy to have a past history of psychiatric and personality disorder associated with chronic anxiety and somatisation disorder. Reilly et al (1999) reported similar findings, comparing patients with PNEAD and epilepsy. Patients in their study with PNEAD were more likely to be depressed and anxious than patients with epilepsy.

The diagnosis of PNEAD must therefore be supported by a comprehensive psychosocial assessment including a detailed family history, personality assessment, and psychological diagnostic interview looking for the existence of concomitant personality disorder, anxiety and depression (Sigurdardottir and Olafsson 1998; Gates 1992; Francis and Baker 1999). However, Berkhoff et al (1998) reported no significant differences between patients with PNEAD and patients with epilepsy on either psychosocial stress or functional disturbances during childhood.

The association between PNEAD and psychopathology is substantial. In a clinical study, Lempert and Schmidt (1990) found that psychiatric findings were documented in 45 (90%) of 50 patients with PNEAD, and were abnormal in 33 (66%). Depression was the most common finding in 12 (24%) patients, anxiety was noted in six (12%), and emotional conflict was noted in a further 5 (10%) patients. Moore et al (1994) in a controlled study examined the functional role of PNEAD behaviour within the family context. Patients with PNEAD were compared with epilepsy, and normal controls. Results indicated that PNEAD patients reported lower cohesion, and moral-religious orientation. Interestingly, control subjects were more depressed than PNEAD and epilepsy groups. No significant differences for self-esteem and anxiety were found between the three groups. The authors in conclusion stated that PNEAD patients perceived their families as displaying less commitment and support and less emphasis on ethical issues and values than people with epilepsy or normal controls. People with PNEAD compared to those with epilepsy have been found to be more likely to meet diagnostic criteria for Axis-II personality disorder (Moor et al 1994). In a more recent study Aldenkamp and Mulder (1997), reported personality disorders in the majority of patients with PNEAD compared to patients with epilepsy, 50% met diagnostic criteria for DSM-IV Axis-II personality disorder, and one fifth of these patients had a family history of psychiatric treatment. Moore and Baker (1997) noted that 10% of 185 PNEAD patients had attempted suicide and 44 (26%) reported significant relationship problems, and family dysfunction. They also noted that 23% (41) of 185 PNEAD patients had previously suffered or were currently significantly depressed. In addition 43% (75) of patients were significantly anxious. Cohen et al (1992), report in patients diagnosed with

PNEAD the presence of a variety of psychiatric diagnoses, typically axis-II personality disorders.

Kristensen and Alving (1992) compared 28 patients with PNEAD, with a control group consisting of 28 patients with epilepsy. The frequency of previous psychiatric problems was significantly higher in the case group (PNEAD) than in the control group (epilepsy). Personality difficulties and social problems were significantly higher in the PNEAD group. Bowman (1993) reports on the aetiology of 27 patients who were diagnosed with PNEAD. Bowman found the presence of many different types of disorder, including somatisation, and major depression. Another study of 32 PNEAD patients found that 11 patients reported both anxiety and depression (Buchanan and Snars, 1993). Lempert and Schmidt (1990) reported the clinical psychological and social findings in 50 patients who have been diagnosed with PNEAD. Twenty-three patients reported severe psychic and social problems such as depression and family conflicts. A history of trauma information has typically been incorporated within a formulation of PNEAD, to assess more exactly the relationship between PNEAD and psychopathology (Francis and Baker, 1999; Moore and Baker, 1997; Bowman, 1993).

More recently, Ettinger et al (1999) describe the relationship between psychiatric and psychosocial characteristics for PNEAD patients. Twenty-two (39.3%) patients reported suicidal ideation. A history of suicide attempts occurred in 11 (19.6%) patients. Another study by Wyllie et al (1999) notes the presentation of psychiatric and personality disorder in patients with PNEAD. Eleven (32%)

patients had mood disorders including major depression alongside severe psychosocial stressors, and 4 (12%) had personality disorders.

1.6 Somatisation

1.6.1 Defining somatisation

Somatisation disorder described within DSM-IV denotes a chronic condition characterized by a lifelong pattern of multiple unexplained somatic symptoms. The diagnosis of somatisation disorder is based on 'a history of many physical complaints or a belief that one is sickly beginning before the age of 30 and persisting for many years' (Othmer and Desouza 1984; Murphy 1990). Such symptoms are normally associated extensive medical consultations and/or significant impairment in social, occupational, or other areas of functioning. The patients must have at least 10-13 physical symptoms from a list of 35 specified in the manual i. e. headache, and sleeping disorder (Ford 1986). Specific physical complaints must include pain symptoms, gastrointestinal symptoms, cardiopulmonary symptoms, and pseudo-neurologic symptoms.

Barskey and Klerman (1983) defined Somatisation as:

'The expression of emotional discomfort and psychosocial stress in the language of bodily symptoms'.

Ford (1986) defines somatisation as:

'A process by which bodily symptoms are used for psychological purposes or personal gain'.

Alternatively Lipowski (1983) defined somatisation as:

'The tendency to experience, conceptualise, and /or communicate somatic distress and symptoms not accounted for by pathological findings, to attribute them to physical illness, and to seek medical help for them'.

The term somatisation is used to cover a broad range of common clinical situations: e.g. patients who present clinically with physical symptoms despite the clear presence of significant psychosocial problems or emotional distress; patients with high levels of worry who say they are physically ill without evidence of disease (Kirmayer and Robbins, 1991). Somatisation is a major public health problem. Somatisation presentations are common particularly in a primary care setting where patients present with a pattern of unexplained or functional somatic symptoms that prompt help seeking and shape iatrogenic disability (Kellner 1991; Kirmayer and Robbins 1991). Typically, patients with somatisation do not accept the psychological basis of their problems and insist on obtaining medical help.

In a UK study examining somatisation in primary care settings, 20% of patients with physical complaints had predominant somatisation difficulties associated with psychiatric disability. As a result, such patients presented to their doctors with

somatic complaints that were in turn ascribed to physical disease (Goldberg & Bridges, 1988).

Murphy (1990) defined somatisation disorder as 'physical symptoms suggesting physical disorder for which there are no demonstrable organic findings or known physiological mechanisms and for which there is positive evidence, or a strong presumption that the symptoms are linked to psychological factors or conflicts'.

Gates (2000) notes that somatisation is more typically associated with women.

Specific physical complaints include pain symptoms, gastrointestinal symptoms, dysfunctional sexual symptoms, cardiopulmonary symptoms and pseudoneurologic symptoms i. e. seizure-like events, dissociative symptoms, and diminished level of consciousness. To meet diagnostic criteria for somatisation disorder-presenting symptoms cannot be explained by a general medical condition. In addition to meet diagnostic criteria for somatisation disorder-presenting symptoms must not be consciously produced or intentionally feigned (Gates, 2000).

1.6.2 Somatisation as conversion

Within DSM-IV (1994), conversion symptoms are losses or alterations in bodily function that mimic physical disease, particularly neurological disorders e.g. seizures, blindness, deafness, or loss of consciousness. DSM-IV (1994) diagnostic criteria include the requirement that symptoms were caused by psychologic distress and had a symbolic significance, and were reinforcing by way of secondary gains e.g. economic rewards or social advantages acquired as a consequence of the

fostered sick role (Kirmayer and Robbins, 1991). Conversion is believed to be facilitated by any factor which tends to impede cognitive evaluation and communication of feelings and affect. Conversion is more commonly found when there is concurrent neurologic disease, lower intelligence, less education or a disadvantaged culture background.

Conversion symptoms are extremely common in the general population particularly where individuals also present with pre-existing organic disease. Conversion is believed to occur more frequently in women than men with reported ratios varying from 2 to 1 to 10 to 1 (Kirmayer and Robbins, 1991; Ford 1993; Gates 2000). Conversion symptoms are much more common than is recognized. For example, in one series of healthy/normal postpartum women, one third reported that they had experienced one or more conversion symptoms during their lives (Farley et al 1968). DSM-IV (1994) specifies four conversion disorder subtypes: (1) with motor symptoms or deficit; (2) with sensory symptoms or deficit; (3) with seizures or convulsion; and (4) with mixed presentation (Gates, 2000). Freud applied the term 'conversion' to explain the psychological mechanism of repressed, conflict driven emotion, that is transformed i.e. converted via somatic discharge so creating physical symptoms (Ford and Parker 1991). In place of Freud's energy metaphor (regarding the conversion process) contemporary views of functional symptoms propose that cognitive processes of self-appraisal may lead to prolonged affective states of anxiety, depression and hopelessness (Kirmayer & Robbins, 1991).

1.6.3 Association of somatisation disorder with PNEAD

In the third edition of the DSM-III the term somatisation was introduced (1980) to describe a new class of psychiatric syndromes, in order to give the term greater specificity. Somatisation disorder is the current diagnostic term used for 'briquets syndrome' or 'hysteria' (Ford, 1993). Bowman and Markand (1996) found severe unexplained headaches were common in 33 (73%) of their patients with PNEAD. Also, Gigineishvili (1999) found some somatic symptoms in few of his cases of PNEAD e.g. numbness or tingling in parts of their body. Ettinger et al (1999) examined the somatic symptoms among patients with PNEAD. More than three-quarters of 56 patients reported that they suffered from pain symptoms and sought medical attention. Twenty-nine of the patients had multiple somatic pain symptoms i.e. headaches, backache, neck pain or others. A study by Eisendrath and Valan (1994) found that some psychiatric factors could be identified in the history of patients with PNEAD, identifying somatisation disorder as a prominent feature.

1.7 Childhood Abuse

1.7.1 Definition

During the 1980's academics, psychiatrists and psychologists recognized that childhood sexual abuse had damaging consequences. Subsequently, a great deal of literature has focused on (1) defining child abuse and (2) examining the effects of childhood abuse (psychological, physical, and sexual) on psychosocial functioning.

There are few acceptable agreed definitions of child abuse (sexual, physical, or psychological). For example definitions of abuse are affected by the types of act-committed, the age of victim and perpetrator, the sex of victim and perpetrator, as well as the differences or similarities in terms of the relationship between victim and perpetrator (Finkelhor 1984). Schecter and Roberge's (1976) definition of childhood sexual abuse is widely accepted as the most acceptable:

'Sexual abuse is defined as the involvement of dependent, developmentally immature children and adolescents in sexual activities they do not truly comprehend and to which they are unable to give informed consent and that violate the sexual taboos of family roles'.

However, some professionals in the field consider this definition to be too abstract and of little practical value. The expression 'sexual abuse' evokes strong reactions and some researchers have preferred instead to use the term 'unwanted sexual experience' (Calam and Slade, 1989). Childhood sexual abuse was also defined by Draijer (1990), as sexual contact by a family member living in the household with a girl/boy aged 15 or younger, which took place against his/her wishes or without his/her feeling able to refuse such contact. Another commonly used definition is given by Mrazek (1983):

'The sexual use of a child by an adult for his or her sexual gratification without consideration of the child's psychosocial sexual development'.

However this does not define child or adult and is dependent upon expert judgement from professionals.

1.7.2 The prevalence of childhood abuse

The wide variety of definitions of sexual abuse illustrates the complexity of generating an accurate account of abuse prevalence. Definitions of child abuse must therefore consider consent issues, linked to legal definitions, that state when childhood ends. For example, the age cut-off point for childhood in North America literature has varied from 14 to 17 years, while in UK this has tended to be 15-16 in line with the law on the age of consent. Other confounding issues here include whether or not to include peers as perpetrators, and whether to include non-contact abuse experiences. Prevalence estimates are typically arrived at by interview or questionnaire within targeted clinical groups, community studies etc (Fry, 1993). As a result of these factors prevalence figures from North American studies range from 6-62% for female and 3-31% for male (Finkehor 1986). In the UK, Baker and Duncan (1985) found that 12% of females and 8% of males reported that had been abused in childhood. Baker and Duncan interviewed 2019 patients in the UK as part of a MORI Survey and used the following definition of sexual abuse.

'A child (anyone under 16 years) is sexually abused when another person, who is sexually mature, involves the child in any activity which the other person expects to lead to their sexual arousal. This might involve intercourse, touching,

exposure of the sexual organs, showing pornographic material or talking about things in an erotic way'.

However, Taylor (1985) argues that such a definition of childhood sexual abuse was very broad and potentially ambiguous i. e. what constitutes sexually mature? Recently Hyun et al (2000) found that females reported higher rates of sexual and physical abuse than males. The authors concluded that the increased incidence of sexual abuse for females supports a growing body of evidence indicating gender differences in reports of sexual abuse among adult depressive cases.

1.7.3 Long-term effects of childhood abuse

Many follow up studies of children who have been abused found that the majority of those abused feel damaged by it and subsequently report social, interpersonal, psychosexual and psychiatric problems (Bentovim 1988). A number of studies report that child sexual and physical abuse led to different types of psychiatric and psychosomatic problems when compared to non-abused cases e.g. Peters (1988). Fry (1993, p91) states that long term abuse effects fall along four broad categories: (1) psychological problems with a psychiatric presentation, for example, depression, eating disorder; (2) psychosexual problems such as sexual dysfunction; (3) severe interpersonal difficulties defined as for example distrust, fear of men, and repeat victimization in adult relationships; and (4) somatic problems and physical ill health.

A considerable body of empirical work supports the link between child abuse and eating disorder psychopathology (Calam and Slade 1989; Waller 1992). A study by Kent and Waller (2000) found a strong association between childhood psychological, physical, and sexual abuse and adult eating disorder psychopathology. Conte and Schuerman (1987) found that problems such as low self-esteem, sleep disturbances, and aggressive behaviour were commonly linked with childhood sexual abuse.

Browne and Finklehor (1986) report that many sexual and physical abused children present with adult depressive disorders. Recently, researchers have examined the relationship between a history of abuse and the presence of medical-somatic symptoms e.g. stress disorder. For example, a study by Lindberg and Distad (1985) examined the symptoms presented by 17 adult women who experienced childhood abuse. Results indicated that all of the women experienced at least one disabling somatic symptom e.g. sleep disturbance, anxiety disorder. Thirteen patients had recurrent dreams of the abuse experience, especially when (1) they were touched physically, (2) when they viewed sexual encounters on television, or (3) when personal memories reminded them of the abuse. All patients reported disabling depressive symptoms. Six had dissociative reactions such as numbing of body parts or amnesic episodes. The authors therefore concluded that childhood traumatic event especially sexual abuse exacted profound, long term, psychophysical, interpersonal costs. Sedney and Brooks (1981) reported that finding from their research that showed that college women with a reported a history of child sexual abuse were more likely to report greater incidence of sleep disturbance and depression than a matched control group. In another non-clinical

study by Salmon and Calderbank (1996) the authors invited a sample of 275 undergraduates to report the nature and experiences of any sexual, physical and verbal psychological abuse in their childhood. Results indicate the association of abuse experiences and somatisation, hypochondriasis and hospital admissions.

Swett et al (1990) examined the experiences of abuse (sexual, and physical) of 125 male patients at an adult psychiatric outpatient clinic. A significant association linking psychiatric symptoms e.g. depression, phobia, somatisation, anxiety, and interpersonal sensitivity with abuse (sexual, and physical) was reported. Results indicated that 60 (48%) patients reported histories of abuse at some time in their lives. Nine (7%) reported sexual abuse only, 44 (34%) reported physical abuse only, and seven (6%) reported both types of abuse. In addition 53 patients have experienced some form of abuse during their childhood. Seven (13%) reported sexual abuse, 34 (64%) reported physical abuse, and 4 (8%) reported both sexual and physical abuse. The authors concluded that patients with early experiences of abuse had higher levels of symptoms. More recently, Newman et al (2000) examined the association between childhood sexual abuse and rates of reported medical problems as an adult. In summary the authors therefore concluded that child sexual abuse represents a potential potent risk factors associated with the development of medical and psychological problems as adults e.g. depression, somatic complaints anxiety and fear of the offender. While some studies report a significant relationship between child physical, and sexual abuse with adult depression, anxiety, and low self-esteem, others report non-significant differences between child abuse victims and non-abused subjects. For example Anderson et al

(2000) did not find positive links between abused and non-abused patients with respect to reports of depression and episodes of disabling anxiety.

1.7.4 Association of somatisation with child abuse

Most of the somatisation literature indicates a strong association between somatisation disorder, psychiatric symptoms, and childhood abuse (Ford 1993). For severely affected sexual abuse victims multiple somatisation symptoms may be present (Fry 1993). Bass (1990) has pointed out that the inability to disclose traumatic childhood events may lead to adverse health outcomes e.g. increases in autonomic nervous activity. Furthermore, if the effects of emotional inhibition are cumulative and chronic it follows that traumas occurring earlier in life will produce even greater health problems than recent onset traumas.

McCauley et al (1997) investigated whether somatisation is related to a childhood history of illness experience, deprivation, life events and abuse, (so determining the independent contributions of these childhood's factors to the predication of adult somatisation). Results were as follows; 22% of patients in his study reported childhood or adolescent physical or sexual abuse. In addition women who reported abuse as children but not adults had more physical symptoms and had higher scores for depression, anxiety, somatisation and low self-esteem. Zlotnick (1996) examined the relationship between child abuse and somatisation. He compared 74 sex abuse survivors who reported an increase in the severity of somatisation symptoms with 34 women without a history of sexual abuse. Results from this study provide support for the idea of child sexual abuse as a risk factor in the

development of complex somatisation presentations. Other studies have examined the effects of childhood trauma experiences. Portogijs (1996) established a clear relationship between deprivation, somatisation and childhood abuse history. This particular study assessed 106 adult patients with high consultation frequency, using a structured questionnaire and assessed illness experience, childhood abuse, and other life events during childhood and adolescence. Sixteen patients reported somatisation, depression and anxiety, 16% reported childhood abuse. Lankveld (1996) however could not establish significant differences within a normal population with respect to levels of psychological distress, somatisation and relationship satisfaction. According to Aldenkamp (1997) many factors contribute to the development of PNEAD: personality disorder, trauma, the behavioural social, and psychological dynamics within somatisation, and a tendency towards epilepsy as a modifying factor.

1.7.5 Association of childhood abuse with PNEAD

Among patients with PNEAD, the most common life events mentioned are childhood sexual and physical abuse (Freud 1959; LaBarbera and Dozier 1980). Some studies have indicated that psychological distress e.g. expression of anger, psychiatric diagnosis e.g. depression, anxiety disorder, or panic is important factors that contribute to the development and maintenance of PNEAD, in addition to trauma e.g. child sexual abuse or rape.

Gross (1979) reports on four young females with PNEAD who had experiences of rape. The author related the onset of PNEAD in three of the patients to rape

within the preceding year. Goodwin et al (1979) also reported six female patients who were diagnosed with PNEAD in adolescence; they found that 4 of those patients had histories of sexual abuse or rape. In three of the six cases, seizures were described as 'violent' movements that purportedly explained the relation between PNEAD and early sexual abuse. For Gross (1986) the genesis of PNEAD was related to the trauma of rape. Gross (1986) reported on 6 females presented with PNEAD; results indicated that all had experienced sexual abuse during childhood or adolescence.

Betts and Boden (1992) have suggested that a previous history of sexual abuse in childhood is associated with PNEAD. In their findings, most patients with PNEAD were females; women with PNEAD were reported to have suffered sexual abuse as children more than women with either epilepsy or psychiatric illness. They also found that women with PNEAD were typically victims of abuse from fathers, or stepfathers. The authors recognised their sample of patients was small. They also noted that there are unknown levels of sexual abuse within the community from which these patients were drawn. An additional difficulty concerned the use of a survey questionnaire to measure abuse in the patient sample. Bowman (1993) reports on the presentation of 27 patients diagnosed with PNEAD. Bowman found that 59% of 27 PNEAD patients reported sexual abuse and 48% reported physical abuse during childhood or adolescence. Bowman and Markand (1996) reported similar findings i.e. that patients with PNEAD reported high rates of sexual and physical abuse. However, female subjects in the study reported significantly more childhood sexual and physical abuse than male subjects. In summary 45 adult PNEAD patients, 24 (69%)

females and 2 (20%) males reported child sexual abuse, and 22 (63%) females and 1 (10%) male reported child physical abuse. Bowman and Markand suggested that patients with PNEAD have high rates of psychiatric diagnosis associated with childhood abuse. Lancman et al (1994) in a study, of 45 patients reported that five of the patients reported history of sexual abuse. A much larger study of 185 outpatients with PNEAD found that 24 (14%) of patients reported having been sexual abused, and 49 (28%) reported having been physical abused (Moore and Baker 1997).

Numerous case studies indicate an association between childhood abuse and PNEAD. Cartmill and Betts (1992) presented the case of a woman in whom sexual trauma occurred as an adult, whose symptoms had been mistaken for epilepsy. The women's experiences were typical of PNEAD associated with prior sexual trauma. They found that the childhood sexual abuse and trauma she had suffered related to paroxysmal behaviour. Fakhoury et al (1993) presented an elderly woman with PNEAD who reported a history of childhood sexual abuse. Another case study by Nash and Tenn (1993) found PNEAD was associated with dissociative phenomena (increasingly understood and linked to childhood trauma, especially of a sexual nature). In Grieg and Betts' study (1992) a comparison was made of 96 females with PNEAD, 132 with epilepsy, and 87 with psychiatric illness. PNEAD patients reported most abuse (54%), although authors pointed out that sexual abuse or assault could not be proven as the direct cause for patients diagnosed with either epilepsy or PNEAD.

Other studies indicate that sexual abuse represents a significant risk factor within PNEAD (Nash and Tenn, 1993). Eisendrath and Valan (1994) attempted to demonstrate an association between PNEAD and a history of sexual, or physical abuse, but found that there were no significant differences between PNEAD and epilepsy patients.

More recently, Reilly et al (1999) illustrated the association of sexual and physical abuse with somatisation in PNEAD patients. Separate groups of patients with physical symptoms in the absence of organic disease (PNEAD or irritable bowel syndrome) were contrasted with organically diseased groups with comparable symptoms (epilepsy and Crohn's disease, respectively). The findings from this study indicated that 21%, and 20% of all patients reported sexual abuse in childhood and adulthood. Reilly et al (1999) confirmed the relationship between abuse and functional disorder. Furthermore, functional groups recalled more sexual and physical abuse; they also reported more psychological distress, but poorer social functioning. Functional groups scored highest on somatisation, disease conviction, and were more depressed. Reilly et al (1999) reported that psychological abuse was associated with somatic distress especially physical abuse. Wyllie et al (1999) studied 34 young girls who were diagnosed with PNEAD. Results were as follows: 11 (32%) of patients had a history of sexual abuse, and 2 (6%) had a history of physical abuse.

A major problem with these studies is that they focused on subjects with PNEAD, mostly female, and the sample sizes were typically small. However, while such studies suggest a link between childhood sexual abuse and PNEAD, some failed to

prove such an association, and others fail to mention abuse as a potential contributory factor (Kristensen and Alving, 1992). In summary a small number of studies have focused on the relationship between sexual abuse i. e. sexual, physical and psychological in both child and adult PNEAD. Some of these studies consist of individual cases. Table 1.3 provides a summary of studies that have investigated the relationship between abuse and PNEAD.

Table 1.3:

Studies Examining the Relationship between Abuse (sexual, and physical) and PNEAD 1993-1999.

Author	Year	Patients N	Sexually abused N	Physically abused N
Betts and Boden	1992	96	52	NS
Bowman ES	1993	27	21	19
Lancman et al	1993	93	9	NS
Jawad et al	1995	95	8	NS
Bowman & Markend	1996	45	30	30
Van-Merode et al	1997	62	18	NS
Wyllie et al	1999	25	11	2
Reilly et al	1999	160	34	45

NS= Not Stated

1.8 Treatment of PNEAD

As mentioned earlier, PNEAD became an established clinical syndrome in neuropsychiatry only 100 years ago. In the second half of 19th century Charcot and Gowers began to develop the psychiatric treatment strategies of PNEAD. Charcot used the ovarian compression test for treatment of hysteria, whereas Gowers prescribed iron tonic to correct the presumed underlying cause. In the late nineteenth century Freud started to treat female sexually abused hysterics using hypnosis and catharsis, unfortunately the success of these approaches have never been systematically reviewed.

In recent years the diagnosis of PNEAD has been significantly strengthened. However there are to date no published randomised trials assessing the treatment of people with PNEAD. A number of therapeutic approaches have been suggested including psychodynamic therapy, behavioural therapy, family therapy, hypnosis, and psychotropic medications for coexisting disorder e.g. depression and anxiety (Ramani, 1993). Treatment of PNEAD is dependent on available resources and the clinical expertise of the multidisciplinary team treating these often-complex cases (Devinsky, 1998). Ozkara and Dreifuss (1993) illustrate the role of treatment in a case study of a twenty-eight-year-old woman who had a long history of seizures; she had been an inpatient for several months. She was diagnosed with psychogenic PNEAD; AED was administered, with no significant change in seizure frequency. Withdrawal of her AED and the initiation of intensive psychotherapy proved to be extremely effective. In another case study, Baker and Moore (1995) presented a single young female who was assessed and

treated using family therapy and individual sessions. Following treatment her attacks ceased, and she remained free of her attacks.

Ramani (1993) suggested that the results of the video-EEG testing along with the diagnosis should be presented in conjunction to the patient and his or her family in a nonjudgmental fashion by the treatment team before initiating treatment. Each case should be considered individually. For example, some patients respond best to anti-depressant medication and psychotherapy, whereas other patients may respond best to anti-anxiety medication and psychotherapy (Rawan 2000). However, treatment varies depending on the level of emotional difficulties of the individual PNEAD patient (Lesser et al 1983). The importance of providing a non-judgmental informed diagnosis with appropriate therapeutic choices is a necessary prerequisite to a successful outcome (Gates 2000).

A review of previous research reveals that there are many studies which have examined the association between PNEAD and childhood abuse, psychological distress, psychiatric disorder and somatisation disorder but there has been no systematic assessment of the different types of abuse in this population. Various studies have focused on physical and sexual abuse only, with very small sample sizes. The role of the family has not been considered and mechanisms linking abuse to PNEAD have not been investigated. As a result the current study used male and female subjects, and examined child and adult abuse. Sexual, physical and psychological abuse were assessed. A large sample was employed to address, not only the association of abuse and PNEAD but also the variables that might cause that association.

Previous research has focused on the differential diagnosis of PNEAD and epilepsy, and on basic diagnostic techniques for PNEAD. Research has neglected the immediate and longer-term impact of a PNEAD diagnosis. This research, therefore, attempts to address the limitations of previous research from which only very limited clinical implications can be drawn.

1.9 Implications for Future Research

While studies have described the possible relationship between PNEAD and clinical, demographic and psychological variables, there has been little attempt to examine these relationships in a formal study. This thesis will therefore attempt to improve understanding of factors that are important in developing and maintaining PNEAD in a series of studies. The first attempts to identify specific psychological variables that are associated with PNEAD. The second study will examine the initial impact of a diagnosis of PNEAD. The third study will examine the longer-term impact of this condition.

CHAPTER 2. STUDY 1: THE IDENTIFICATION OF PSYCHOSOCIAL VARIABLES ASSOCIATED WITH PSYCHOGENIC NON-EPILEPTIC ATTACK DISORDER

2.1 Introduction

There are significant clinical implications associated with a misdiagnosis of PNEAD (Betts 1990). A failure to recognize PNEAD can lead to the inappropriate use of anti-epileptic medication, and increased risk of toxicity and polypharmacy (Liske and Forster 1964). Additionally, unnecessary demands might also be placed upon social and health services with consequent economic costs to be accounted for. Further, the treatment of psychological factors associated with the development and maintenance of PNEAD has typically been neglected. Understanding and identifying the psychological factors involved PNEAD is critical for both assessment and treatment.

A review of the literature reveals that there are few studies which have examined the nature of psychological symptoms in patients with PNEAD (Kirmayer and Robbins 1991). However, psychiatric symptoms in PNEAD have been reported as being strongly associated with child abuse (Ford 1993). According to Ford PNEAD equates to pseudoneurologic symptoms reflecting conversion of repressed, unconscious, conflict driven material. Recently there have been a number of studies which have examined factors associated with PNEAD. Childhood abuse was strongly associated with PNEAD when compared with patients with epilepsy (Betts and Boden 1992; Goodwin 1993; Bowman and

Markend 1996; Reilly et al 1999). Clinicians, on the basis of anecdotal evidence, have suggested that patients with PNEAD can be identified by a variety of factors e.g. reported a history of sexual abuse, dysfunctional family, the presence of psychiatric disorder and somatisation disorder.

Previous research has failed to examine the relationship between psychopathology and different kinds of abuse in PNEAD. This study attempts to address limitations in previous research by:

- Examining different forms of abuse, both in childhood and adulthood.
- Examining several measures of psychological distress and family disturbance.
- Examining the relationship between abuse and psychological distress and family disturbance.
- Studying both male and female patients - in contrast to previous studies that have included only females.
- Examining differences between patients with PNEAD (matched for age and gender) and patients with epilepsy.
- Utilizing a large sample.

2.2 Aims of Study 1

- To identify psychosocial variables characteristic of PNEAD compared with epilepsy.
- To understand the relationship between clinical, social and psychological variables characteristic of people with PNEAD.

2.3 Methodology

2.3.1 *Participants*

A total of 162 participants between the ages of 16 and 60 years were recruited into two groups. Each group contained 56 females and 25 males. Patients with PNEAD were matched in terms of age and gender with epilepsy patients. PNEAD participants were recruited via the neuropsychological outpatients' clinic and epilepsy patients were recruited via the epilepsy out patient's clinic at the Walton Centre - Liverpool.

2.3.1.1 PNEAD Group Inclusion Criteria

Patients were initially recruited on the basis of the following selection criteria:

Participants were diagnosed with PNEAD following (1) assessment by an experienced neurologist who undertook a comprehensive neurologic evaluation, based on the patient's clinical history; (2) results of EEG correlates and/or; (3)

video EEG monitoring showing characteristic episodes during recording; and (4) assessment by a clinical neuropsychologist with comprehensive assessment interview skills.

2.3.1.2 PNEAD Group Exclusion Criteria

PNEAD subjects were excluded from the study if they presented with epilepsy (n=11). A number of patients refused to fill out the questionnaire because they had no time (n=9), or were unable to read (n=2). A number of questions were of a personal and sensitive nature (e.g. sexual and physical abuse questions), which some patients refused to answer (n=7). As a result, these patients were excluded from the study.

2.3.1.3 The Procedure for PNEAD Patients

The neuropsychologist following clinical appointments gave a brief explanation to those PNEAD patients who were suitable for the research that a researcher was conducting a study involving patient participation. The neuropsychologist introduced the researcher to the patient; the patient was then taken to a private room to complete the study questionnaires, with the researcher present for guidance.

The study was then outlined in brief. A further description was provided about a series of questionnaires, which documented demographic, psychological, and personal experiences. Patients were informed that the information provided would

not be disclosed to any hospital staff or form part of their case notes, and that non-participation in the study would not affect their treatment. Before the patient agreed to participate, he/she read the information sheet on the front of each questionnaire (appendix 2.1), which reminded participants that the questions asked about personal experiences, which might in turn affect how they felt about their health. Patients completed the questionnaires, with the researcher present. Finally, it was explained; (a) that if any question was unclear to patients; or (b) if they had any other questions about the project, that the researcher was available to help explain and clarify their questions and concerns. Each subject was thanked for their participation and asked to hand the questionnaire back to the researcher.

2.3.1.4 Epilepsy Group Inclusion Criteria

Participants in the control epilepsy group were attending the epilepsy outpatients' clinic at the Walton Centre. Diagnoses of epilepsy were made by a consultant neurologist on the basis of EEG correlates and clinical evidence.

2.3.1.5 Epilepsy Group Exclusion Criteria

Epilepsy control subjects were excluded from the study if they presented with PNEAD (n=3). A number of patients with epilepsy did not fill out the questionnaires because they either had no glasses or because of physical difficulties (n=6). Some patients indicated that they had no time (n=6).

2.3.1.6 The Procedure for Epilepsy Patients

Epilepsy subjects were attending the epilepsy out patients' clinic at the Walton Centre, Liverpool for assessment and treatment. The researcher initially examined patient's records to check participant's suitability for the study; all information was gained from medical records. Patients' age and gender were also checked from medical records to match with PNEAD patients. The researcher, in person, approached epilepsy control patients as they waited for their scheduled appointments with the neurologists. The study was outlined in brief. The procedure for epilepsy patients participating in the study was the same as for PNEAD patients. Epilepsy patients were asked to complete a battery of study questionnaires whilst waiting to see their appointed consultant neurologist. Following agreement, participants then completed the battery of study questionnaires. Subjects spent approximately 25 to 30 minutes completing the questionnaires (Appendix 2.2), although a number spent approximately 40 minutes.

2.3.2 Design of Questionnaire

2.3.2.1 Socio-demographic Information

Questionnaire responses focused upon patient's demographic details including questions about patient's age, gender, marital status, and religion. In terms of socio-economic information, questions focused upon patients' current work status, and current employment, as defined by a) unskilled manual, b) skilled manual, c)

office/shop work, d) skilled technical, e) professional/managerial positions, and f) those who are unemployed. Patients were asked to identify their education level. There were seven levels: 1) O level, 2) A level, 3) University degree, 4) Trade/Technical qualification, 5) Professional qualification, 6) C.S.E, and 7) No formal qualifications.

2.3.2.2 Questionnaires

The author employed questionnaires rather than formal interview to obtain sensitive information from patients, in particular for the assessment of abuse. Although different disciplines have tended to prefer different approaches, there are several advantages to the use of questionnaires by comparison with interview, and these have been well-documented. First, questionnaires used in psychological research have typically been subjected to rigorous statistical appraisal to ensure that they are reliable and valid. Secondly, questionnaires are less intrusive, and therefore, less likely to cause emotional distress than a structured interview. Thirdly, patients may be more likely to provide information about abuse from a questionnaire due to its anonymity. Drossman's questionnaire assessing child and adult abuse has been shown to be acceptable in previous studies with hospital outpatients (Colegrave et al (2001), Reilly et al (1999), Salmon and Calderbank (1995), Drossman et al (1990), and Lowman et al (1987)). Finally, interviews are open to bias by the interviewer and coder.

Somatisation Scale

The Hopkins Symptom Checklist (HSCL) is a self-report symptom inventory, which has undergone several major revisions and numerous minor alterations. An early form of the HSCL was defined at the time as a discomfort scale by Parloff et al (1954). The HSCL was first utilised as an outcome measure in psychotropic drug trials by Cole, Park and Richels in 1965 (Derogatis et al, 1974). The HSCL has been utilized primarily as a symptom measure with psychiatric in and out patient study groups (Raskin et. al, 1970). The HSCL comprises 58 items which are representative of symptom configurations commonly observed among outpatients; the questionnaire is composed of 5 factors namely somatisation, obsessive-compulsive, interpersonal sensitivity, depression, and anxiety. The somatisation sub-scale was used in the current study. The somatisation scale is short, easy to complete, and comprises 12 items that reflect distress arising from perceptions of bodily dysfunction (sample item: in the past 7 days, including today, have you felt low in energy, slowed down?).

Patients are instructed to rate themselves on each symptom question using a four-point scale of distress, from “not at all” (scored 0) through to “extremely distressed” (scored 4). A total somatisation score was calculated by summing all item scores. The higher the somatisation scores the greater the level of somatisation. Reliability coefficients for the somatisation scale of the HSCL range from 0.73-0.87; test-retest coefficients based upon a sample of 425 anxious/neurotic outpatients were 0.82 (Derogatis et al, 1974).

Parental Bonding Instrument (PBI)

This was developed by Parker et al (1979) to measure parental behaviour and attitudes. From an initial pilot study 114 items were developed and given to 50 fifth year medical students who were asked to score each of their parents' attitude and behaviour on a 4-point scale as recalled from childhood/adolescence. The initial inventory of 114 items was subsequently reduced to 99 items. Four factors emerged from an initial analysis of the scale. The first factor was Care/Involvement versus Indifference/Rejection; the second factor was Control/Overprotection versus Encouragement of Independence; the third factor comprised overprotection versus encouragement of autonomy items; the fourth factor was difficult to interpret because of its diverse item content. The final scales from the PBI consisted of 25 items, comprising 12 'Care' items and 13 'Overprotection' items. The care factor was strongly bipolar, and suggested a dimension of care/involvement v. indifference/rejection e.g. When you were a child did your mother show love? The 'Overprotection' factor does not appear to be so readily definable but suggests a dimension of psychological control over the child e.g. when you were a child did your mother try to control everything you did?

Using a Likert scaling from 0 to 3, the 12 items of the 'Care' factor allow a maximum score of 36 (good Care), and the 13 items from the 'Overprotection' factor allow a maximum score of 39 (Overprotected). Test-retest reliability for the PBI questionnaire was calculated from 17 subjects who completed the Care and Overprotection scales over a three-week interval. A Pearson correlation coefficient of 0.761 ($p < 0.001$) was obtained for the Care factor and 0.628

($p < 0.001$) for the Overprotection factor.

Illness Behaviour (hypochondriasis)

The Measure of Illness Behaviour defined by Pilowsky and Spence (1975) covers hypochondriacal responses, as well as negative changes in affect, and is designed to indicate the extent to which such psychological states mediate apparent exaggerated responses to illness. The illness behaviour questionnaire is a self-administered questionnaire that uses a (yes/no) response format - 52 questions were introduced to the patients as 'Here are some questions about you and your illness, please circle either Yes or No to answer each question'. Two scales were employed in the current study. *Factor One* (9 questions – called general hypochondriasis, Disease Concern) represents a general factor that is characterised by phobic concern about one's state of health e.g. Do you think you worry about your health more than most people? *Factor Two* (6 questions– Disease Conviction) is characterised by symptom preoccupation, and rejection of the doctor's opinion e.g. If the doctor told you that he could find nothing wrong with you, would you believe him?

Respondents choose either yes or no to answer each question. High scores suggest maladaptive ways of perceiving or evaluating one's state of health (Disease Concern and Disease Conviction). Test-retest reliability for the seven scales was reported for 42 cases and fell within the range (0.63 to 0.76) (McDowell and Newell, 1996).

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was developed to control for the presence of physical symptoms within affective disorders (Bowling, 1991). The HADS has been found to be a reliable instrument for identifying states of depression and anxiety across different groups of non-psychiatric hospital patients (Zigmond and Snaith, 1983). The scale consists of 14 items; seven items measure Anxiety (e.g. I can sit at ease and feel relaxed), while seven items measure Depression e.g. I still enjoy the thing I used to enjoy.

Overall Anxiety and Depression are both rated on a four-point scale; individual items are scored from 0-3 or 3-0, depending on the item wording. Total scores for each subscale are calculated. Respondents who score 11 and above for either anxiety or depression subscales are identified as a case, i.e. as significantly disabled. Evidence supports the validity of the HADS scale. In relation to sensitivity, further tests indicate that physically ill non-depressed patients had similar scores to a normal sample. Scores were not found to be affected by physical illness. Bowling (1991) assessed the internal consistency of the HADS scale. Inter item correlations for the Anxiety subscale correlations ranged from 0.41-0.76. Inter item correlations for the Depression subscale ranged from 0.30-0.60 (Zigmond & Snaith, 1983).

Drossman's questionnaire of sexual, physical, and psychological abuse

Using the questionnaire devised by Drossman et al (1990), a history of abuse was assessed using questions that referred to the period during childhood (less than 14 years old) and during adulthood (14 years old and more). Questions about sexual abuse concerned exposure 'Has anyone ever exposed the sex organs of their body to you when you didn't want it?' threat 'Has anyone ever threatened to have sex with you when you didn't want this?' physical contact 'Has anyone ever touched the sex organs of your body when you didn't want this?' and 'Has anyone ever made you touch the sex organs of their body when you didn't want this?' and rape 'Has anyone ever tried forcefully or succeeded to have sex with you when you didn't want this?'. Each question was answered Yes or No. A patient was considered to have been sexually abused if s/he gave a positive score to any one of the threat and contact questions (See Appendix 2.2, p 7).

The question for physical abuse during childhood was framed in the following way 'When you were a child, did an older person hit, kick, or beat you?' As an adult the question was framed 'Now, that you are an adult, does any other adult hit, kick, or beat you?' Possible answers included 'Never', 'Seldom', 'Occasionally', or 'Often'. The psychological abuse question (childhood) was asked in the following way 'When you were a child, did an older person insult or humiliate you, or try to make you feel guilty?' The psychological abuse question (adults) was asked in the following way 'Now, that you are an adult, does any other adult insult or humiliate you, or try to make you feel guilty?' Responses: 'Never', 'Seldom', 'Occasionally', or 'Often'. A final question asked those reporting abusive

experiences if they had discussed these experiences with a friend, a family member, a minister, or a professional counselor.

Each sexual abuse question was scored 1 = 'Yes' or 0 = 'No'. For physical and psychological abuse possible scores ranged from 0 'never' to 3 'Often'. Patients were considered have been sexually abused if s/he gave a positive score to any of the questions describing threat or contact, while a patient was considered to have been physically or psychologically abused if s/he answered 'Occasionally' or 'Often' to the relevant question.

Rosenberg's Self-esteem Scale

Rosenberg (1965) describes self-esteem as self-acceptance or basic personal feelings that individuals have regarding their own self-worth. Rosenberg (1965), based on Guttman scaling, for a study of 5024 students from public schools in New York developed the self-esteem scale. Rosenberg (1965) reported that positive self-esteem predicted reduced shyness and depression, increased assertiveness, and increased social functioning. The scale was intended to be brief, and global. The scale consists of ten items. Responses are made along a four-point continuum from 'strongly agree' to 'strongly disagree' e.g. 'I feel that I have a number of good qualities'.

Each item was scored from 1 = strongly agree to 4 = strongly disagree. Possible scores range from 10 to 40 with high scores indicating high levels of self-esteem.

Test-retest reliability for the self-esteem scale ranged from 0.72-0.92 (Rosenberg, 1965).

Family Environmental Scale (FES)

The Family Environmental Scale (FES) by Moos and Moos (1981) was developed (comprising ten subscales) to measure the social and environmental characteristics of different family types. Subscales assess three sets of dimensions. Relationship dimensions are measured by Cohesion (*the degree of commitment, help, and support family members provide for one another*), Expressiveness (*the extent to which family members are encouraged to act openly and to express their feelings directly*), and Conflict (*the amount of openly expressed anger, aggression, and conflict among family members*). In addition the relationship subscale assess the degree of commitment and support family members provide for one another including the extent to which family members are in conflict with another family member. Personal Growth dimensions are measured by Independence (*the extent to which family members are assertive, are self-sufficient, and make their own decisions*), Achievement Orientation (*the extent to which activities, such as school and work, are cast into an achievement-oriented or competitive framework*), and Intellectual Cultural Orientation (*the degree of interest in political, social, intellectual, and cultural activities*), Active-Recreational Orientation (*the extent of participation in social and recreational activities*), Moral-Religious Emphasis (*the degree of emphasis on ethical and religious issues and values*). System Maintenance dimension is measured by Organisation (*the degree of importance of clear organization and structure in planning family activities and responsibilities*)

and Control (*the extent to which set rules and procedures are used to run family life*). Respondents were asked to read all statements about their origin family and to decide whether it was 'true', 'mostly true', 'mostly false' or 'false'.

On each item the possible scores ranged from 0 to 9. The average scores were calculated for each sub-scale. Higher scores represent stronger perceptions or endorsement of the outlined family characteristics. Test-retest reliabilities were calculated (for the 10 subscales) for 47 family members from 9 families who completed the FES scale, twice, over an 8-week interval. The test-retest reliabilities were found to be acceptable ranging from 0.68 for independence to 0.86 for cohesion. Acceptable test-retest reliability coefficients were also found (over a 4-month interval), for 35 families and a 12-month interval for 241 families.

2.3.3 Statistical Analysis

Statistical analyses were performed with the aid of the Statistical Package for the Social Sciences (SPSS 8.0) (Coolican 1994). Parametric statistics were chosen for this study following tests of normality indicating that continuous variables approximated normal distributions. The education, employment status, and religion of patients with PNEAD vs epilepsy were compared by chi-square. Chi-square also examined interrelationships of different forms of abuse, the relationship of child to adult abuse and the relationship of abuse to patients' gender and education. Chi-square examined the association between the two diagnostic groups' reports of different abuse experiences. Pearson correlation coefficients

examined the association between psychological variables, and between age and psychological status.

Multiple two-factor analyses of variance (two-way ANOVA) examined differences between clinical groups (PNEAD vs epilepsy), gender (male vs female) and their interaction on each psychological variable. Further two-way analyses of variance, with psychological variables as dependent variables, contrasted male vs female, and abused vs non-abused patients for each type of abuse in both childhood and adulthood. Main and interaction effects were examined. Education was entered as a covariate in every analysis; age was not needed as a covariate because it was matched between the clinical groups. Further t-test analysis was performed to examine differences between patients when significant interactions were found.

Logistic regression analyses were then carried out. Tests for multicollinearity were first performed. Because gender was matched between clinical groups it was not used as a covariate. The association of education with clinical group and abuse was examined so that, in the event of significant relationships, it would be entered first in all analyses as a covariate. The effects of variables entered subsequently therefore controlled for education.

In analysis 1, all abuse variables that were associated with PNEAD in the previous chi-square analyses were included, in order to discover which abuse variables were uniquely associated with PNEAD. Only the significant abuse variables were used in subsequent analyses.

In analysis 2, parental care variables (Parental Care or Overprotection) that were associated with abuse and PNEAD were included after education, and before the significant abuse variables in order to find out whether Parental Care accounted for the effects of the significant abuse variables.

In analysis 3, psychological variables were included after education, and before the significant abuse variables. Only those psychological variables that were associated with both PNEAD and the significant abuse variables were included. This analysis was to find out whether psychological disturbance could account for the association of the significant abuse variables with PNEAD.

In analysis 4, scales from the Family Environmental Scale were included after education, and before the significant abuse variables. Only those FES scales that were related to PNEAD and the significant abuse variables were included. This analysis was to find out whether family functioning could account for the association of abuse with PNEAD.

2.4 Results

2.4.1 Sample

Table 2.1 summarises demographic data for the whole sample, which is further subdivided by diagnostic group. There were 81 participants in each of the PNEAD and epilepsy groups. Both diagnostic groups were of similar age (Means, 35.12 vs 34.48); in both diagnostic groups the number of female patients was greater than males (56/81 vs 25/81). There were no differences between diagnostic groups in terms of marital status, employment type, employment status, and religion. The majority of subjects reported having few qualifications. Fewer PNEAD patients had O level, A level, or university degrees than epilepsy patients. Overall the number of PNEAD patients with educational qualifications was lower when compared with epilepsy patients.

Table 2.1:**Demographic Data in each Diagnostic Group**

	PNEAD N=81	Epilepsy N=81	χ^2	p
Gender				
Male	25	25		
Female	56	56		
Marital status				
Single	25	28		
Divorce	7	10		
Widowed	1	1		
Married/living with a partner	46	41		
Other	2	1	1.32	.86
Employment				
Employee	16	28		
Unemployed	31	31		
Self employed	1	1		
Housewife	18	11		
Retired	7	3		
Student	8	5	7.32	.20
Job				
No job	50	44		
Unskilled	8	9		
Skilled	11	7		
Shop-work	7	11		
Skilled technical	0	3		
Professional	5	7	5.55	.35
Education				
O level	25	40	5.78	.01
A level	11	28	9.76	.00
University	2	11	6.77	.00
Trade/Technical qualification.	6	8	.31	.57
Professional qualification	12	15	.40	.52
CSE	17	25	2.05	.15
No formal education	36	22	5.26	.02
Religion				
Church of England/Protestant	43	45		
Catholic	24	22		
Muslim	2	1		
None	7	7		
Other	5	6	.56	.97

2.4.2 Intercorrelation of Education and Age with Psychological Variables

Significant correlation coefficients of education and age with psychological variables are shown in Table (2.2). Education was positively associated with Parental Care, Self-esteem, Cohesion and Active-Recreational Orientation, and negatively associated with Somatisation, Disease Conviction, and Anxiety. Age was positively associated only with Self-esteem, Active-Recreational Orientation, and Control.

Table 2.2:

Pearson Product Moment Correlations for Subject Education and Psychological Status with psychological variables

(Note: only significant correlations are shown)

Psychological variables	Education	Age
Somatisation	-.137*	-
Parental Care	.187**	-
Disease Conviction	-.200**	-
Anxiety	-.135*	-
Self-esteem	.240**	.184*
Cohesion (FES)	.153*	-
Active-Recreational Orientation (FES)	.195**	.215**
Control	-	.215**

** . Correlation is significant at the 0.01 level

* . Correlation is significant at the 0.05 level

2.4.3 Patterns of Abuse

2.4.3.1 Relationship of Child to Adult Abuse

Table 2.3 indicates the number of subjects who reported each type of abuse (sexual, physical, and psychological) at each time (childhood and adulthood). In total, sexual abuse was reported by 38 patients in childhood and 38 patients in adulthood. For the physical abuse question, 46 patients as children and 14 as adults responded as having been abused. For psychological abuse 69 patients (as children) and 46 (as adults) responded as having been abused. For each type of abuse, table 6 shows that patients reporting childhood abuse also reported adult experiences of abuse. For both childhood and adulthood, patients experiencing one type of abuse were more likely to experience other types also. Sexual abuse was experienced in both childhood and adulthood by 18 patients, physical abuse by 8 patients, and psychological abuse by 40 patients.

Table 2.3:

Relationship of Child to Adult Abuse.

	<u>Abused when a child</u>					
	Sexual		Physical		Psychological	
	No	Yes	No	Yes	No	Yes
<u>Abused when adult</u>						
No	104	20	110	38	87	29
Yes	20	18	6	8	6	40
χ^2	15.81		6.22		51.70	
p	.001		.01		.001	

2.4.3.2 Relationship between Different Types of Abuse (sexual, psychological, and physical)

Table 2.4 shows the interrelationships between different abuse experiences. In childhood, 12 sexually abused patients also reported psychological and physical abuse, while 24 non-sexually abused patients reported psychological and physical abuse only. In addition 7 of the adult sexually abused patients reported psychological and physical abuse in adulthood, whilst 6 of the non-sexually adult abused patients reported psychological and physical abuse in adulthood, (See Figures. 2.1, and 2.2).

Table 2.4:

The Frequency of Abuse (physical and psychological) for Sexually Abused and Non-sexually Abused Children and Adults.

<u>As a child</u>	<u>Sexually abused</u>			<u>Not Sexually abused</u>			<u>Total Psychologically abuse</u>	
	Psychologically No	Yes	Total	Psychologically No	Yes	Total	No	Yes
Physically abused								
No	11	10	21	72	23	95	83	33
Yes	5	12	17	5	24	29	10	36
			χ^2			32.36		
			p			.001		

<u>As an adult</u>	<u>Sexually abused</u>			<u>Not sexually abused</u>			<u>Total Psychologically abuse</u>	
	Psychologically No	Yes	Total	Psychologically No	Yes	Total	No	Yes
Physically abused								
No	21	10	31	92	25	117	115	33
Yes	0	7	7	1	6	7	1	13
			χ^2			16.09		
			p			.001		

Figure 2.1: Number of Subjects Recalling Sexual, Physical, and Psychological Abuse in Childhood.

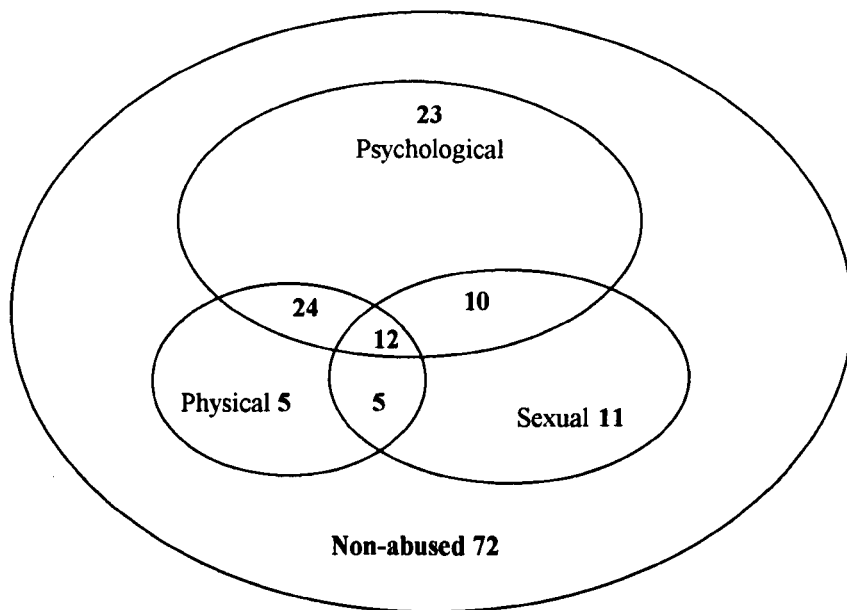
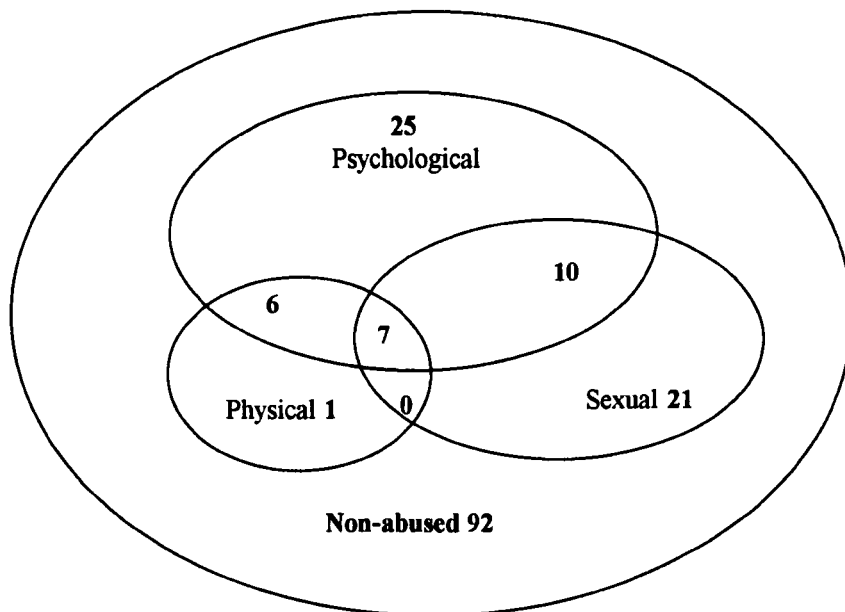


Figure 2.2: Number of Subjects Recalling Sexual, Physical, and Psychological Abuse in Adulthood.



2.4.3.3 Relationship of Abuse to Gender, Education and Age

A significant association between gender and the report of sexual abuse in childhood and adulthood was found. Females were more likely than males to report sexual abuse both as a child, and an adult. Gender was not linked to either psychological or physical abuse both for child or adult reports (Table 2.5). Age was linked to adult psychological abuse only ($t=2.59$, $p<0.01$), the mean age of non-abused patients was 33.57 years and for abused was 37.91.

Table 2.6 shows that patients with educational qualifications were less likely than those without qualifications to report child sexual abuse, and adult physical abuse. No other significant associations of abuse experiences with gender or education were found.

Table 2.5:

The Frequency of Child and Adult Abuse (Sexual, Physical and Psychological) for Males and Females.

As A Child	Male N=50	Female N=112	χ^2
Sexual abuse	5	33	7.29***
Psychological	17	52	2.18
Physical	14	32	.00
As An Adult			
Sexual abuse	3	35	12.27***
Psychological	13	33	.20
Physical	5	9	.16

*** $p<.001$; ** $p<.01$; * $p<.05$

Table 2.6:

The Frequency of Child and Adult Abuse (Sexual, Physical, and Psychological) for Subjects with and without Education Qualifications.

As A Child	Educational qualifications N=58	Non-educational qualifications N=104	χ^2
Sexual abuse	18	20	6.11**
Psychological	46	23	.31
Physical	29	17	.03
As An Adult			
Sexual abuse	21	17	1.72
Psychological	27	19	.84
Physical	4	10	8.46***

*** p<. 001; ** p<. 01; * p<. 05

2.4.4. Comparisons between Diagnostic Groups

2.4.4.1 Differences between Diagnostic Groups on Reports of Abuse

Differences in the frequency and type of sexual abuse experience between the two diagnostic groups were found both for childhood and adulthood (Table 2.7). Responses to abuse questions are described in detail although only the definition of abuse previously described is used in subsequent analyses. Significant associations between diagnostic group and most types of sexual abuse experienced during both childhood and adulthood were found; PNEAD in contrast to epilepsy patients were more likely to report exposure, threat, and contact experiences as a child and

adult; more serious forms of childhood and adulthood sexual abuse (contact) were also reported by PNEAD patients.

Table 2.7:

The Frequency and Type of Child and Adult Sexual Abuse, Across PNEAD vs Epilepsy Patients.

(χ^2 compares PNEAD vs Epilepsy Group)

As a Child	PNEAD		Epilepsy		χ^2	P
	Male N=25	Female N=56	Male N=25	Female N=56		
Exposed	3	20	1	9	6.43	.01
Threatened	3	12	0	9	1.76	.18
Touch your body	4	20	1	8	8.56	.001
Touch their body	3	15	1	4	8.56	.001
Have sex	1	11	0	5	3.22	.07
Other unwanted sex	0	5	0	3	.52	.47
Exposure	4	24	1	15	4.49	.03
Threat (sexual abuse)*	4	21	1	12	4.95	.02
Contact	4	21	1	9	8.20	.001
As an Adult						
Exposed	1	14	0	7	3.36	.06
Threatened	2	16	0	8	4.58	.03
Touch your body	2	13	1	9	1.18	.27
Touch their body	1	6	0	5	.36	.54
Have sex	0	16	0	9	2.31	.12
Other unwanted sex	1	6	0	1	4.73	.03
Exposure	2	26	1	13	6.30	.01
Threat (sexual abuse)*	2	24	1	11	6.73	.001
Contact	2	21	1	11	4.41	.03

* The definition used in the remainder of analysis (See Page 10)

Exposure = Exposure, threat, or contact events.

Threat = Threat, or contact events.

Contact = Contact experiences of abuse.

Table 2.8 indicates, by diagnostic groups, patient experiences of physical abuse as a child and adult. PNEAD patients were more likely to report having been physically abused than were epilepsy patients during childhood, and during adulthood. For psychological abuse (Table 2.9), PNEAD patients were more likely, once again, to report experiences of psychological abuse (as a child) when compared with epilepsy patients; there were no significant differences between the two diagnostic groups in terms of psychological abuse experienced as an adult.

Table 2.8:

The Frequency and Type of Physical Abuse for PNEAD vs Epilepsy Patients both as Children and Adults.

<u>As a Child</u>	PNEAD		Epilepsy		χ^2	P
	Male N=25	Female N=56	Male N=25	Female N=56		
Child physical abused						
Never	10	34	21	33		
Seldom	4	4	1	9		
Occasionally	8	14	3	10		
Often	3	4	0	4		
Physical abuse	11	18	3	14	4.37	.03
<u>As an Adult</u>						
Adult physical abused						
Never	21	46	23	50		
Seldom	0	3	1	4		
Occasionally	2	3	1	0		
Often	2	4	0	2		
Physical abuse	4	7	1	2	5.00	.02

(Physical abuse = reporting "Occasionally or Often")

Table 2.9:

The Experience of Psychological Abuse for PNEAD vs Epilepsy Patients both as Children and Adults.

<u>As a Child</u>	PNEAD		Epilepsy		χ^2	P
	Male N=25	Female N=56	Male N=25	Female N=56		
Child psychological abused						
Never	14	19	15	25		
Seldom	0	5	4	11		
Occasionally	7	18	2	11		
Often	4	14	4	9		
Psychological abuse	11	32	6	20	7.29	.01
<u>As an adult</u>						
Adult psychological abused						
Never	17	32	17	30		
Seldom	0	7	3	10		
Occasionally	6	7	3	11		
Often	2	10	2	5		
Psychological abuse	8	17	5	16	4.86	.48

(Psychological abuse = reporting "Occasionally or Often")

2.4.4.2 How do PNEAD Patients differ from Epilepsy Patients in Terms of Psychological Status?

Main effect of clinical group (PNEAD vs Epilepsy)

A two-way analysis of variance revealed significant differences between the two diagnostic groups in psychological status (with educational qualification as covariate), (Table 2.10 and 2.11). Patients with PNEAD as opposed to epilepsy reported significantly higher levels of Somatisation and hypochondriacal concerns i. e. perceived Disease Conviction. PNEAD patients reported significantly lower Self-esteem. In addition PNEAD patients reported parenting styles defined by higher negative Parental Overprotection. From the family environmental scale, patients with PNEAD reported less Expression, as well as higher levels of Control. Other psychological measures that compared PNEAD and epilepsy patients, i. e. hypochondriacal distress (Disease Concern), Depression, Anxiety, and subscales from the FES (Organization, Conflict, Independence, Achievement Orientation, Intellectual Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis) failed to differ significantly.

Main effect of gender

Tables 2.10 and 2.11 show the main effect for male v. female patients in relation to psychological status. Male patients did not differ from females on measures of psychological status.

Table 2.10:

Means (Std. Error) of Psychological Variables and Family Environmental Scale for PNEAD and Epilepsy in Male and Female Patients.

Psychological status	PNEAD		Epilepsy	
	Male	Female	Male	Female
Somatisation	15.52 (1.73)	17.07 (1.15)	7.04 (1.73)	10.44 (1.15)
Disease Concern	3.36 (.42)	2.91 (.28)	2.92 (.26)	3.01 (.22)
Disease Conviction	3.96 (.29)	3.17 (.19)	2.68 (.29)	2.98 (.19)
Anxiety	10.00 (.95)	10.00 (.63)	8.24 (.95)	8.75 (.53)
Depression	7.00 (.85)	6.94 (.57)	6.44 (.85)	6.48 (.57)
Self esteem	28.96 (1.15)	28.83 (.77)	31.60 (1.15)	31.65 (.77)
Parental Care	21.48 (1.70)	22.05 (1.13)	26.08 (1.70)	23.48 (1.13)
Parental Overprotection	17.32 (1.88)	17.35 (1.25)	12.24 (1.88)	15.55 (1.25)
<u>Family environmental scale</u>				
Cohesion	6.00 (.51)	4.80 (.34)	6.40 (.51)	6.25 (.34)
Expression	4.24 (.44)	3.80 (.29)	4.72 (.44)	5.30 (.29)
Conflict	3.64 (.49)	4.67 (.32)	3.80 (.49)	3.37 (.32)
Independence	5.84 (.40)	5.08 (.26)	6.00 (.40)	6.01 (.26)
Achievement Orientation	5.32 (.36)	4.71 (.24)	4.96 (.36)	4.60 (.24)
Intellectual Cultural Orientation	4.28 (.43)	4.64 (.29)	4.00 (.43)	5.00 (.29)
Active-Recreational Orientation	5.04 (.44)	4.25 (.29)	3.80 (.44)	5.19 (.29)
Moral-Religious Emphasis	5.00 (.41)	4.76 (.27)	4.36 (.41)	4.03 (.27)
Control	4.84 (.38)	5.41 (.25)	4.16 (.38)	4.07 (.25)
Organization	5.48 (.43)	4.94 (.29)	5.28 (.43)	5.30 (.29)

Interactions (group x gender)

Tables 2.10 and 2.11 show 2-way interactions for gender by diagnostic group. A significant interaction was found for Disease conviction. Male, PNEAD patients reported higher levels of Disease Conviction compared to male, epilepsy patients ($t= 3.2, p<0.01$). Male patients with PNEAD recorded higher levels of Disease Conviction compared to female patients with PNEAD, ($t= 2.26, p<0.05$). There were no significant differences between female patients in either diagnostic group. In addition there were no significant differences between male and female epilepsy patients ($p>0.05$). A significant interaction was also found for family Active-recreational orientation. Male PNEAD patients perceived higher levels of family Active-recreational orientation when compared with male, epilepsy patients, ($t= 2.00, p<0.05$). Female PNEAD patients reported lower levels of family Active-recreational orientation compared with female epilepsy patients, ($t= 2.55, p<0.01$). There were no significant differences between male and female patients with PNEAD ($p>0.05$). Female epilepsy patients reported higher levels of family Active-recreational orientation compared to male epilepsy patients ($t= 2.67, p<0.01$).

Table 2.11:

Summary of Statistical Analyses: $F_{1,157}$ Values Showing Main Effects for Group (PNEAD vs Epilepsy), Gender (Male vs Female), and Interaction (Group x Gender) on Psychological Status (with Educational Qualification as Covariate).

	Male vs Female	PNEAD vs Epilepsy	Group x Gender
Somatisation	3.03	23.84**	.41
Disease Concern	.12	.50	.70
Disease Conviction	.72	6.87*	5.01*
Anxiety	.16	2.57	.11
Depression	.01	.23	.01
Self-esteem	.04	5.60*	.01
Parental Care	.70	2.97	1.27
Parental Overprotection	1.17	4.05*	1.05
<u>Family Environmental Scale</u>			
Cohesion	2.64	3.27	1.38
Expressiveness	.02	5.89*	1.81
Conflict	.65	1.35	3.05
Independence	1.25	2.08	1.25
Achievement Orientation	2.70	.91	.16
Intellectual Cultural Orientation	3.12	.01	.72
Active-Recreational Orientation	.44	.61	8.38**
Moral-Religious Emphasis	.53	3.05	.02
Control	.63	8.64**	1.02
Organization	.36	.23	.60

*** $P < .001$; ** $< .01$; * $< .05$

2.4.5 How do Abused Patients differ from Non-abused Patients in Terms of Psychological Status?

2.4.5.1 Main Effect for Child Sexual Abuse

The main effects for sexually abused v. non-sexually abused patients on psychological status (with educational qualification as a covariate), are reported in tables 2.12 - 2.15 which show the mean and standard error for psychological variables across abused and non-abused patients. Abused patients reported significantly lower levels of Parental Care. From the family environmental scale, abused patients reported significantly lower levels of Expression, and higher levels of Conflict.

2.4.5.2 Main Effect of Child Psychological Abuse

Patients who defined themselves as psychologically abused children in comparison to non-abused, reported significantly higher levels of Somatisation, negative Parental Overprotection, Anxiety, and Depression; abused patients reported lower levels of positive Parental Care, and Self-esteem. From the family environmental scale significant differences between abused and non-abused patients were found: abused patients reported higher levels of Conflict, and Control. Abused patients reported lower levels of Cohesion, Expression, Independence, Intellectual cultural orientation, and Organization.

2.4.5.3 Main Effect for Child Physical Abuse

Physically abused patients differed from non-abused patients on measures of psychological status; physically abused patients reported significantly higher levels of negative Parental Overprotection. Abused patients reported lower levels of positive Parental Care, and Self-esteem. From the family environmental scale abused patients scored higher than non-abused on measures of Conflict, and Control. Abused patients in comparison to non-abused patients scored lower on Cohesion, Expression, Active-Recreational Orientation, and Independence.

Table 2.12:

Mean (Std. Error) of Psychological Variables in groups Defined by the Presence or Absence of Abuse.

<u>Psychological status</u>	<u>Abuse when a child</u>				<u>Abuse when adult</u>							
	Sexual		Psychological		Physical		Sexual		Psychological		Physical	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Somatisation	12.22 (2.24)	12.46 (.87)	15.45 (1.27)**	10.80 (.99)	14.53 (1.48)	11.69 (.93)	16.60 (2.79)	12.09 (.85)	15.87 (1.49)**	11.19 (.90)	20.28 (2.56)**	11.73 (.80)
Disease Concern	3.27 (.50)	2.93 (.19)	2.97 (.29)	2.97 (.23)	2.87 (.34)	2.99 (.21)	3.33 (.62)	2.84 (.19)	3.84 (.33)**	2.62 (.20)	4.71 (.58)**	2.78 (.18)
Disease Conviction	3.56 (.35)	3.14 (.13)	3.45 (.20)	3.05 (.16)	3.23 (.23)	3.18 (.15)	3.04 (.44)	3.20 (.13)	3.58 (.23)	3.05 (.14)	3.72 (.41)	3.14 (.13)
Anxiety	8.80 (1.15)	9.35 (.44)	10.35 (.66)*	8.58 (.51)	10.17 (.76)	8.89 (.48)	8.92 (1.44)	9.17 (.44)	11.17 (.76)**	8.49 (.46)	11.73 (1.34)	8.99 (.42)
Depression	7.52 (1.02)	6.62 (.39)	7.87 (.59)**	6.01 (.45)	7.02 (.68)	6.58 (.43)	6.44 (1.27)	6.56 (.39)	8.71 (.67)***	5.96 (.41)	7.59 (1.21)	6.61 (.38)
Self esteem	27.94 (1.33)	30.29 (.52)	28.76 (.79)**	31.19 (.61)	28.61 (.91)*	30.96 (.57)	30.81 (1.73)	30.29 (.53)	27.60 (.91)***	31.29 (.55)	26.33 (1.60)**	30.70 (.50)
Parental Care	16.88 (1.95)***	24.48 (.76)	21.05 (1.13)**	25.07 (.87)	19.16 (1.29)***	24.95 (.80)	19.95 (2.52)	23.92 (.77)	19.47 (1.33)***	24.77 (.81)	17.06 (2.35)**	23.94 (.74)
Parental Overprotection	17.71 (2.27)	14.75 (.88)	18.80 (1.29)***	13.50 (1.00)	20.78 (1.45)***	13.57 (.91)	19.69 (2.85)	15.36 (.87)	21.18 (1.47)***	13.55 (.89)	21.23 (2.65)*	14.98 (.83)

Table 2.13:

Mean (Std. Error) of Family Environmental Scale in groups Defined by the Presence or Absence of Each Type of Abuse.

<u>Family environmental scale</u>	<u>Abuse when a child</u>				<u>Abuse when adult</u>							
	Sexual		Psychological		Physical		Sexual		Psychological		Physical	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Cohesion	5.01 (.60)	6.19 (.23)	4.60 (.33)***	6.77 (.26)	4.68 (.40)***	6.34 (.25)	4.62 (.76)	6.19 (.23)	4.60 (.41)***	6.35 (.25)	4.81 (.74)	5.97 (.23)
Expression	3.57 (.54)*	4.75 (.21)	3.35 (.29)***	5.25 (.23)	3.17 (.34)***	5.05 (.21)	3.52 (.66)	4.81 (.20)	3.27 (.35)***	4.99 (.21)	3.30 (.64)*	4.64 (.20)
Conflict	4.16 (.57)*	3.63 (.22)	5.30 (.31)***	2.93 (.24)	5.13 (.38)***	3.37 (.24)	5.17 (.71)*	3.53 (.22)	5.43 (.37)***	3.27 (.23)	5.84 (.69)**	3.66 (.21)
Independence	5.33 (.48)	5.89 (.18)	5.03 (.27)***	6.22 (.21)	4.75 (.31)***	6.13 (.20)	5.28 (.60)	5.89 (.18)	4.85 (.32)**	6.07 (.19)	4.36 (.56)**	5.87 (.17)
Achievement Orientation	4.97 (.43)	4.94 (.16)	5.09 (.25)	4.79 (.19)	4.88 (.29)	4.91 (.18)	4.61 (.54)	4.93 (.16)	5.09 (.29)	4.82 (.17)	4.66 (.50)	4.92 (.16)
Intellectual Cultural Orientation	4.58 (.51)	4.60 (.19)	3.89 (.30)**	4.84 (.23)	3.99 (.34)	4.68 (.21)	4.55 (.64)	4.61 (.19)	3.97 (.35)	4.67 (.21)	3.82 (.61)	4.55 (.19)
Active-Recreational Orientation	4.59 (.52)	4.72 (.20)	4.09 (.31)	4.91 (.24)	3.98 (.35)*	4.82 (.22)	5.32 (.66)**	4.67 (.20)	4.01 (.36)	4.80 (.22)	3.90 (.63)	4.64 (.20)
Moral-Religious Emphasis	4.93 (.50)	4.47 (.19)	4.69 (.29)	4.43 (.23)	4.53 (.33)	4.54 (.21)	5.70 (.61)**	4.52 (.19)	4.53 (.34)	4.52 (.20)	4.85 (.59)	4.50 (.18)
Organization	5.32 (.50)	5.39 (.19)	4.63 (.29)**	5.68 (.23)	4.71 (.34)	5.46 (.21)	5.12 (.64)	5.36 (.19)	5.07 (.35)	5.31 (.21)	5.01 (.61)	5.25 (.19)
Control	4.97 (.46)	4.45 (.18)	5.63 (.26)***	3.98 (.20)	5.86 (.29)***	4.13 (.18)	5.15 (.58)	4.47 (.18)	5.55 (.31)***	4.26 (.19)	17.06 (2.35)*	23.94 (.74)

2.4.5.4 Interaction of Child Abuse with Gender

Table 2.15 shows two-way interactions, for child abuse (sexual, psychological, and physical) by gender (males v. females) on psychological status. A significant interaction for sexual abuse by gender was found on one variable. Abused, male patients, reported lower levels of Self-esteem than female, abused patients ($t=2.69$, $p<0.01$); abused, male patients, also reported lower levels of Self-esteem than non-abused, male patients ($t=2.73$, $p<0.01$).

From the family environmental scale, abused, male patients reported higher levels of Intellectual cultural orientation than abused, female patients ($t=6.12$, $p<0.001$); non-abused, male patients reported lower levels of Intellectual Cultural Orientation than non-abused female patients ($t=3.03$, $p<0.001$); abused, female patients, reported lower levels of Intellectual Cultural Orientation than non-abused, female patients ($t=3.30$, $p<0.001$). Sexually abused, male patients reported higher levels of Organization than abused, female patients ($t=3.28$, $p<0.001$); abused, female patients reported lower levels of Organization than non-abused, female patients ($t=2.66$, $p<0.01$); abused, male patients reported higher levels of Organization than non-abused, male patients ($t=2.09$, $p<0.05$). Abused, male patients reported lower levels of Conflict than abused, female patients ($t=3.03$, $p<0.001$); abused, male patients reported lower levels of Conflict than non-abused, male patients ($t=2.66$, $p<0.01$); abused, female patients reported higher levels of Conflict than non-abused, female patients ($t=4.19$, $p<0.001$). Abused, female patients reported lower levels of Active-Recreational Orientation than non-abused, female patients ($t=3.76$, $p<0.001$); and non-abused, female patients, reported higher levels of

Active-Recreational Orientation than non-abused male patients ($t = 2.07, p < 0.05$).

From the family environmental scale, abused, male patients reported higher levels of Control when compared with non-abused, male patients ($t = 4.96, p < 0.001$); abused, female patients reported higher levels of Control when compared with non-abused, female patients ($t = 2.1, p < 0.05$); non-abused, female patients reported higher levels of Control compared with non-abused, male patients ($t = 2.18, p < 0.05$). Effects of psychological abuse by gender failed to reach significance (See Table 2.14).

Table 2.14:

Means (Std. Error) of the Psychological Variables for Sexually, Physically, and Psychologically Abused and Non-abused Male and Female Patients.

Self esteem

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	23.80	(2.60)	31.00	(.85)
Female	31.33	(1.04)	29.79	(.65)

Intellectual Cultural Orientation

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	5.20	(.73)	4.02	(.31)
Female	3.91	(.33)	5.20	(.25)

Conflict

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	3.00	(.71)	5.80	(.37)
Female	5.39	(.36)	3.46	(.28)

Active-Recreational Orientation

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	5.40	(.93)	4.31	(.35)
Female	3.64	(.34)	5.18	(.25)

Organization

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	6.60	(.60)	5.24	(.27)
Female	4.24	(.40)	5.49	(.25)

Control

	Physically abused		Non physically abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	6.36	(.45)	3.78	(.27)
Female	5.34	(.35)	4.50	(.21)

Table 2.15

Summary of Statistical Analyses: $F_{1,157}$ Values Showing the Interaction between Genders x Child Abuse (Sexual, Psychological and Physical) on Psychological Status (with Educational Qualification as Covariate).

	Child sexual abuse x gender	Child psychological abuse x gender	Child physical abuse x gender
Somatisation	.09	3.57	2.76
Disease Concern	.88	.20	.40
Disease Conviction	.74	.97	2.06
Anxiety	.02	1.20	.00
Depression	.77	1.49	.77
Self-esteem	11.45***	1.84	1.22
Parental Care	2.41	2.51	.22
Parental Overprotection	.14	.11	2.24
<u>Family Environmental Scale</u>			
Cohesion	2.18	.83	.00
Expressiveness	.00	.61	1.29
Conflict	4.56*	.56	1.27
Independence	.66	.90	.46
Achievement Orientation	1.04	.14	.73
Intellectual Cultural Orientation	4.78*	.88	.66
Active-Recreational Orientation	4.58*	.01	.55
Moral-Religious Emphasis	.40	.00	1.19
Organization	6.95**	.44	.59
Control	1.57	2.41	7.17**

***< .001; **< .01; *< .05

2.4.5.5 Main Effect of Adult Sexual Abuse

Tables 2.12 and 2.13 show the mean and standard error of psychological variables for adult abused and non-abused patients. Patients sexually abused as adults differed from non-abused patients on several family scales i. e. Conflict, Active-Recreational Orientation and Moral-Religious Emphasis; non-abused patients reported higher levels of Conflict, Active-Recreational Orientation and Moral-Religious Emphasis. On measures of psychological variables no significant differences between abused and non-abused patients were found.

2.4.5.6 Main Effect of Adult Psychological Abuse

A two-way analysis of variance revealed significant differences between adult psychologically abused and non-abused patients. Abused patients in comparison with non-abused patients reported significantly higher levels of Somatisation, negative Parental Overprotection, Disease Concern, Anxiety, and Depression. Abused patients reported lower levels of positive Parental Care, and Self-esteem. On measures from the family environmental scale, differences between psychologically abused and non-abused patients were found. Psychologically abused patients reported significantly lower Cohesion, Expression, and Independence. Abused patients reported significantly higher levels of Conflict and Control.

2.4.5.7 Main Effect of Adult Physical Abuse

Patients physically abused as adults in comparison with non-abused counterparts reported significantly higher levels of Somatisation, negative Parental Overprotection, and Disease Concern. Abused patients reported lower levels of positive Parental Care, and Self-esteem. On measures from the family environmental scale, abused patients reported higher levels of Conflict, and Control; physically abused patients reported lower levels of Expression, and Independence.

2.4.5.8 Interaction of Adult Abuse with Gender

Table 2.17 shows two-way interactions for adult abuse (sexual, physical, and psychological) by gender (males vs females) on measures of psychological status. A significant interaction for adult sexual abuse and gender was found for Moral-Religious Emphasis. Abused, male patients reported higher levels of Moral-Religious Emphasis compared to abused, female patients ($t = 7.85, p < 0.001$); male, non abused patients reported lower levels of Moral-Religious Emphasis compared to male, abused patients ($t = 6.40, p < 0.001$). Abused, male patients reported higher levels of Active-Recreational Orientation compared to abused, female patients ($t = 2.95, p < 0.01$); non abused, female patients reported higher levels of Active-Recreational Orientation when compared with non abused, female patients ($t = 2.02, p < 0.05$).

An interaction between gender and adult psychological abused for negative Parental Overprotection was found. Abused, male patients reported significantly higher levels of negative Parental Overprotection compared with non-abused, male patients ($t = 3.11, p < 0.001$); non-abused, female patients reported higher levels of negative Parental Overprotection compared with non-abused males ($t = 2.03, p < 0.05$).

A significant interaction for physical abuse by gender, in relation to negative Parental Overprotection was found. Physically abused, male patients reported higher levels of negative Parental Overprotection compared to non-abused, male patients, ($t = 3.67, p < 0.001$) (See Table 2.16).

Table 2.16:

Means (Std. Error) of the Psychological Variables for (Sexually, Physically, and Psychologically) Abused and Non-abused, Male and Female Patients.

Moral-Religious Emphasis

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	7.33	(.33)	4.51	(.33)
Female	4.11	(.28)	4.53	(.24)

Active-Recreational Orientation

	Sexually abused		Non sexually abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	6.67	(1.45)	4.28	(.33)
Female	3.91	(.32)	5.09	(.26)

Parental Overprotection

	Psychologically abused		Non psychologically abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	23.23	(2.60)	11.81	(1.43)
Female	19.21	(1.75)	15.30	(.97)

Parental Overprotection

	Physically abused		Non physically abused	
	Mean	(Std. Error)	Mean	(Std. Error)
Male	26.00	(3.08)	13.53	(1.45)
Female	17.22	(3.69)	16.39	(.89)

Table 2.17:

Summary of Statistical Analyses: $F_{1,157}$ Values Showing the Interaction Between Male vs Female Patients x Adult Abuse (Sexual, Psychological and Physical) on Psychological Status (with Educational Qualification as Covariate).

	Adult sexual abuse x gender	Adult psychological abuse x gender	Adult physical abuse x gender
Somatisation	1.47	.01	.01
Disease Concern	.04	1.33	.43
Disease Conviction	.09	1.64	.15
Anxiety	.31	.35	.21
Depression	.94	2.19	.03
Self-esteem	.17	2.28	1.52
Parental Care	.13	.01	.57
Parental Overprotection	2.28	5.20*	4.72*
<u>Family Environmental Scale</u>			
Cohesion	.09	.14	.08
Expressiveness	.33	.32	.10
Conflict	.10	.34	.98
Independence	.24	.51	.02
Achievement Orientation	.12	.29	1.27
Intellectual Cultural Orientation	1.98	.15	.00
Active-Recreational Orientation	5.89**	.00	.99
Moral-Religious Emphasis	6.80**	.73	.02
Organization	.76	.07	1.57
Control	.04	.52	.19

***< .001; **< .01; *< .05

2.4.6 *Logistic Regression Analyses*

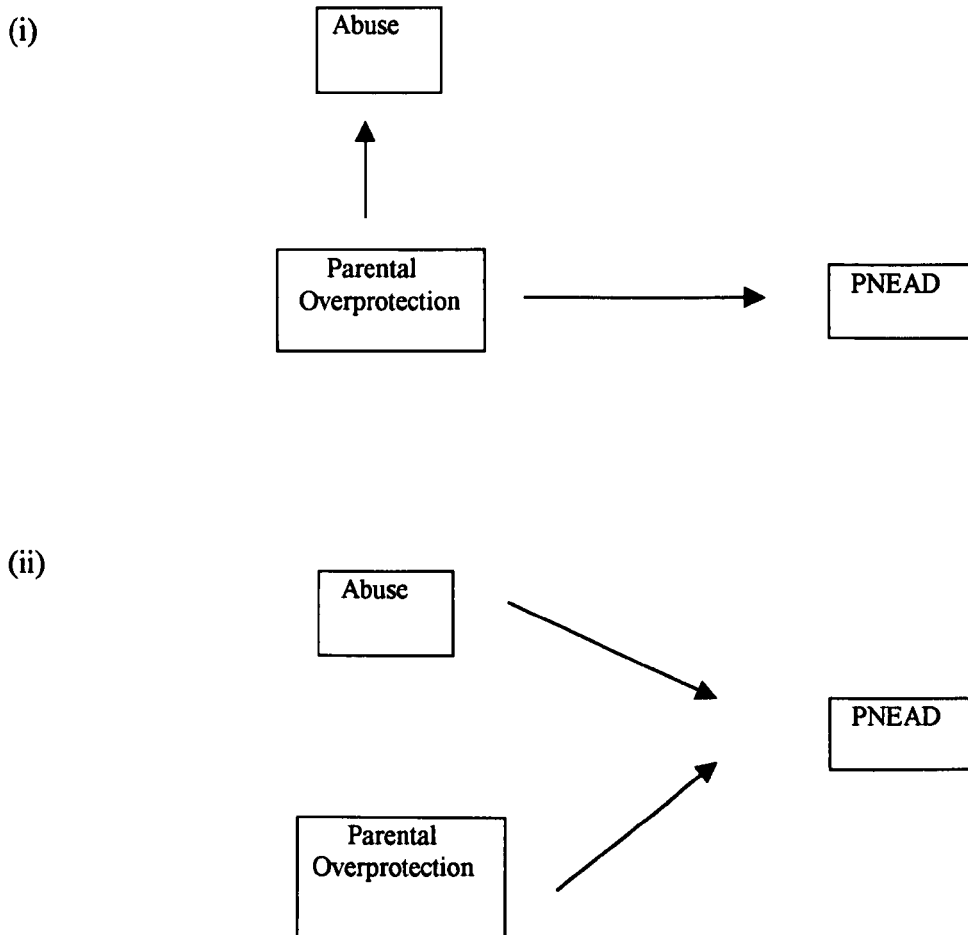
A test for multicollinearity was carried out on the variables that were to be used in the following analyses. Minimum tolerance was 0.60 and maximum conditioning index was 24.58. Acceptable levels of tolerance are considered to be $>.01$ and acceptable values for the conditioning index are <30 (Tabachnik and Fidell 1996). Therefore there was no evidence of collinearity and the complete set of variables was used.

Education was related to clinical group and to abuse. Therefore it was entered first in all analyses so that the effects of variables entered subsequently controlled for this. Subsequent sets of variables were entered as separate blocks.

Each form and time of abuse experience except for adult psychological abuse (see Table 12) was associated with PNEAD. Therefore all abuse variables, except for adult psychological abuse, were included in analysis 1 in order to identify which ones were uniquely associated with PNEAD. The model fit was improved significantly ($\chi^2=14.41$, $df=5$, $p=.01$). However, no specific abuse variable reached significance by the Wald test. Therefore the analysis was repeated with stepwise entry (criteria: $p=.05$ for entry, $p=.10$ for removal). Only child psychological abuse was significant (Wald test: $p<.01$; odds ratio and 95% confidence interval: 2.57, 1.33, 4.96). Only this abuse variable was therefore used in subsequent analyses.

A second analysis then found out whether the relationship of abuse to PNEAD could be accounted for by poor parenting (i. e. Fig 2.3 (i) v Fig 2.3 (ii)). Parental Overprotection was entered in block 2 (i.e. after education in block 1), followed by child psychological abuse in block 3. Parental Overprotection was not significant ($\chi^2=3.13$, $df1$, $p>.05$). Childhood psychological abuse remained significant ($\chi^2=8.24$, $df1$, $p<.01$; Wald test: $p<.01$; odds ratio and 95% C. I.: 2.57, 1.33, 4.96).

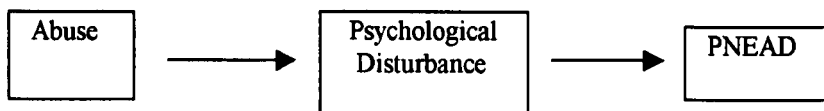
Figure 2.3: How Might Abuse and Parental Overprotection be Associated with PNEAD?



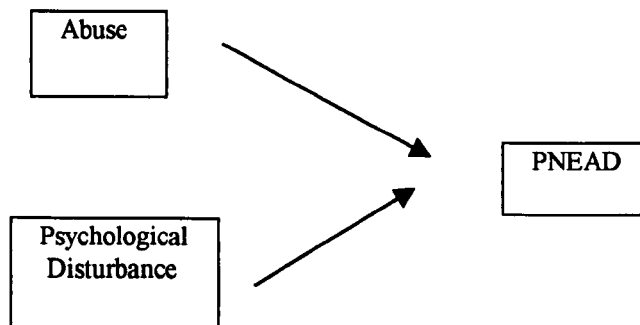
A third analysis examined whether the relationship of abuse to PNEAD could be accounted for by psychological disturbance (i. e. Fig 2.4 (i) v Fig 2.4 (ii)). Psychological variables entered in block 2 were those that were related to both clinical group and child psychological abuse (Somatisation, Self-esteem). Child psychological abuse was then entered in block 3. Psychological variables as a block were highly significant ($\chi^2=24.10$, $df=1$, $p<.001$). Somatisation was the only significant variable (Wald test: $p<.001$; odds ratio and 95% C.I. associated with unit increase in scale score: 1.10,1.06,1.15). However child psychological abuse remained significant ($\chi^2=4.83$, $df=1$, $p<.05$; Wald test: $p<.05$; odds ratio and 95% C. I.: 2.18,1.08,4.39).

Figure 2.4: How Might Abuse and Psychological Variables be related to PNEAD?

(i)



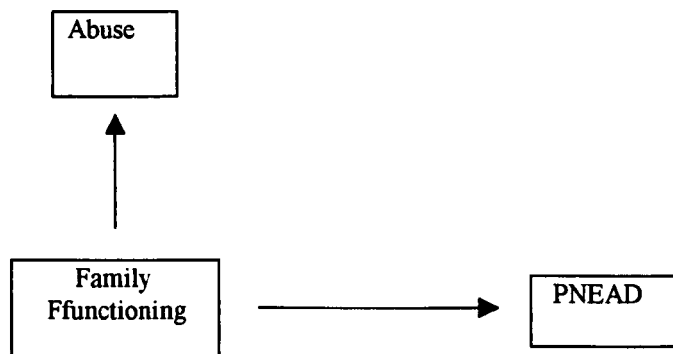
(ii)



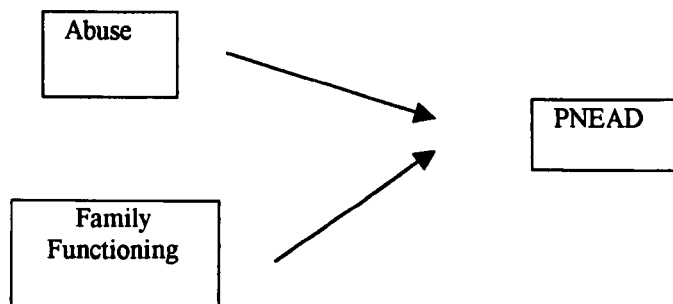
The fourth analysis examined whether disturbed family functioning could account for the link between abuse and PNEAD (i. e. Fig 2.5 (i) v Fig 2.5 (ii)). The FES scales that were related to clinical group and child psychological abuse (Expressiveness and Control) were entered in block 2 followed by child psychological abuse in block 3. The FES scales as a block were significant ($\chi^2=12.54$, $df=2$, $p=.001$). Within this set of variables, only Control reached significance (Wald test: $p<.001$; odds ratio and 95% C. I. associated with unit increase in score: 1.35, 1.14, 1.61). Child psychological abuse was no longer significant when entered in block 3.

Figure 2.5: How Might Abuse and Family Functioning be related to PNEAD?

(i)



(ii)



2.5 Discussion

2.5.1 *Strengths of the Study*

The current study explored differences in term of social and family functioning of two groups: patients with PNEAD and patients with epilepsy. Key strengths of the current study include:

- The sample compared to previous research was large.
- Groups were matched by age and gender.
- Both child and adult abuse were examined.
- In addition the definition of abuse was widened to include physical, sexual, and psychological abuse.
- Each patient completed an extensive battery of validated measures.

The current study confirms previous findings indicating that the majority of PNEAD patients are female (Betts and Boden 1992). In this sample marked differences were observed between the two groups in terms of educational qualifications. Patients with PNEAD were noted to report fewer educational qualifications than patients with epilepsy. As a consequence, education was

entered as a covariate in subsequent analysis. No significant differences in employment, marital status and religion were found between the two clinical groups.

2.5.2 Main Findings

2.5.2.1 Association of Abuse with PNEAD

An important finding is that patients who reported one type of abuse were more likely to report other abuse experiences, both in childhood and adulthood (See Figure 2.1 and Figure 2.2). The findings were similar to previous research. Reilly et al (1999) found that there were a significant number of patients who reported multiple abuse experiences. Patients with limited educational qualifications were more likely to report sexual abuse in childhood. Indeed, lack of education was found to be strongly associated with child sexual abuse and adult physical abuse. Patients with PNEAD recalled more frequent types of abuse as children compared with patients with epilepsy (sexual, physical, and psychological). As adults, patients with PNEAD again reported more frequent abuse experiences both sexual, and physical. In line with previous research patients with PNEAD reported more frequent experiences of sexual abuse than female patients with epilepsy (Cartmill and Betts 1992; Fakhoury et al 1993; Nash and Tenn 1993; Bowman and Markend 1996; Moore and Baker 1997; and Reilly et al 1999). Unlike most of the previous research, the present study was able to identify which form of abuse was important. Logistic regression analyses revealed that child psychological abuse was the only unique abuse factor associated with PNEAD.

Abused patients were more likely to report family dysfunction and also showed higher levels of psychological and somatic distress compared with non-abused patients. It was therefore necessary to find out which variables from these different areas were uniquely important in predicting whether patients were in the PNEAD vs epilepsy group.

2.5.2.2 Psychological Profile of PNEAD

In a subsequent analysis, both PNEAD and epilepsy groups were compared in terms of psychological status. In this study, patients with PNEAD, in comparison with patients with epilepsy were more psychologically distressed and reported greater social and family difficulties. These combined findings are similar to previous work, for example, Moore and Baker (1997). Patients with PNEAD were more somatically distressed, and reported stronger hypochondriacal concerns (as measured by the Disease Conviction scale) than patients with epilepsy. These findings are also in line with previous researchers e.g. Reilly et al (1999) although Frances et al (1999) found that patients with PNEAD did not differ psychologically when compared with epilepsy patients. Patients with PNEAD reported lower Self-esteem compared with epilepsy counterparts. Patients with PNEAD also reported higher levels of negative Parental Overprotection, less Expression and more Control in their families than their epilepsy counterparts. In addition the current study also found that there were few differences between male and female subjects for psychological status.

2.5.2.3 Relationship between Abuse, Psychological Profile and PNEAD

Logistic regression attempted to examine the predictive power or strength of specific abuse experiences, psychological disturbance, and family function variables that lead to PNEAD. The first analysis revealed as previously noted that child psychological abuse in particular was a predictor of PNEAD. Subsequent analysis explored whether the association of poor parenting with child psychological abuse could account for PNEAD. Logistic regression analysis showed child psychological abuse remained significant and that Parental Overprotection could not account for the link between abuse and PNEAD presentation. The next analysis examined whether the relationship of abuse to PNEAD presentation could be accounted for by psychological disturbance. Child psychological abuse remained significant, although psychological distress did not modify the relationship between abuse and PNEAD. However, further logistic regression analysis showed that the link between child psychological abuse and PNEAD was not significant when family functioning variables were entered into the equation. As a result, family dysfunction could account for the relationship between child psychological abuse and PNEAD.

2.5.3 Clinical Implications of Results

The results from this study highlight a number of key points for the clinical management of PNEAD and these include the following:

- Clinicians need to investigate whether patients have a history of abuse, in terms of physical, sexual and psychological experiences.
- Psychological disturbance can be a marker of abuse.
- History of abuse is likely to be associated with dysfunction in the family of origin.
- Family dysfunction may be a significant factor in understanding the development and perhaps maintenance of PNEAD.
- Individual psychological therapy and family therapy may therefore be important in treatment of people with PNEAD.

2.5.4 Summary

Findings from the current study indicate that abuse represents a common yet largely undisclosed experience. As a result, clinicians undertaking assessment should be mindful to sensitively question patients around such experiences. PNEAD is a complex problem requiring expert psychotherapeutic support and treatment.

CHAPTER 3. STUDY 2: THE ASSESSMENT OF IMPACT OF RECEIVING A DIAGNOSIS OF PNEAD

3.1 Introduction

There is a wealth of literature documenting that epilepsy has a negative impact on day – to-day living. A person with epilepsy faces uncertainty over the diagnosis of his condition, over whether and when seizures will occur, over the nature of the seizures and how best they can be controlled, and over whether or not they will, ultimately, remit (Baker 2001). The unpredictability of the nature and course of epilepsy is a key factor in the psychosocial handicaps it engenders for people who develop it. Another centrally defining aspect of epilepsy is its stigmatising nature. For centuries and across continents, epilepsy has been a condition with extremely negative connotations, and even now the label of ‘epilepsy’ is one many people whom develop seizures reject (Baker et al 1999). By contrast, there is very little evidence about either the immediate or longer-term consequences of diagnosis of PNEAD. While much of the research into PNEAD has focused on basic issues of diagnostic techniques and clinical characteristics of the condition, little attention has been paid to understanding its impact. In this chapter, the focus will be on the immediate impact of the diagnosis. The following chapter will focus on the longer term consequences of the disorder.

Because of the absence of serious physical disease, it might be expected that the consequences of PNEAD would be less severe than those of epilepsy. However, there are reasons to expect that the impact of a diagnosis of PNEAD could be even

greater than that of epilepsy. Patients may perceive the lack of a physical diagnosis as denying the reality of their problems or as indicating a mental health problem (Salmon et al, 1999). Indeed, diagnosis of PNEAD is typically followed by referral to psychiatric or psychological services, confirming a patient's fears about what the doctor thinks about their mental health. Even worse, the patient may think that the doctor suspects that they are deliberately presenting symptoms as a form of 'attention-seeking'. Moreover, patients are left with no satisfactory explanation for their symptoms. A further reason to expect more negative impact of PNEAD is that patients are likely to be dissatisfied with consultations that lead to diagnoses of non-physical disorders. In other unexplained disorders, it has been shown that dissatisfaction with the consultation predicts poorer prognosis (Hopkins, 1992). Indeed, a significant proportion of patients reject the diagnosis and seek further medical consultation in the search for a more satisfactory explanation for their symptoms (Peters et al, 1998).

3.2 Aim of study 2

To find out how patients react to the diagnosis of PNEAD compared with patients who receive a diagnosis of epilepsy.

3.3 Methodology

3.3.1 *Participants*

A total of 60 participants between the ages of 16 and 60 years were recruited into two groups. Each group contained 20 female and 10 male patients. Patients with PNEAD were matched in terms of age and gender with patients with epilepsy. Recruitment to the current study began in October 1998, and was completed in September 1999. New patients were recruited via the epilepsy clinic at the Walton Centre for Neurology. A consultant neurologist identified epilepsy and PNEAD subjects on the basis of EEG correlates and clinical evidence.

3.3.1.1. The Procedure for Patients

New patients were attending the epilepsy out patient clinic - the researcher having checked patient's age and gender from medical records. The researcher approached patients as they waited for their scheduled appointments. Patients were individually asked if they would participate in a follow up study, which required filling out a questionnaire whilst waiting to see their appointed consultant neurologist. Patients were informed that they would have to fill out another questionnaire after a 3-month period. Before the patient agreed to participate, s/he read the information sheet (Appendix 3.1). Patients were informed that non-participation in the study would not affect their treatment. Following agreement, participants then completed the questionnaire in the waiting area, with the researcher present for guidance. Participants spent approximately 45 minutes

completing the questionnaires (appendix 3.2), although a number spent approximately 60 minutes.

3.3.1.2. Refusals

A number of patients chose not to take part in the current study; 8 patients did not have sufficient time, 15 patients did not provide a reason for not participating, and 9 patients felt unable to participate having examined the questionnaire.

3.3.1.3. Three Months Follow up

Each patient was followed up at three months. Patients who met with a consultant at three months follow up were asked to fill out the study questionnaire following their appointment. For other subjects, each patient was written to and asked if they would, for the final time (Appendix 3.3), complete the necessary questionnaires. Questionnaires were sent out from the Neuropsychological Department at Walton Centre, Liverpool. A Clinical Psychologist signed the letters followed by up to two reminder letters which were sent to those patients who had not yet replied. A further copy of the study questionnaire was sent with each reminder. A stamped addressed envelope was once again provided at each mailing.

3.3.1.4. Non-responders at Follow-up

Three patients with epilepsy and one patient with PNEAD were excluded, as they failed to return their assessment questionnaires. One patient with epilepsy had moved out of the area and could not be contacted. As a result, 5 patients were excluded from subsequent analysis. Follow-up was completed for all remaining patients.

3.3.2 *Design of Questionnaires*

3.3.2.1 Socio-demographic Information

Questionnaire responses included patient's demographic details, with questions about patient's age, gender, marital status, and religion. For socio-economic information, questions asked about patients' current work status, and current employment: a) unskilled manual, b) skilled manual, c) office/shop work, d) skilled technical, e) professional/managerial positions, and f) those who are unemployed. Patients were asked to identify their education level i.e. whether they had; 1) O level, 2) A level, 3) University degree, 4) Trade/Technical qualification, 5) Professional qualification, 6) C.S.E, and 7) No formal qualifications.

3.4.2.2 Questionnaires

Features and Types of attacks

Patients were asked to describe their attacks e.g. a grand mal. Patients were asked how old they were when they had their first attack. In addition, patients were also asked to define over the past year how many attacks they had experienced (none, less than 1 per month, or one or more per month). Patients were asked whether they had any long-term health problems associated with their attacks, and if any family members experienced seizures. Patients were additionally asked to indicate whether they were currently taking any medication to control their attacks. Finally, patients were asked to state whether (and if so, how often) they had visited their GP in the past year.

The Illness Perception Questionnaire (IPQ)

The Illness Perception Questionnaire (IPQ) was developed to assess beliefs about illness. The IPQ is a theoretically derived measure comprising five components of illness representation described in Leventhal's self-regulation model (Weinman, 1996). The *Identity* component is concerned with patients' ideas about the nature of their condition i.e. associated symptoms. The *Illness Identity* scale comprises of 12 core symptoms, 10 of which were used in the current study. Patients were asked to indicate how frequently s/he experienced specific symptoms as part of her/his attacks on a 4 point scale ranging from 'All of the time' to 'Never'. Items from the four other scales are on a 5-point scale from 'Strongly Disagree' to

‘Strongly Agree’. The *Cause Items* component consists of patient’s ideas about the likely causes of their illness e.g. Diet played a major role in causing my attacks. The *Time-line* component concerns patients’ perception of the likely duration of their problems. The *Consequences* component reflects the patient’s beliefs about illness severity and impact on physical and psychological functioning. Finally, the *Control/Cure* component indicates patient’s beliefs with respect to how well their illness can be controlled or cured.

Scoring is as follows. (1) For the Illness Identity scale items endorsed as ‘occasionally’ or greater were summed, so that the total score ranged from 0 to 10. (2) For Time-line, Consequences and Control/Cure scales, items are arranged in a mixed order, and rated by the patient on a 5 point Likert scale ranging from ‘Strongly agree’ to ‘Strongly disagree’. Where necessary, items were reverse scored. Mean scores were calculated. (3) For the Cause Items scale an average score is not completed, as each response represents a specific causal belief. The test-retest reliability, for both the Control/Cure (0.68) and Consequences (0.68) scale, over a 3-month period were higher than the Illness Identity (0.34) and Time-line scales (0.51). Expected findings as patient’s perceptions of the Consequences and Control/Cure of their illness are less likely, over time, to change (Weinman et al 1996).

Symptom Beliefs Questionnaire

The symptom belief questionnaire was developed to measure patients’ beliefs about the cause of physical symptoms when attending their general practitioner

(Salmon et al 1996). The questionnaire has 71 items, each on a 3-point scale. Items from three scales i.e. Stress; Weak constitution and Concern were used in the current study in response to the following question 'whether it probably has or probably has not helped to cause your attack'. Patients were asked to tick one of the following responses 'Probably does', 'Don't know' or 'Probably does not'. For the Concern scale items asked whether the patient believed that s/he knew the cause of their attacks; whether the patients had thought about the cause; and whether the attacks were caused by longstanding factors.

Each questionnaire item ranged from 0 'Probably does not' to 2 'Probably does'. For each scale scores are found by summing all scale items, the higher score representing stronger beliefs. Cronbach Alpha estimated the internal consistency of the beliefs scales, 406 patients having completed the questionnaire. The alpha reliability coefficient was 0.47 for Concern, 0.54 for the Weak constitution, and 0.87 for the Stress scale.

The Short-Form-36 Health Survey (SF-36)

The SF-36 was derived from the work of the Rand Corporation during the 1970s. The SF-36 items were drawn from the original 245-item Medical Outcomes Questionnaire (Ware and Sherbourne 1992). The SF-36 was designed as a generic indicator of health status for use in evaluative studies of health policy. The SF-36 can be used as an outcome measure in clinical research and practice. The SF-36 measures both physical and psychological outcomes. The SF-36 includes multi-item scales to measure eight dimensions: *Physical Functioning* includes 10 items

to represent levels and kinds of limitations including lifting and carrying groceries, climbing stairs, bending, kneeling, and walking moderate distances. *General Health* includes 5 items to represent general health. *Bodily Pain* includes two questions. Question one relates to the intensity of bodily pain or discomfort. Question two measures the level of interference with normal activities due to pain. *Fatigue* measures energy or fatigue level. The *Mental Health* dimension measures anxiety, depression, loss of emotional control, and psychological wellbeing. *Social Functioning* measures the impact of physical ill health or emotional problems on social activities. *Role-Physical* includes 4 items and defines levels of role limitation due to physical health problems. *Role-Emotional Limitations* includes 3 items and defines role limitations due to emotional health problems. The SF-36 may be used in personal or telephone interviews. The SF-36 is self-administered and takes 5 to 10 minutes to complete.

Scoring transforms the answers of each question into scaled scores from 0 to 100 so that high values represent more favourable physical and psychological states. The formula is transformed scale = $(\text{actual score} - \text{lowest possible score}) / \text{possible raw score range} \times 100$. Alpha internal consistency coefficients for the scales have been reported (McDowell and Newell, 1996). Results showed that the alpha reliability for all scales exceeded 0.80, except for the social functioning scale (2 items) 0.76. Test retest correlations for the scales after a delay of six months ranged between 0.60 and 0.90, although for the pain dimension a test retest correlation of 0.43 was found (McDowell and Newell, 1996).

Seizure Severity Scale

Developed by Baker et al (1991) on the basis of clinical experience, the Seizure severity is often used by clinicians. The Seizure Severity Scale is subdivided into two parts: (1) Seizure Severity (Percept) including 8 items such as the absence or presence of warning signs, whether seizures occur in clusters or at random and whether they occur at a specific time of day or night e.g. How often have your attacks occurred at a particular time of day or night? (2) Seizure Severity (Ictal/Post-ictal) effects refers to manifestations of seizures and their immediate consequences and includes 11 items such as loss of consciousness and its duration, tongue-biting, etc e.g. when you recover from your attacks, how often do you find that you have wet yourself?

Patients are asked to tick the response that best describes their attacks. The individual items are rated on a four-point Likert scale where 1 is the least severe and 4 the most severe. The reliability of the Seizure Severity scale was assessed in two ways. Test-retest reliability was confirmed to be consistent in tests completed by 35 individuals, over a 2-3 week period. The coefficients were 0.79 for Percept and 0.8 for Ictal/Post-ictal. The internal consistency Cronbach's alpha scores for both subscales (completed by 94 individuals) were 0.69 for Percept and 0.85 for Ictal/Post-ictal (Baker et. al 1998). The construct validity of the Seizure Severity scale has been assessed in 2 ways. First, a one-way ANOVA was used to compute differences between 94 individuals each of those had a single seizure type. Using this procedure, the Seizure Severity (Ictal/Post-ictal) was capable of discriminating between seizure types although the Seizure Severity (Percept) was not. In

addition, multiple regression analysis demonstrated that both the Percept and Ictal/Post-ictal subscales represented significant independent predictors of anxiety, self-esteem and mastery.

Impact of Epilepsy Scale

The Impact of Epilepsy Measure was devised by Jacoby et al (1993) to measure the impact of epilepsy upon a number of different aspects of daily life. The scale covers the most important areas of everyday life, e.g. relationship with spouse or partner, friends, social life, employment, health, self-esteem, plans for the future and standard of living. Patients are asked to respond to each item by stating how much they thought a particular aspect of their life was affected by their attacks.

Responses ranged from 'not at all' to 'a lot' and scored 1 to 4 respectively. A total impact score was calculated by summing all item scores. The higher the total score the greater the perceived impact of the attacks. The internal consistency alpha score for the whole scale was 0.65. The validity of the Impact scale has been assessed by multiple regression analysis demonstrating that Impact was a significant predictor of self-esteem, life-fulfillment and perceived quality of life.

Consultation Satisfaction

The satisfaction questionnaire was developed by Baker (1990) to evaluate degree of satisfaction with those areas of care that are of concern to patients. The questionnaire was intended to be brief, understandable and easy to complete. Four

scales comprise the Consultation Satisfaction Questionnaire as follows: (1) *General Satisfaction (3 items)*; (2) *Professional Care (7 items)*; (3) *Depth of Relationship (5 items)*; and (4) *Perceived Length of Consultation (3 questions)*. *Overall Consultation Satisfaction* is computed by adding each of the 18 items together. Each of eighteen statements was followed by five possible answers ranging from 5 'Strongly agree' to 1 'Strongly disagree'. Some questions are worded positively and some negatively. As a result the question direction must be then taken into account.

A score of 1 indicates dissatisfaction and 5 satisfaction. Scores are converted to a scale, with a maximum score of 100 for each component, the higher score equating to greater satisfaction. Test-retest reliability has been undertaken; one hundred and thirty one patients were mailed both questionnaires twice, 2-weeks apart. The questionnaires have excellent levels of test reliability, 0.91 for the General Satisfaction, 0.95 for the Professional Care, 0.88 for the Depth of Relationship and 0.90 for the Perceived Length of Consultation.

The Stigma Scale

The scale was developed to measure patient perceptions of the stigma of another neurological condition i.e. stroke, and reworded for epilepsy (Jacoby, 1994). The stigma scale contained 3 items that examine how patients feel about their seizures and whether other people (1) were uncomfortable with them, (2) treated them as inferior, and (3) preferred to avoid them.

For each item patients answered Yes = 1 if they agreed or No = 0 if they disagreed. The overall score comprised the sum of positive responses, so that the higher the score the greater the sense of stigma. The internal consistency of the Stigma scale was examined using Cronbach's alpha and found to be satisfactory - the alpha score was 0.72.

Attitude toward Diagnosis

There is no scale available to assess patient's reaction to diagnosis. Therefore, a scale was created exploring both patients' and their families' views of the diagnosis provided. The questionnaire comprises six questions, each on a 5-point scale. Respondents answered the following questions about their families' attitudes: what is your family's view of the doctor's diagnosis; does your family believe that more tests should be carried out to check the diagnosis; and does your family believe that a second opinion is needed? Further questions examined patient attitudes towards diagnosis: what is your view of the doctor's diagnosis; do you believe that more tests should be carried out to check the diagnosis; and do you believe that a second opinion is needed?

Each question was given scores ranging from 4 'Certainly not' to 0 'Certainly correct', higher scores reflecting disagreement with the doctor's diagnosis (questions 1 and 4), and for question (2, 3, 5, and 6) high scores reflecting dissatisfaction or concern with the diagnosis provided.

Cohesion (FES)

The Family Environmental Scale (FES) by Moos and Moos (1981) was developed (comprising ten subscales) to measure the social and environmental characteristics of different family types. In the current study Cohesion (the degree of commitment, help, and support family members provide for one another) was measured. Respondents were asked to read all statements about their origin family and to decide whether it was 'true', 'mostly true', 'mostly false' or 'false'. On each item the possible scores ranged from 0 to 9.

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) has been found to be a reliable instrument for identifying states of depression and anxiety across different groups of non-psychiatric hospital patients. The scale consists of 14 items; seven items measure anxiety e.g. I can sit at ease and feel relaxed, while seven items measure depression e.g. I still enjoy the thing I used to enjoy. Overall anxiety and depression are both rated on a four-point scale; individual items are scored from 0-3 or 3-0, depending on the item wording. Total scores for each subscale are calculated. Respondents who score 11 and above for either anxiety or depression subscales are identified as a case, i.e. as significantly disabled.

3.3.3 Statistical Analysis

Statistical analyses were performed with the aid of SPSS 10.0 for windows. Parametric statistics were chosen for those continuous variables where tests of normality indicated that they approximated a normal distribution. Non-parametric tests were also chosen for this study following tests of normality, which indicated that some of the data were not normally distributed.

The education, marital status, employment status, and religion of patients with PNEAD *vs* epilepsy were compared by chi-square. Chi-square tests also examined associations between the two diagnostic groups' reports of clinical features i.e. long-term health problems, relatives with attacks, visiting the GP, and receiving medication. T-test was used to examine differences between PNEAD *vs* epilepsy on patient satisfaction with the consultation, and attack frequency.

Parametric statistics

Repeated measures analysis of variance contrasted PNEAD and epilepsy groups and compared (pre *vs* post) diagnosis on given dependent variables. A significant F-ratio for interaction effects was interpreted by the use of post hoc t-tests. Age, education, and gender were not entered as covariates in this analysis as they did not change over the three-month period.

New variables were computed using the formula (pre diagnosis – post diagnosis) leading to difference scores to indicate change over time. Mann-Whitney tests were used to check for differences between PNEAD and epilepsy patients. For each variable that showed a significant difference, the Wilcoxon non-parametric test was used to compare pre v post diagnosis scores for PNEAD and epilepsy groups. Then Mann-Whitney tests were used to compare PNEAD vs epilepsy groups pre and post diagnosis.

3.4 Results

3.4.1 Sample

The patient sample is described in detail in Table 3.1. There were 30 patients in each of the PNEAD and epilepsy groups. Groups were of similar age (Mean = 31.97). For PNEAD and epilepsy patients, gender was matched, the majority of patients being female (female 20/30 v. male 10/30 in each group). Patients were typically single or married, and unemployed. The majority of patients in both epilepsy and PNEAD groups were not employed. No significant differences between clinical groups in terms of employment status were found.

The majority of subjects reported having few qualifications. For the PNEAD group, the number of patients who reported having O level, A level, and a university degree was lower than that of the epilepsy patients. However, overall

there were no significant differences between PNEAD and epilepsy patients in terms of the number of patients with no educational qualifications. There were no significant differences between the groups in terms of religion description: patients in PNEAD and epilepsy groups were typically Protestant or Catholic.

Table 3.1:**Demographic Data in Each Diagnostic Group.**

	PNEAD N=30	Epilepsy N=30	χ^2	p
Gender				
Male	10	10		
Female	20	20		
Marital status				
Single	11	11		
Divorce	4	2		
Widowed	1	0		
Married/living with a partner	14	17	1.96	.58
Employment				
Employee	8	12		
Unemployed	18	10		
Self employed	1	2		
Housewife	2	2		
Retired	1	3		
Student	0	1	5.42	.36
Job				
No job	22	14		
Unskilled	4	10		
Skilled	0	1		
Shop-work	4	3		
Professional qualification	0	2	7.50	.11
Education				
O level	13	24	8.53	.01
A level	8	16	4.44	.04
University	3	9	3.75	.05
Trade/Technical qualification.	6	7	.10	.75
Professional qualification	2	7	3.27	.07
CSE	7	12	1.93	.16
No formal education	9	5	1.49	.22
Religion				
Church of England/Protestant	20	16		
Catholic	8	10		
None	2	3		
Other	0	1	1.87	.60

3.4.2 Comparisons between diagnostic groups

3.4.2.1 Differences between Diagnostic Groups on Clinical Features of Attacks

There were no significant differences between PNEAD v epilepsy groups concerning long-term health problems, and whether any relative was also reporting attacks. Differences between the diagnostic groups on attack descriptions were found. Epilepsy patients were more likely to report attacks with a trance-like state, of falling with brief loss of consciousness, and with brief jerks of the arms and body when compared with PNEAD patients. No other significant differences between the two groups were found, see table (3.2).

Table 3.2:

The Differences Between PNEAD vs Epilepsy Groups on Features of Attacks and Types of Attacks

	PNEAD N=30	Epilepsy N=30	χ^2	p
Features of Attacks				
Long-term health problems	8	10	.31	.57
Family members with attacks	7	14	3.59	.06
Types of Attacks				
Generalized seizures	13	20	3.30	.07
Absence seizures	11	14	.62	.43
Attacks with a trance-like state	3	14	9.93	.01
Attacks of falling with brief loss of consciousness	6	15	5.93	.02
Brief jerks of the arms and body	3	11	5.96	.02

3.4.2.2 Differences between Diagnostic Groups on Medication

Table 23 indicates by diagnostic group, those patients who were receiving anti-epileptic drugs pre and post diagnosis. There were no differences between PNEAD and epilepsy patients receiving anti-epileptic drugs before diagnosis ($\chi^2=0.07$, $p> 0.05$). However, significantly fewer PNEAD patients received anti-epileptic drugs after diagnosis than epilepsy patients ($\chi^2=24.31$, $p< 0.001$). There were no significant differences between diagnostic groups in terms of the average frequency of attacks during the previous 1-year (Table 3.4).

Table 3.3:

The Differences Between PNEAD vs Epilepsy on Receiving Medication Pre and Post diagnosis.

Pre.

	YES	NO
PNEAD (N=30)	16	14
Epilepsy (N=30)	17	13
χ^2	.02	-

Post

	YES	NO
PNEAD (N=30)	4	26
Epilepsy (N=30)	23	7
χ^2	24.31***	-

*** < .001; ** < .01; * < .05

Table 3.4:

Frequency of Attack for PNEAD and Epilepsy

Attack frequency	PNEAD N=30	Epilepsy N=30
None in past year	7	3
Less than one a month	11	8
One or more a month	12	19

**3.4.2.3 Differences between Diagnostic Groups on Patient Satisfaction
with Consultation**

Table 3.5 shows the mean consultation satisfaction scores for PNEAD and patients with epilepsy. Significant differences between diagnostic groups were found. Patients with PNEAD reported less General Satisfaction than patients with epilepsy. There were no differences between groups in satisfaction regarding Depth of Relationship, quality of Professional Care, or in Perceived Length of Consultation with the doctor. In terms of Overall Consultation Satisfaction, PNEAD patients were significantly less satisfied than epilepsy patients.

Table 3.5:

Group Means and Std. Errors of Patient Satisfaction with the Consultation.

High scores indicate greater satisfaction.

	PNEAD N=30 Mean (Std. Error)	Epilepsy N=30 Mean (Std. Error)	t
Consultation Satisfaction			
General Satisfaction	8.30 (.52)	10.57 (.52)	3.47**
Professional Care	22.70 (1.32)	24.30 (1.17)	1.39
Depth of Relationship	15.10 (.67)	17.30 (.82)	1.78
Perceived Length of Consultation	8.87 (.59)	9.30 (.50)	1.39
Overall Consultation Satisfaction	55.57 (2.10)	61.47 (2.27)	2.49*

*** < .001; ** < .01; * < .05

3.4.2.4 Comparisons between Diagnostic Groups on Psychological Variables

Parametric analysis

Repeated measures ANOVA compared diagnostic groups (PNEAD v. epilepsy) across time (pre v. post diagnosis) for normally distributed variables: Anxiety and Depression (HAD); the Illness Perception Questionnaire (Illness Identity, Consequences, Time-line, and Control/Cure); the Seizure Severity (Percept) and Seizure Severity (Ictal/Post-ictal); Impact of Epilepsy Scale; and one Family Environmental Scale (Cohesion) (Table 3.6).

The HAD

No significant effects over time were found for Anxiety or Depression (Table 3.6.A and B). Significant overall differences between PNEAD vs epilepsy group were found. Post hoc tests indicate that PNEAD patients reported significantly higher levels of Anxiety ($p < 0.001$), and Depression ($p < 0.001$) than epilepsy patients. Non-significant interactions were found for both Anxiety and Depression.

The Illness Perception Questionnaire (IPQ)

For the Illness Identity scale main effect for diagnostic group was found (Table 3.6.C). PNEAD patients had stronger Illness Identity than epilepsy patients ($p < 0.05$). There were no differences between the diagnostic groups in Time-line (Table 26.D), belief in serious Consequences (Table 3.6.E), or perception that attacks were Controllable (Table 3.6.F). There were significant changes over time for the Illness Identity and consequences scales. Patients reported higher levels of Illness Identity post diagnosis than pre diagnosis ($p < 0.05$), and lower levels of concern regarding the serious Consequences of their attacks post diagnosis ($p < 0.05$).

Seizure Severity Scale

Across both groups Seizure Severity (Percept) ($p < 0.05$) (Table 3.6.G) and Seizure Severity (Ictal/Post-ictal) ($p < 0.01$) (Table 26.H) were significantly lower

at follow-up. Furthermore there were significant group differences, PNEAD patients scored lower than epilepsy patients on the Seizure Severity (Percept) ($p < 0.05$) and Seizure Severity (Ictal/Post-ictal) subscales ($p < 0.001$). Interactions were not significant.

The Impact of Epilepsy

No significant change over time was found for the perceived Impact of Epilepsy scale (Table 3.6.I). PNEAD patients generally reported a greater Impact of illness than epilepsy patients ($p < 0.001$). A significant interaction over time across groups was found. PNEAD patients scored higher post than pre diagnosis in terms of the perceived Impact of Epilepsy Scale, whereas epilepsy patients scored lower post than pre diagnosis. PNEAD patients scored higher than epilepsy patients both before and after diagnosis ($p < 0.01$).

Cohesion (FES)

No changes over time were found for Cohesion subscale (Table 3.6.L). PNEAD patients reported generally lower levels of Cohesion than epilepsy patients throughout ($p < .01$). No significant interaction was found.

Table 3.6:

Mean (Std. Error) over Time for PNEAD and Epilepsy Groups for HAD, Illness Perception, Seizure Severity, Perceived Impact of Epilepsy and Cohesion Measures.

***< .001, **< .01, *< .05

Table 3.6.A:

F_{1,58}: Group 28.61*; Time .37; Time x Group .54**

Anxiety	PNEAD	Epilepsy	Total
Pre	9.27 (.97)	3.87 (.97)	6.57(.69)
Post	10.30 (.95)	3.77 (.95)	7.03(.67)
Overall	9.78(.79)	3.82(.79)	-

Table 3.6.B:

F_{1,58}: Group 32.42*; Time .07; Time x Group 2.62**

Depression	PNEAD	Epilepsy	Total
Pre	11.20 (.90)	6.20 (.90)	8.70(.64)
Post	12.03 (.83)	5.03 (.83)	8.33(.59)
Overall	11.62(.75)	5.62(.75)	-

Table 3.6.C:

F_{1,58}: Group 4.99*; Time 5.13*; Time x Group 3.63

Illness Identity	PNEAD	Epilepsy	Total
Pre	4.27 (.54)	4.20 (.54)	4.23 (.38)
Post	6.60 (.53)	4.40 (.53)	5.50 (.38)
Overall	5.43 (.36)	4.30 (.36)	-

Table 3.6.D:

F_{1,58}: Group .08; Time 2.14; Time x Group .03

Time-line	PNEAD	Epilepsy	Total
Pre	2.76 (.15)	2.79 (.15)	2.78 (.11)
Post	2.94 (.15)	3.01 (.15)	2.98 (.11)
Overall	2.85 (.11)	2.90 (.11)	

Table 3.6.E:

F_{1,58}: Group .06; Time 4.81*; Time x Group 1.46

Consequences	PNEAD	Epilepsy	Total
Pre	2.82 (.15)	2.95 (.15)	2.89 (.11)
Post	2.68 (.13)	2.47 (.13)	2.58 (.09)
Overall	2.75 (.10)	2.71 (.10)	

Table 3.6.F:

F_{1,58}: Group .03; Time 1.59; Time x Group 1.08

Control/cure	PNEAD	Epilepsy	Total
Pre	2.64 (.14)	2.80 (.14)	2.79 (.12)
Post	2.94 (.14)	2.83 (.14)	2.81 (.10)
Overall	2.79 (.10)	2.81 (.10)	

Table 3.6.G:

F_{1,58}: Group 4.99*; Time 20.53*; Time x Group .14**

Seizure Severity (Percept)	PNEAD	Epilepsy	Total
Pre	23.80 (.79)	25.93 (.80)	24.87 (.56)
Post	20.33 (.86)	21.83 (.85)	21.08 (.61)
Overall	22.07 (.58)	23.88 (.58)	

Table 3.6.H:

F_{1,58}: Group 36.62*; Time 7.51**; Time x Group .04**

Seizure Severity (Ictal/Post-ictal)	PNEAD	Epilepsy	Total
Pre	19.33 (1.10)	27.07 (1.10)	23.20 (.78)
Post	16.20 (1.29)	24.37 (1.29)	20.28 (.91)
Overall	17.77 (.93)	25.72 (.93)	

Table 3.6.I:

F_{1,58}: Group 56.82*; Time .15; Time x Group 7.92****

Impact	PNEAD	Epilepsy	Total
Pre	19.23 (1.54)	11.30 (1.54)	15.27 (1.09)
Post	23.27 (1.25)	8.23 (1.25)	15.75 (.89)
Overall	21.25 (1.08)	9.77 (1.08)	

Table 3.6.L:

F_{1,58}: Group 10.60; Time .25; Time x Group .55**

Cohesion	PNEAD	Epilepsy	Total
Pre	5.53 (.43)	7.47 (.43)	6.50 (30)
Post	5.60 (.41)	7.13 (.41)	6.37 (.29)
Overall	5.57 (.38)	7.30 (.38)	

Non-parametric analysis

For the Illness Perception Questionnaire (IPQ) Cause Items, Stigma Scale and Beliefs about Physical Symptoms, the SF-36 Survey and Attitudes to diagnosis, non-parametric tests were chosen as the data was not normally distributed. To assess whether there were significant differences over time, between PNEAD and epilepsy groups, variables were transformed to form differences (i.e. pre diagnosis score– post diagnosis score). Mann-Whitney U test was performed to compare the difference scores between groups. The Wilcoxon Signed Ranks Test was then used to compare pre vs post scores within each diagnostic group. Mann-Whitney U was then used to compare groups at each time. Summary statistics are shown in table 3.7.

The IPQ (Cause Items)

The diagnostic groups changed differently regarding a genetic explanation (Table 3.7). Epilepsy patients' belief in a Genetic cause increased post diagnosis ($z=2.80$, $p< 0.01$), whereas there was no significant change for PNEAD patients. There were significant differences post diagnosis between diagnostic groups regarding a Genetic cause. Epilepsy patients reported a significantly higher preference in favour of a Genetic cause than PNEAD patients ($U=262.50$, $p< 0.01$). There were no significant differences between groups pre diagnosis.

Stigma Scale

No significant differences in Stigma were found.

Symptom Beliefs Questionnaire

There were different changes between groups concerning belief in a Weak-constitution explanation (Table 3.7). Epilepsy patient attributions of a Weak-constitution explanation significantly decreased ($z=2.36$, $p< 0.05$), whereas those of PNEAD patients did not change (Wilcoxon test non significant). Epilepsy patients favoured a Weak-constitution explanation when compared with PNEAD patients pre diagnosis ($U= 273.00$, $p< 0.01$); there were no significant differences between diagnostic groups post diagnosis.

The Short-Form-36 Health Survey

Only one SF-36 scale, Social Functioning, changed differently between PNEAD and epilepsy groups (Table 3.7, also see Figures 3.1; 3.2; 3.3). For patients with Epilepsy Social Functioning increased significantly. ($z=4.73$, $p<0.001$), whereas patients with PNEAD did not change (Wilcoxon test non significant). Further Mann-Whitney tests showed that there was no significant differences pre or post diagnosis between diagnostic groups.

Attitude toward Diagnosis

There were significant differences between groups in the way they viewed their diagnosis (immediately post diagnosis vs 3 months post diagnosis). Epilepsy Patients' opinion of their diagnosis at 3 months decreased significantly ($z=3.19$, $p<0.001$), whereas patients with PNEAD did not change (Wilcoxon test non significant). PNEAD patients were more satisfied with their diagnosis 3 months post diagnosis when compared with epilepsy patients. There were no significant differences immediately post-diagnosis between groups regarding views of their diagnosis. The groups differed in terms of their belief in the need for more tests (Table 3.7 a and b). Patients with PNEAD did not change their belief (Wilcoxon test non significant), whereas epilepsy patients belief at 3 months decreased significantly ($z=3.64$, $p<0.001$). three months post-diagnosis, patients with PNEAD believed that further tests were required when compared with patients with epilepsy ($U=209.00$, $p<0.001$). Further Mann-Whitney tests revealed that there was no significant difference between diagnostic groups immediately post diagnosis.

Table 3.7 a:

Mean, Standard Error, and Median of Variables for which Non-parametric Statistic were used: Cause Items (IPQ), Stigma, Symptoms Beliefs, SF-36 and Attitude Toward Diagnosis. Values Shown are for Pre and Post Diagnosis, and the Difference Scores, for PNEAD and Epilepsy.

	PNEAD		PNEAD		PNEAD		Epilepsy		Epilepsy		U	p		
	Pre diagnosis Mean (S.E.)	Median	Post diagnosis Mean (S.E.)	Median	Difference(pre-post) Mean (S.E.)	Median	Pre diagnosis Mean (S.E.)	Median	Post diagnosis Mean (S.E.)	Median				
Cause items (IPQ)														
Germes	1.80 (.17)	2.00	1.30 (.11)	1.00	.50 (.19)	.00	2.00 (.18)	2.00	1.97 (.13)	2.00	.03 (.18)	.00	346.00	.09
Diet	1.93 (.19)	2.00	1.60 (.16)	1.00	.33 (.15)	.00	1.97 (.19)	2.00	2.00 (.13)	2.00	-.03 (.24)	.00	346.00	.10
Pollution	1.63 (.14)	1.00	1.73 (.15)	2.00	-.10 (.16)	.00	1.70 (.15)	1.50	2.03 (.17)	2.00	-.33 (.23)	.00	414.00	.57
Genetic	1.83 (.15)	2.00	1.73 (.15)	2.00	.10 (.17)	.00	1.73 (.20)	1.00	2.77 (.27)	2.50	-1.03 (.32)	-.50	278.00	.01
Chance	2.97 (.24)	3.00	2.80 (.28)	2.50	.17 (.27)	.00	3.07 (.24)	3.00	2.57 (.20)	2.00	.50 (.27)	.00	411.00	.55
Stress	3.27 (.26)	3.50	3.90 (.24)	4.00	-.63 (.24)	.00	3.07 (.25)	3.00	3.00 (.24)	3.00	6.67 (.27)	.00	360.50	.17
My behaviour	1.93 (.20)	2.00	2.87 (.29)	3.00	-.93 (.25)	.00	2.23 (.20)	2.00	2.97 (.26)	3.00	-.73 (.26)	-1.00	433.50	.92
Others' behaviour	2.10 (.23)	2.00	2.73 (.28)	3.00	-.63 (.30)	.50	2.53 (.22)	2.50	2.73 (.23)	3.00	-.20 (.29)	.00	372	.23
My state of mind	2.17 (.21)	2.00	2.97 (.26)	3.00	-.80 (.31)	1.00	2.80 (.24)	3.00	2.87 (.26)	3.00	-.07 (.29)	.00	325.00	.06
Stigma	1.57 (.24)	1.50	1.47 (.23)	1.50	.10 (.24)	.00	2.13 (.18)	2.00	2.33 (.18)	3.00	-.20 (.19)	.00	376.000	.23
Symptom Beliefs														
Stress	9.13 (.98)	10.00	8.93 (1.01)	10.00	.20 (1.02)	.50	7.33 (.86)	7.00	5.20 (.99)	3.00	2.13 (1.19)	2.00	376.00	.27
Weak-constitution	1.80 (.27)	2.00	2.13 (.35)	2.00	-.33 (.42)	.00	3.10(.35)	3.00	1.70(.31)	1.50	1.40(.51)	1.00	307.50	.03
Concern	3.03 (.31)	3.00	3.03 (.39)	3.00	.00 (.41)	.00	3.13 (.35)	3.00	2.40 (.36)	2.00	.73 (.46)	1.00	363.00	.19

Table 3.7 b

	PNEAD Pre diagnosis Mean (S.E.) Median		PNEAD Post diagnosis Mean (S.E.) Median		PNEAD Difference(pre-post) Mean (S.E.) Median		Epilepsy Pre diagnosis Mean (S.E.) Median		Epilepsy Post diagnosis Mean (S.E.) Median		Epilepsy Difference(pre-post) Mean (S.E.) Median		U	P
SF-36 Survey														
General Health	29.33 (4.20)	25.00	24.17 (3.56)	20.00	5.17 (4.60)	5.00	51.50 (3.50)	50.00	51.00 (3.04)	55.00	.50 (4.69)	.00	365.50	.21
Physical Function	77.50 (4.66)	90.00	61.67 (6.04)	75.00	15.83 (5.99)	17.50	75.17 (5.17)	92.50	75.50 (5.30)	82.50	-.33 (7.59)	.00	334.00	.09
Role-Physical	55.83 (8.10)	75.00	56.67 (6.88)	62.50	-.83 (5.68)	.00	48.33 (6.88)	50.00	67.50 (5.64)	75.00	-19.17 (9.02)	-25.00	333.50	.08
Role-Emotional Limitations	63.33(8.20)	100.00	50.00 (7.95)	33.33	13.33 (9.13)	.00	58.89 (6.91)	66.67	73.33 (6.47)	100.00	-14.44 (8.41)	.00	326.00	.06
Social Functioning	71.67 (6.54)	75.00	67.50 (6.36)	75.00	4.17 (8.31)	.00	59.17 (5.93)	75.00	78.33 (4.75)	87.50	-19.17 (8.01)	-25.00	316.50	.04
Bodily Pain	75.56 (5.62)	94.44	71.49 (5.58)	77.78	4.07 (6.25)	.00	69.63 (5.22)	72.22	58.52 (5.81)	55.56	11.11 (8.66)	.00	436.00	.84
Mental Health	52.13 (2.78)	54.00	51.07 (4.74)	52.00	1.07 (5.44)	6.00	22.00 (3.43)	20.00	22.53 (3.27)	20.00	-.53 (4.23)	.00	431.00	.78
Fatigue	47.50 (4.06)	50.00	47.67 (5.43)	42.50	-1.17 (7.31)	-2.50	36.00 (4.42)	32.50	32.00 (4.55)	35.00	4.00 (6.47)	5.00	434.50	.82
Attitude Toward Diagnosis*														
Family's view of the incorrectness of the diagnosis	2.87 (.21)	3.00	1.93 (.22)	2.00	.93 (.34)	1.00	2.97 (.14)	3.00	.16 (.27)	1.00	1.30 (.32)	2.00	406.50	.51
Family's belief that more tests needed	1.93 (.28)	1.50	1.33 (.21)	1.00	.60 (.41)	1.00	2.07 (.26)	2.00	.83 (.24)	.00	1.23 (.38)	2.00	372.00	.24
Family's belief that a second opinion is needed	1.17 (.26)	1.00	.67 (.17)	.00	.50 (.31)	.00	1.23 (.23)	1.00	.43(.16)	.00	.80(.28)	.50	377.00	.26
Patient's view of the incorrectness of the diagnosis	2.73 (.22)	3.00	2.87 (.22)	3.00	-.13 (.29)	.00	3.10 (.16)	3.00	1.90 (.23)	2.00	1.20 (.30)	1.00	252.00	.01
Patient's belief that more tests needed	1.80 (.27)	2.00	1.73(.19)	2.00	.07 (.33)	.00	2.33(.26)	3.00	.70 (.20)	.00	1.63(.31)	2.00	235.00	.001
Patient's belief that a second opinion is needed	1.27 (.24)	1.00	.97 (.22)	1.00	.30 (.33)	.00	1.23 (.24)	1.00	.23 (.11)	.00	1.00 (.22)	1.00	357.00	.15

* These items are completed immediately following diagnosis

Figure 3.1: Mean Difference (Pre - Post Diagnosis) for PNEAD and Epilepsy Groups on SF-36 Scores.

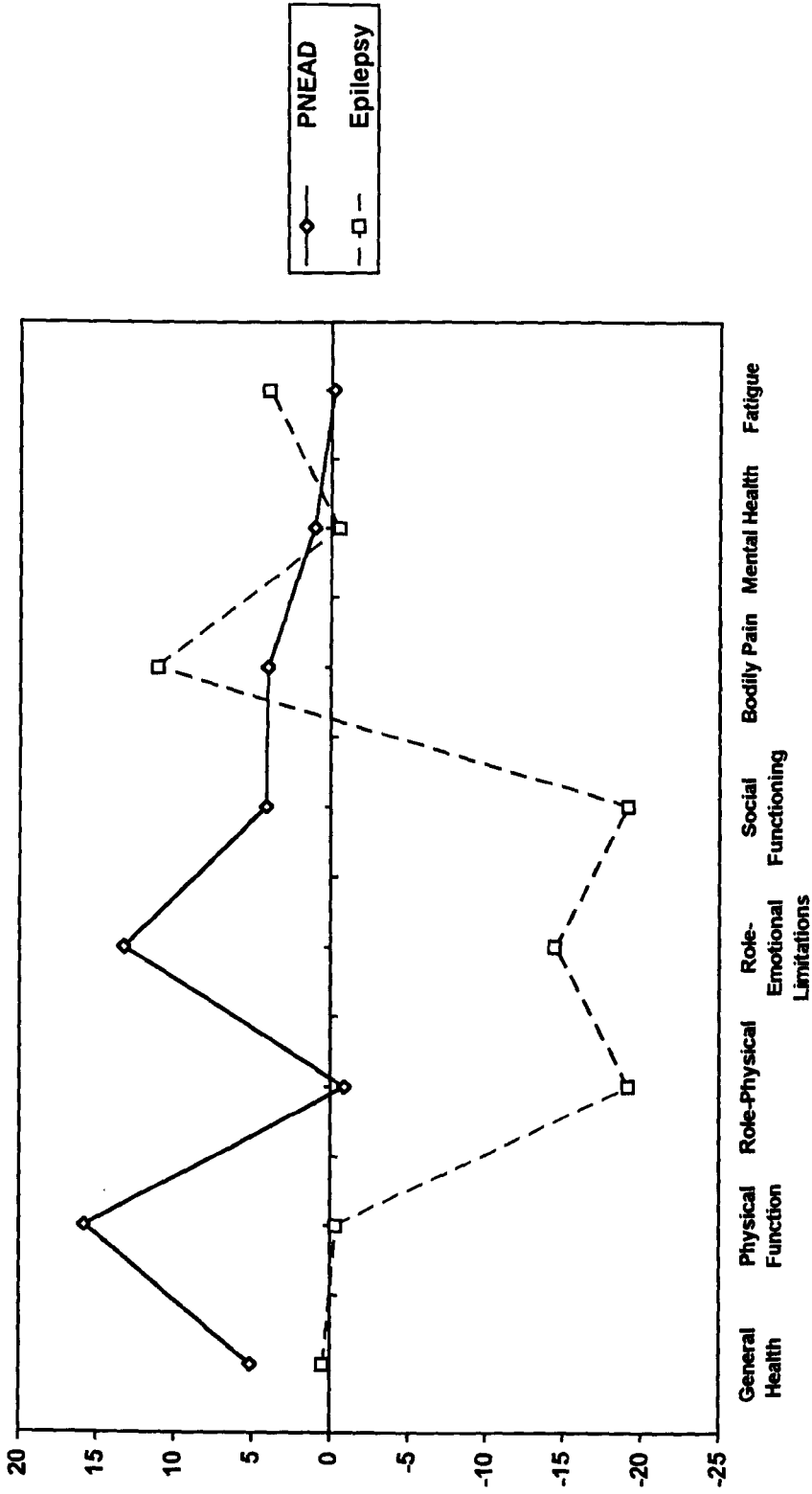


Figure 3.2: Mean Scores on Sf -36. Comparison of PNEAD vs Epilepsy - Before Diagnosis

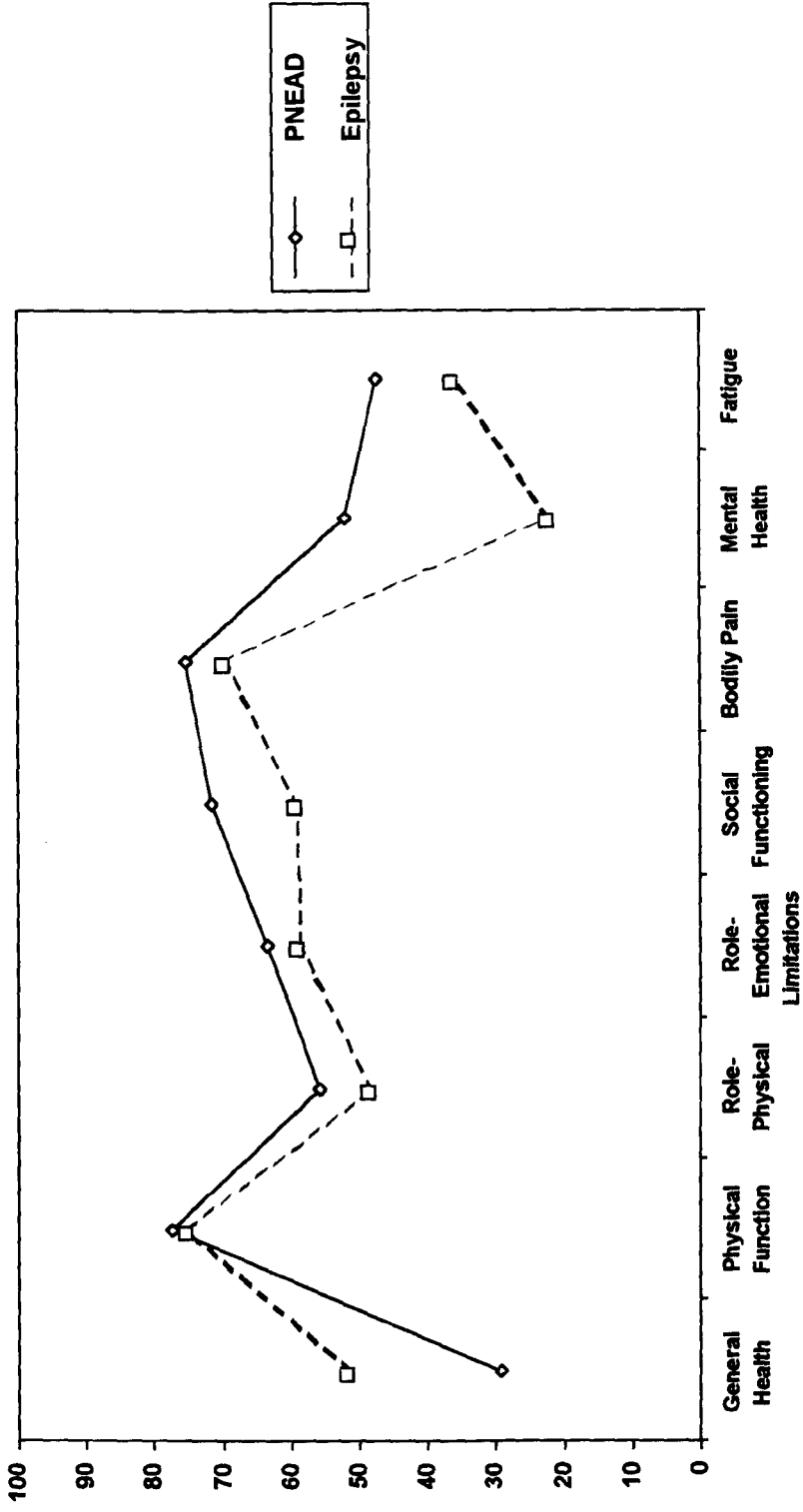
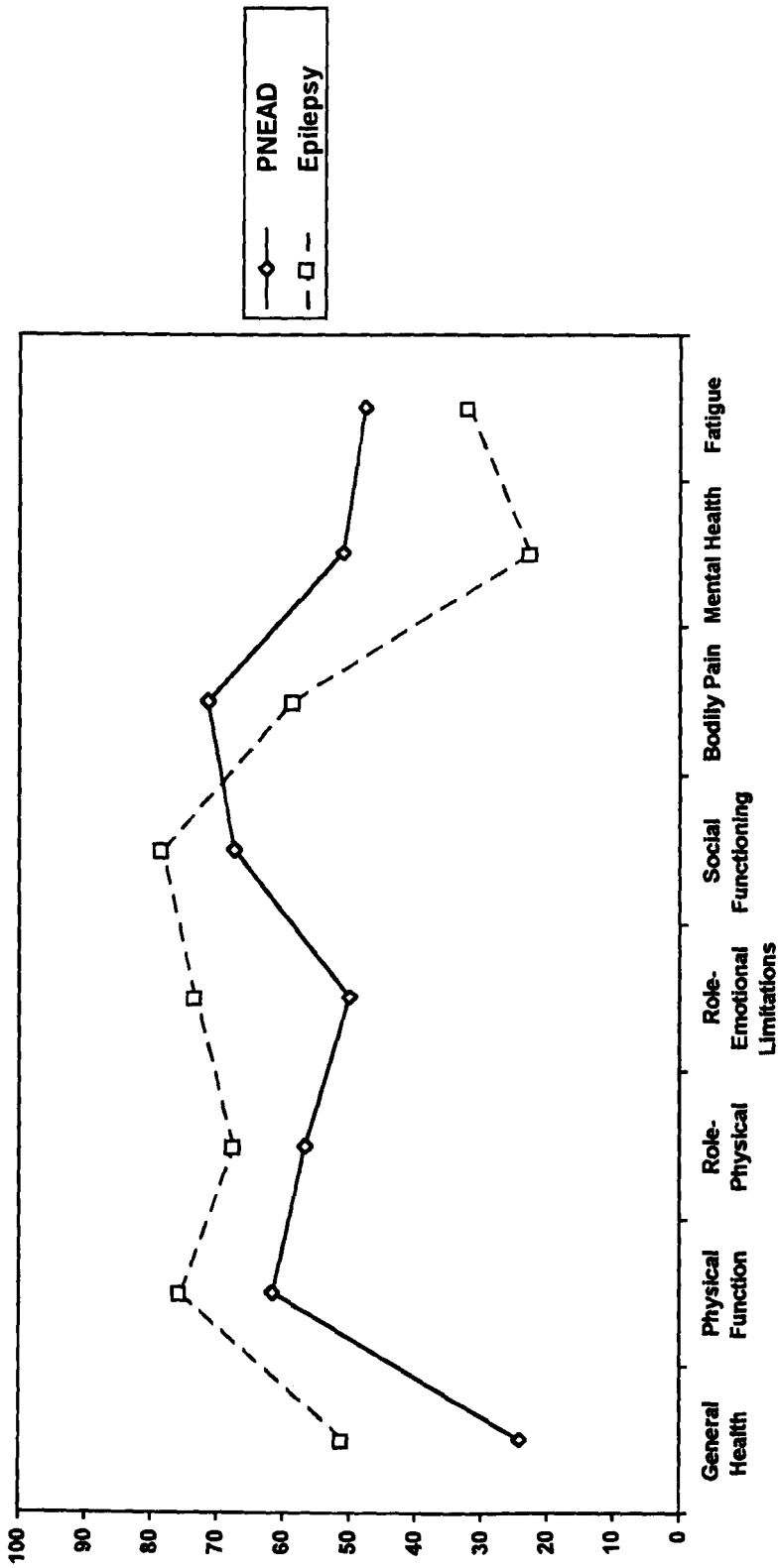


Figure 3.3: Mean Scores on SF-36. Comparison of PNEAD vs Epilepsy - After Diagnosis



3.5 Discussion

3.5.1 *Strengths of this study*

- This is the first study to the author's knowledge that has attempted to document the immediate impact of a diagnosis of PNEAD.
- Diagnosis of PNEAD was made by a consultant neurologist using EEG and, where necessary, video-ambulatory monitoring.
- PNEAD patients were matched with a comparison group of patients with epilepsy.
- There was a high level of compliance with the study and follow-up was successful in virtually all cases.
- Assessment included questionnaires that measured patients' views of the consultation, the disease and their lives.

3.5.2 *Main findings*

3.5.2.1 Attacks and Medication

Each group reported a similar frequency of attacks. However, as expected, the patients' description of seizures differed somewhat between PNEAD and epilepsy. In

particular, PNEAD patients were more likely to report generalised than partial seizures. Before diagnosis, more than half of both PNEAD and epilepsy groups were taking anti-epileptic medication. Again as would be expected, diagnosis of PNEAD was followed by almost all patients being taken off this medication.

Both measures of seizure severity decreased by 3 months and the groups did not differ in the way that severity changed. Although impact of illness was greater in PNEAD than epilepsy at both times, impact decreased at 3 months in epilepsy, but increased in PNEAD. Therefore the difference between the groups was greater 3 months after diagnosis than it was before diagnosis.

3.5.2.2 Satisfaction with Consultation

PNEAD patients were generally less satisfied with their consultation than were epilepsy patients. However, there were no differences in satisfaction with Depth of Relationship with the doctor, perceived Length of Consultation, or Quality of Care. Therefore PNEAD patients may have been less satisfied because of the diagnosis they received. However, analysis of the Attitudes Towards Diagnosis scale found that the groups did not differ in how much they believed that the diagnosis was correct immediately after diagnosis. Three months later, epilepsy patients had decreased in their belief in its correctness, but PNEAD patients had not changed.

3.5.2.3 Psychosocial Function

Anxiety, Depression and family Cohesion did not change following the diagnosis. From the SF-36, the only scale to show a different change between PNEAD and epilepsy groups was Social Functioning. This increased in epilepsy patients, but did not change in PNEAD.

3.5.2.4 Beliefs

Although both groups increased in Illness Identity, and decreased in concern about serious Consequences by 3 months, the groups did not differ on these, or beliefs in how long the illness would last or in how Controllable it was. Whereas epilepsy patients decreased in their belief that a Weak-constitution caused their symptoms (they had stronger beliefs than PNEAD in a Weak-constitution pre-diagnosis), PNEAD patients did not change in this belief. Only one causal belief changed differently between the two groups. Belief in Genetic cause increased in epilepsy patients but did not change in PNEAD patients.

3.5.3 *Clinical implications*

- As is well known, this study confirms that PNEAD patients are likely to show generalised seizures, whereas people with epilepsy are likely to have both generalised and partial seizures.

- Almost half those with PNEAD were receiving anti-epileptic medication before diagnosis was confirmed. An accurate diagnosis resulted in nearly all of them being taken off this medication.
- An early accurate diagnosis will therefore reduce inappropriate treatment of this condition.
- Diagnosis helped to reduce the impact of illness in people with epilepsy. However, even an accurate diagnosis did not mean that the impact of PNEAD was reduced. Whereas diagnosis reduced the impact of the condition on psychosocial functioning in people with epilepsy, this did not happen for people with PNEAD.
- PNEAD patients were just as satisfied as those with epilepsy in terms of the doctor's professional behaviour. However, they were much less satisfied with what the consultation as a whole. Perhaps this is because they were dissatisfied with the diagnosis.

One possible criticism of the study is that patients with epilepsy were not, in fact, newly diagnosed and had previously been exposed to anti-epileptic drug treatment. A review of the sample in this study demonstrated that, in fact, 16/30 had previously been exposed to anti-epileptic drug treatment. The length of exposure to anti-epileptic drug treatment in most of these patients, however, was less than 2 months. These patients had attended the Walton Centre in order to have their diagnosis of epilepsy confirmed or rejected (see Smith et al 1999). Interestingly, a similar proportion of the PNEAD

group had also been exposed to anti-epileptic medication. Therefore the epilepsy group could be considered as a reasonable comparison group for studying the immediate impact of a diagnosis of PNEAD. The author accepts that future research should attempt to match carefully for the timing of diagnosis and exposure to previous anti-epileptic drug treatment.

3.5.4 Summary

This is the first attempt to compare the impact of diagnosis of epilepsy vs diagnosis of PNEAD. The main finding is that the reaction to the diagnosis itself helps to explain the greater Impact of PNEAD than epilepsy. The next study will therefore aim to find out whether the greater Impact of PNEAD is maintained over a longer time. It will also try to find out what other factors help to explain the Impact of PNEAD.

CHAPTER 4. STUDY 3: QUALITY OF LIFE OF PEOPLE WITH PSYCHOGENIC NON-EPILEPTIC ATTACK DISORDER: A COMPARATIVE STUDY

4.1 Introduction

As described in chapter 3, the impact of PNEAD seems to be greater than that of epilepsy soon after diagnosis, and the reaction to diagnosis helps to explain this. While a lot of literature describes the long-term impact of epilepsy (Jacoby et al, 1997), there is very little information about the long-term impact of PNEAD. One of the few studies to describe the natural history and outcome of PNEAD looked at 50 patients with an average 2 years follow-up (Limpert and Schmidt 1990). Results showed that 34% became seizure free. Adverse outcome was strongly associated with long history of PNEAD and significant psychological distress. At follow-up, 56% of patients were described as being in a 'poor' or 'very poor' state because of psychological distress and ill health. A later study by Krahn et al (1997) examined 71 patients with PNEAD with duration of illness ranging from 6 months to 3 years and who had received psychiatric treatment. In their results, they concluded that at follow-up the majority of patients had benefited from psychiatric treatment - over half the respondents reported an improved quality of life. A more recent study by Riaz et al (1998) investigated the natural history and outcome of 15 patients with PNEAD who were followed up between 8-21 months. Over one quarter were found to be seizure-free on follow-up and 40% had experienced a significant reduction in seizure frequency. Further, two thirds of the sample reported that their quality of life had improved since their initial diagnosis.

There are to date no published randomised trials assessing the treatment of people with PNEAD. A number of therapeutic approaches have been suggested including psychodynamic therapy, behavioural therapy, family therapy, hypnosis, and psychotropic medications for coexisting disorder e.g. depression and anxiety (Ramani, 1993). None of these approaches has been systematically investigated to find out whether one particular one is better than another. There is also little data, as mentioned previously, on the natural history of PNEAD. Nor is there any information about the quality of life of this group of patients.

The present study therefore attempts to address these gaps in the literature by examining the quality of life of patients with PNEAD and by investigating the factors which may influence the overall impact of the condition. Again, patients with epilepsy provide a comparison group.

4.2 Aims of Study 3

- To compare levels of disability between patients with PNEAD and patients with epilepsy.
- To identify factors that contributes to differences in impact of PNEAD vs epilepsy.

4.3 Methodology

4.3.1 *Participants*

A total of 194 participants between the ages of 16 and 60 years were recruited into two groups. Each group contained 69 female and 28 male participants. Patients with PNEAD were matched in terms of age and gender with patients with epilepsy; the mean age was 33.40 years. Recruitment to the current study began in April 1998 and was completed in August 2000. Patients with PNEAD were recruited via the neuropsychological outpatients clinics, and patients with epilepsy were recruited via the epilepsy outpatients clinics at the Walton Centre for Neurology, Liverpool.

4.3.1.1 PNEAD Group Inclusion Criteria

Subjects were initially recruited on the basis of the diagnosis of PNEAD made between 12-36 months previously.

4.3.1.2 PNEAD Group Exclusion Criteria

Subjects with PNEAD were excluded from the study if they presented with epilepsy (n=18), were unable to read (n=6), or felt unwell/stressed (n=1).

4.3.1.3 Refusals

A number of subjects refused to fill out the questionnaire because they had no time (n=5), or did not provide a reason for not participating (n=2). 6 subjects started the questionnaire but failed to complete it and were therefore discarded.

4.3.1.4 The Procedure for PNEAD Patients

The neuropsychologist gave a brief explanation to those assessed patients with PNEAD following clinic appointment that a researcher was undertaking a study involving patient participation. Following agreement to participate the neuropsychologist introduced patients with PNEAD to the researcher; the patient was then taken to a private room to complete the study questionnaire with the researcher present for guidance. Further information was provided about the study questionnaires, including a patient's information sheet (Appendix 4.1). Patients were informed that the information provided would not be disclosed to any hospital staff or form part of their case notes, and that non- participation in the study would not affect their treatment. Patients completed the questionnaires (Appendix 4.2), with the researcher present. Finally, it was explained that (a) if any question was unclear to patients, or (b) if they had any other questions about the project, that the researcher was available to help explain and clarify their concerns. Each subject was thanked for their participation and asked to hand the questionnaire back to the researcher. A number of patients were unable to complete the study questionnaire at the clinic. In such cases, the patient was

provided with an addressed envelope, thanked for their participation and asked to return the questionnaires by post.

4.3.1.5 Epilepsy Group Inclusion Criteria

Participants in the epilepsy group were recruited via the Epilepsy Outpatient's Clinic. Patients with epilepsy were considered suitable if they had been diagnosed by a consultant neurologist 12-36 months period previously.

4.3.1.6 Epilepsy Group Exclusion Criteria

Epilepsy control subjects were excluded from the study if they had been diagnosed with epilepsy either in the previous 12 month or more than 36 months previously, were unable to read (n=7), or were too distressed to participate (n=14).

4.3.1.7 Refusals

A number of patients refused to fill out the study questionnaires because they had no time (n=20). A number of subjects did not provide a reason for not participating (n=16). 15 subjects started the questionnaire but failed to complete it and were therefore discarded.

4.3.1.8 The Procedure for Epilepsy Patients

Epilepsy subjects were attending the Epilepsy Outpatients Clinic for assessment and treatment. The researcher initially examined patients' records to check patients suitability for the study; information was gained from medical records, including age, gender, and time of diagnosis to match with PNEAD patients. The researcher approached epilepsy patients as they waited for their scheduled appointments with the consultant neurologists. They were individually asked if they would participate in the study, which was outlined in brief. The procedure for patients with epilepsy participating was the same as for PNEAD. Participants then completed the questionnaire in the waiting area, with the researcher present for guidance. Participants spent approximately 45 minutes completing the questionnaires, although a number spent approximately 60 minutes.

4.3.2 *Design of Questionnaires*

4.3.2.1 Socio-demographic Information

Questionnaire responses focused upon patients' demographic details i.e. patients' age, gender, marital status, employment, and religion. Patients were asked to identify their education level and whether they had: 1) O level, 2) A level, 3) University degree, 4) Trade or Technical qualification, 5) Professional qualifications, 6) C.S.E or 7) No formal qualifications.

4.3.2.2 Questionnaires

Details of questionnaires are summarized here. Further information is provided in Chapter 3.

Features and Types of Attacks

Patients were asked to describe their attacks e.g. a grand mal. In addition, patients were also asked to define (over the past year) how many attacks they had experienced (none, less than 1 per month, or one or more per month). Patients were asked whether they had any long-term health problems associated with their attacks, and if any other family members experienced seizures. Patients were additionally asked to indicate whether they were currently taking any medication to control their attacks. Finally, patients were asked to state whether (and if so, how often) they had visited their GP in the past year.

The Illness Perception Questionnaire (IPQ)

The Illness Perception Questionnaire (IPQ) was developed to assess beliefs about illness. The IPQ is a theoretically derived measure comprising five components (Illness Identity, Cause Items, Time-line, Consequences, and Control/Cure) of illness representation described in Leventhal's self-regulation model (Weinman, 1996). Patients were asked to indicate how frequently s/he experienced specific symptoms as part of their attacks on a 4 point scale ranging from 'All of the time' to 'Never'. Items from the four other scales are on a 5-point scale from 'Strongly

Disagree' to 'Strongly Agree'. Scoring is as follows. (1) For the Illness Identity scale items endorsed as occasionally or greater were summed, so that the total score ranged from 0 to 10. (2) Scores for Time-line, Consequences and Control/Cure scales, items are arranged in a mixed order, and rated by the patient on a 5 point Likert scale ranging from 'Strongly agree' to 'Strongly disagree'. Where necessary, items were reverse scored. Mean scores are found by summing all scale items and dividing by the number of items responded to. (3) For the Cause Items scale an average score is not completed, as each response represent a specific causal belief.

Symptom Beliefs Questionnaire

The Symptom Belief Questionnaire was developed to measure patients' beliefs about the cause of physical symptoms when attending their General Practitioner (Salmon et al 1996). The questionnaire has 71 items, each on a 3-point scale. Items from three scales i.e. Stress, Weak-constitution and Concern were used in the current study in response to the following question 'whether it probably has or probably has not helped to cause your attack'. Patients were asked to tick one of the following responses 'Probably does', 'Don't know' or 'Probably does not'. The Concern scale items asked whether the patient believed that s/he knew the cause of the attacks; whether the patient had thought about the cause; and whether the attacks were caused by longstanding factors. For each scale scores are found by summing all scale items, higher scores representing stronger beliefs about physical symptoms.

The Short-Form-36 Health Survey (SF-36)

The SF-36 was designed as a generic indicator of health status for use in evaluative studies of health policy. The SF-36 can be used as an outcome measure in clinical research and practice. The SF-36 measures both physical and psychological outcomes. The SF-36 includes multi-item scales to measure eight dimensions (*Physical Functioning, General Health, Bodily Pain, Fatigue, Mental Health, Social Functioning, Role-Physical, Role-Emotional Limitations*). The SF-36 is self-administered and takes 5 to 10 minutes to complete. Scoring transforms the answers of each question into scaled scores from 0 to 100 so that high values represent more favourable physical and psychological states. The formula is: $\text{Transformed scale} = (\text{actual score} - \text{lowest possible score}) / \text{possible raw score range} \times 100$.

Seizure Severity Scale

The Seizure Severity Scale (Baker et al 1991) is subdivided into two parts: (1) Seizure Severity (Percept) includes 8 items such as the absence or presence of warning signs, whether seizures occur in clusters or at random and whether they occur at a specific time of the day or night. (2) Seizure Severity (Ictal/Post-ictal) refers to manifestations of seizures and their immediate consequences and includes 11 items such as loss of consciousness and its duration, tongue-biting etc. Patients are asked to tick the response that best describes their attacks. The individual items are rated on a four-point Likert scale where 1 is the least severe and 4 the most severe.

Impact of Epilepsy

The Impact of Epilepsy Measure was devised by Jacoby et al (1993) to measure the Impact of epilepsy upon a number of different aspects of daily life. The scale covers the most important areas of everyday life, e.g. relationship with spouse or partner, friends, social life, employment, health, self-esteem, plans for the future and standard of living. Patients are asked to respond to each item by stating how much they thought a particular aspect of their life was affected by their attacks. Responses ranged from 'not at all' to 'a lot' and scored 1 to 4 respectively. A total impact score was calculated by summing all item scores.

Consultation Satisfaction Questionnaires

The Consultation Satisfaction Questionnaire was developed by Baker R. (1990) to evaluate degree of satisfaction with those areas of care that are of concern to patients. Four scales comprise the Consultation Satisfaction Questionnaire as follows: General Satisfaction, Professional Care, Depth of Relationship, and Perceived Length of Consultation. Overall Consultation Satisfaction is computed by adding each of the 18 items together. Each statement was followed by five possible answers ranging from 5 'Strongly agree' to 1 'Strongly disagree'. Some questions are worded positively and some negatively. As a result the question direction must be then taken into account. A score of (1) indicates dissatisfaction and (5) satisfaction.

The Stigma Scale

The Stigma Scale (Jacoby 1994) contained 3 items that examine how patients feel about their seizures and whether other people (1) were uncomfortable with them, (2) treated them as inferior, and (3) preferred to avoid them. For each item patients answered Yes = 1 if they agreed or No = 0 if they disagreed. The overall score comprised the sum of positive responses, so that the higher the score the greater the sense of perceived Stigma.

Cohesion (FES)

The Family Environmental Scale (FES) by Moos and Moos (1981) was developed (comprising ten subscales) to measure the social and environmental characteristics of different family types. In the current study Cohesion (the degree of commitment, help, and support family members provide for one another) was measured. Respondents were asked to read all statements about their origin family and to decide whether it was 'true', 'mostly true', 'mostly false' or 'false'. On each item the possible scores ranged from 0 to 9.

The Hospital Anxiety and Depression Scale (HADS)

The HADS has been found to be a reliable instrument for identifying states of depression and anxiety across different groups of non-psychiatric hospital patients. The scale consists of 14 items; seven items measure anxiety e.g. I can sit at ease and feel relaxed, while seven items measure depression e.g. I still enjoy the things I

used to enjoy. Overall Anxiety and Depression are both rated on a four-point scale; individual items are scored from 0-3 or 3-0, depending on the item wording. Total scores for each subscale are calculated. Respondents who score 11 and above for either anxiety or depression subscales are identified as a case, i.e. as significantly disabled.

Social Support Scale

This scale was developed by the Rand Medical Outcomes Study (MOS) teams to evaluate how different types of support relate to health outcomes (Sherbourne and Stewart, 1991). The MOS measure contained 50 items, and was reduced to 19 functional support items, hypothesised to measure four dimensions of social support: (i) *Tangible Support* (4 items): the provision of behavioural assistance e.g. someone to help you if you were confined to bed; (ii) *Positive social interaction* (4 items): the availability of other people to do fun things with you (someone to have a good time with); (iii) *Affectionate Support* (3 items): involving expressions of love and affection (e.g. someone who shows you love and affection); and (iv) *Emotional Support* (8 items): the offering of advice and the expression of feelings e. g. someone to give you good advice about a crisis. One structural support item asks about the respondent's number of close friends or relatives. In the present study, a score for Overall Social Support was also calculated by summing all items.

For each item respondents were asked the following question: 'People sometimes look to others for assistance, or other types of support. How often is each of the

following kinds of support available to you if you need it?' Response choices were 'none of the time', 'a little of the time', 'some of the time', 'most of the time', and 'all of the time'. Internal-consistency reliability for the overall scale was high, 0.97. One year test-retest reliability coefficients for all subscales was high at 0.78. Criterion validity was tested using variables included in the Medical Outcome Study. The Social Support Survey showed significant convergent correlations with indicators of social activity within the range 0.24 to 0.33. Correlations between the four subscales ranged from 0.69 to 0.82 (McDowell and Newell, 1996).

4.3.3 Statistical Analyses

Data were analysed using the Statistical Package for the Social Sciences, (SPSS 9.0), on a personal computer. Parametric statistics were chosen when data were normally distributed. Non-parametric statistics were also chosen for data that were not normally distributed.

Parametric statistics included Pearson correlation coefficients, and two-way ANOVA. Pearson correlation coefficients examined the association of age and education with psychological variables. A two-way analysis of variance examined the effects of gender and diagnostic group on given psychological variables, including main and interaction effects. Education was entered as a covariate. Pot hoc t-test analysis examined differences between patients when significant interactions were found.

For non-parametric variables, the Mann-Whitney test was used to check (first) for differences between male and female patients in each diagnostic group. Where significant differences were found, the Mann-Whitney test also checked for differences between males with PNEAD vs males with epilepsy and between female with PNEAD vs female with epilepsy. The Mann-Whitney test then checked for differences between PNEAD vs epilepsy patients. Spearman correlation coefficients were used for non-parametric variables.

Education, religion, and employment status for patients with PNEAD vs epilepsy were compared by chi-square. The chi-square test also examined the association between diagnostic groups and features and types of attacks.

Multiple linear regression was used to test the second aim of the study, which was to identify factors that might help to explain different levels of Impact, including differences between PNEAD vs epilepsy groups. Education was related to Impact and to several other variables. Therefore it was entered first, as block 1, in all analyses. The first analysis examined whether clinical characteristics explained differences in Impact. Therefore clinical characteristics (Seizure Severity (Percept), Seizure Severity (Ictal/Post-ictal), Illness Identity) were entered in block 2. In each subsequent analysis, an additional block of variables was added in a further attempt to explain differences in Impact. The second analysis examined whether psychological disturbance explained differences in Impact. Therefore relevant variables (Depression, Anxiety, Role-emotional Limitations, Mental Health) were entered in block 3. The third analysis examined the influence of social support. Therefore Overall Social Support was included in block 4. The

fourth analysis examined the role of physical dysfunction. Variables added as block 5 included: General Health, Physical Functioning, Bodily Pain, and Fatigue. The fifth analysis examined the role of beliefs. Stress and Concern were included in block 6. The sixth analysis examined the role of Consultation Satisfaction. Therefore Overall Satisfaction was included as block 7. Entry of variables was stepwise within each block. In every analysis, Group (PNEAD vs epilepsy) was included as the final block. Collinearity diagnostics were calculated for the complete set of variables.

4.4 Results

4.4.1 Sample

Table (4.1) summarises demographic data for the whole sample, which is further subdivided by diagnostic group. There were 97 patients in each of the PNEAD and epilepsy groups, who were of similar age (mean = 33.40); in both groups the number of female patients was greater than male (69/97 vs 28/97 in each group). There were no statistical differences in terms of marital status, employment, and religion. A significant difference between both diagnostic groups was found for education. In the PNEAD group the number of patients who reported having G.C.S.E., A level, and university degrees was lower than that of the epilepsy patients. No significant differences between the diagnostic groups were found concerning trade/technical qualifications, or for professional and C.S.E. qualifications. Overall across both diagnostic groups, the number of PNEAD

patients with educational qualifications was lower than the number of patients with epilepsy.

Table 4.1:**Demographic Data in Each Diagnostic Group**

	PNEAD N=97	Epilepsy N=97	χ^2	p
Gender				
Male	28	28		
Female	69	69		
Marital status				
Single	37	39		
Divorced	20	14		
Widowed	2	1		
Married/living with a partner	30	42		
Other	8	1	8.89	.06
Employment				
Unemployed	22	19		
Employed	24	32		
Self employed	34	28		
Housewife	10	13		
Retired	1	1		
Student	6	4	2.73	.74
Job				
No job	69	65		
Unskilled	4	16		
Skilled	5	1		
Shop-work	11	9		
Skilled technical	2	0		
Professional	6	6	12.19	.03
Education				
O level	43	61	6.72	.01
A level	19	37	8.13	.01
University	6	19	7.76	.01
Trade/Technical qualification.	12	21	2.96	.09
Professional qualification	15	13	.16	.68
CSE	29	26	.22	.63
No formal qualification	39	22	6.91	.01
Religion				
Church of England/Protestant	46	57		
Catholic	36	29		
Muslim	1	0		
None	6	8		
Other	8	3	5.49	.24

4.4.2 Relationship of Age and Education with Psychological Variables

The relationship between age education and psychological variables is shown in table 4.2. Age was significantly associated with beliefs about physical symptoms: i. e. Stress was negatively associated with age; perceived Weak-constitution was positively correlated with age; perceived Seizure Severity (Ictal/Post-ictal) was negatively correlated with age. From the SF-36, Physical functioning and Role physical scales were negatively associated with age. Education was correlated negatively with belief in a Genetic cause, perceived Impact of attacks, Mental health, Anxiety, Depression and Affectionate support. Education was correlated positively with Physical Functioning, Role Physical, Role Emotional Limitation, Social Functioning and Bodily Pain, and Fatigue. Degree of Cohesion, perceived Emotional and Social Support, and Depth of Relationship (with the Doctor) were also associated positively with education.

Table 4.2:

Correlations of Psychological Variables with Age and Education (Having a Qualification vs no Qualification). Only Significant Pearson or Spearman Correlations are Shown.

Psychological variables	Age	Education
(IPQ) Cause Items		
Genetic	-	-.17**
Beliefs physical symptoms		
Stress	-.13*	-
Weak-constitution	.14*	-
Seizure Severity Scale		
Ictal/Post-ictal	-.14*	-
Impact	-	-.17**
SF-36		
Physical Functioning	-.26*	.28**
Role Physical	-.18*	.16*
Role-Emotional Limitations	-	.14*
Social Functioning	-	.19**
Bodily Pain	-	.22**
Mental Health	-	-.20**
Fatigue	-	.13*
HADS		
Anxiety	-	-.27**
Depression	-	-.24**
FES		
Cohesion	-	.21**
Social Support		
Affectionate Support	-	-.13*
Emotional Support	-	.16**
Overall Social Support	-	.15*
Consultation Satisfaction		
Depth Relationship	-	.17**

** . Correlation is significant at the 0.01 level

* . Correlation is significant at the 0.05 level

4.4.3 Comparisons between the Diagnostic Groups

4.4.3.1 Differences between Diagnostic Groups on Clinical Features and Types of Attacks

PNEAD patients were more likely to report long-term health problems. No significant differences between diagnostic groups in relation to whether another relative was reporting attacks were found. There were significant differences between diagnostic groups regarding attack descriptions. PNEAD patients were less likely to report attacks as trance-like states when compared with epilepsy patients. There were no significant differences between PNEAD vs epilepsy patients regarding other attack descriptions, i.e. generalised attacks, absence attacks, attacks of falling with brief loss of consciousness, and brief jerks of the arms and body. Fewer patients with PNEAD received anti-epileptic medication compared to patients with epilepsy ($\chi^2=69.37$, $p<0.001$) (Table 4.3). There were no significant differences between diagnostic groups in terms of visits to their General Practitioner. Patients with PNEAD were more likely to report more attacks during the previous 1-year than patients with epilepsy ($p<0.001$), (Table 4.4).

Table 4.3:

The Differences Between PNEAD vs Epilepsy groups on Features and Types of Attacks, Receiving Anti-epileptic Medication and Seeing the General Practitioner

	PNEAD N=97	Epilepsy N=97	χ^2
Features of attacks			
Long-term health problems	37	23	4.73*
Relative with attacks	22	26	.44
Receiving anti-epileptic	20	78	69.37***
Visit the GP over the past 12 months (Yes/No)	62	50	3.04
<u>Type of attack</u>			
Generalised attacks	48	55	1.01
Absence attacks	34	42	1.38
Attacks with a trance-like state	22	40	7.68*
Attacks of falling with brief loss of consciousness	31	35	.37
Brief jerks of the arms and body	27	33	.87

Table 4.4:

Frequency of Attacks for PNEAD vs Epilepsy

Attack frequency	PNEAD N=97	Epilepsy N=97
None in past year	5	22
Less than one a month	29	33
One or more a month	63	42

4.4.3.2 How do PNEAD Patients differ from Epilepsy Patients on Psychological Variables?

Parametric Analysis

Main effect of PNEAD vs epilepsy

Mean and standard errors on each psychological variable are shown in table 4.5 and F-ratios in table 4.6 (the education variable was treated as a covariate). In relation to patient beliefs about Physical Symptom dimensions, the PNEAD group were distinguished from epilepsy patients by higher scores on two Symptom Beliefs: Stress ($p < 0.001$), and Concern ($p < 0.01$). The two groups did not differ in their belief regarding a Weak-constitution ($p < 0.05$). There were significant differences between the two groups on the Seizure Severity Scale. Patients with PNEAD scored lower on the Severity Severe (Percept) subscale ($p < 0.01$), and on Seizure Severity (Ictal/Post-ictal) ($p < 0.001$). Differences in appraisals of Impact were also significant; PNEAD patients scored higher on the perceived Impact of attacks when compared with patients with epilepsy ($p < 0.001$). Patients with PNEAD as opposed to patients with epilepsy reported significantly higher levels of Depression ($p < 0.01$), Anxiety ($p < 0.001$), and lower perceived Cohesion ($p < 0.01$). Levels of Consultation Satisfaction were also significantly different between the two diagnostic groups. Patients with PNEAD reported less General Satisfaction ($p < 0.001$); Professional Care ($p < 0.001$); Depth of Relationship ($p < 0.001$); Perceived Length of Consultation ($p < 0.001$); and Overall Consultation Satisfaction ($p < 0.001$). The Illness Perception Scale (Consequences and Control/Cure) failed

to reach statistical significance and discriminate between PNEAD vs epilepsy groups. There was a significant difference between groups for Time-line, i. e. patients with PNEAD were more likely to perceive their illness as lasting longer ($p < 0.05$).

Main effect of Gender

Means are shown in table 4.5 and F-ratios in table 4.6. No significant differences were found between male and female patients in relation to the main psychological variables. Male patients however scored lower on level of Professional Care ($p < 0.05$), and Overall Consultation Satisfaction ($p < 0.05$).

Interaction (Group x Gender)

Table 4.6 shows F ratios and two-way interaction, for gender and diagnostic groups. In summary there were only a few significant interaction effects for gender and diagnostic groups. PNEAD vs epilepsy and male vs female interacted for Anxiety ($F_{189} = 5.83$, $p < 0.05$). Male patients with PNEAD reported higher levels of Anxiety than male patients with epilepsy ($t = 4.69$, $p < 0.001$). Female patients with PNEAD compared to female patients with epilepsy reported higher levels of Anxiety ($t = 2.67$, $p < 0.01$). In the PNEAD group, female patients were more likely than male patients to report higher levels of Anxiety ($t = 1.98$, $p < 0.05$). There were no significant differences between male and female patients with epilepsy.

Table 4.5:

Means (Std. Error) of Normally Distributed Psychological Variables for PNEAD and Epilepsy in Male and Female Patients (Education as Covariate). F ratios Showing the Main Effects for Group, Gender and Interactions for Group x Gender are Presented in Table 4.6.

	PNEAD		Epilepsy	
	Male	Female	Male	Female
Illness perception				
Time-line	2.99 (.15)	2.92 (.100)	2.61 (.14)	2.61 (.10)
Consequences	3.25 (.15)	3.24 (.10)	3.10 (.15)	2.92 (.10)
Control/Cure	2.85 (.12)	3.03 (.08)	2.89 (.11)	2.77 (.08)
Symptom Beliefs				
Stress	12.10 (1.02)	10.53 (.67)	7.94 (.99)	8.67 (.68)
Weak-constitution	2.68 (.32)	2.10 (.21)	2.12 (.31)	2.53 (.21)
Concern	3.44 (.34)	3.70 (.22)	2.53 (.33)	3.05 (.23)
Seizure Severity Scale				
Seizure Severity (Percept)	19.69 (1.22)	20.88 (.80)	24.15 (1.17)	21.81 (.81)
Seizure Severity (Ictal/Post-ictal)	20.02 (1.42)	20.17 (.93)	28.89 (1.37)	27.55 (.94)
Impact	26.66 (1.72)	24.44 (1.12)	14.73 (1.66)	16.19 (1.14)
HAD				
Anxiety	12.86 (.92)	10.68 (.60)	6.91 (.88)	8.41 (.61)
Depression	10.05 (.91)	8.47 (.60)	6.62 (.88)	7.24 (.61)
FES				
Cohesion	5.21 (.43)	6.06 (.27)	6.60 (.42)	6.98 (.27)
Consultation Satisfaction				
General Satisfaction	7.92 (.51)	9.14 (.33)	11.33 (.49)	11.24 (.34)
Professional Care	17.47 (1.25)	18.85 (.82)	24.37 (1.21)	26.20 (.83)
Depth Relationship	11.55 (.84)	13.10 (.55)	18.48 (.81)	18.24 (.56)
Perceived Length of Consultation	8.01 (.49)	8.99 (.32)	10.70 (.47)	10.55 (.32)
Overall Consultation Satisfaction	44.91 (2.03)	49.78 (1.32)	66.36 (1.96)	66.28 (1.35)

Table 4.6:

Summary of Statistical Analyses: $F_{1,189}$ values Showing Main Effects for Group (PNEAD vs Epilepsy), Gender (Male vs Female) and Interactions for (Group x Gender) on Different Measures (Education as Covariate)

*** $P < .001$; ** $P < .01$; * $P < .05$

	Male v. Female	PNEAD v. Epilepsy	Group x Gender
Illness Beliefs			
Time-line	.01	3.38	.13
Consequences	.79	3.32	.41
Control/Cure	.31	1.12	1.52
Symptom Beliefs			
Stress	.35	12.51***	2.31
Weak-constitution	.45	.06	2.89
Concern	2.75	8.24**	.75
Impact			
	.04	47.69***	2.01
Seizure Severity			
Seizure Severity (Percept)	.01	7.10**	3.03
Seizure Severity (Ictal,/Post-ictal)	.88	42.11***	.19
HAD			
Anxiety	.59	28.90***	6.54*
Depression	.75	8.36**	1.39
FES			
Cohesion	3.02	10.26**	.44
Consultation Satisfaction			
General Satisfaction	1.95	36.58***	1.06
Professional Care	3.96*	40.41***	.57
Depth Relationship	.99	71.74***	1.82
Perceived Length of Consultation	1.69	24.27***	.86
Overall Consultation Satisfaction	5.82*	101.13***	.10

Non-parametric analyses

IPQ Illness Identity

There were no significant differences between male and female patients in either PNEAD or epilepsy groups in terms of Illness Identity. Patients with PNEAD were more likely to report stronger illness identity than patients with epilepsy ($U=2028.00$, $p<0.001$) (Table 4.7).

Table 4.7:

Mean (Std. Error) and Median of Illness Identity Scale for PNEAD and Epilepsy in Male and Female Patients.

	Male		Female	
	Mean (Std. Error),	Median	Mean (Std. Error),	Median
PNEAD N=97	6.86 (.59)	8.00	6.35 (.36)	6.00
Epilepsy N=97	3.21 (.60)	2.00	3.20 (.36)	2.00

IPQ Cause Items

In terms of illness attribution, there were no significant differences between male and female patients in either diagnostic group. Patients with PNEAD were more likely than patients with epilepsy to attribute their illness to Germs or Viruses ($U=3515.50$, $p<0.001$). Patients with PNEAD believed that their attacks were triggered by Chance more than patients with epilepsy ($U=3653.50$, $p<0.01$). Patients with PNEAD were more likely than patients with epilepsy to attribute their illness to their own behaviour ($U=3822.00$, $p<0.05$), and to their thoughts ($U=3327.50$, $p<0.001$). Differences between diagnostic groups were not found on other illness attribution dimensions (Table 4.8).

Table 4.8:

Means (Std. Error) and Median of IPQ Cause Items for PNEAD and Epilepsy in Male and Female Patients.

	PNEAD N=97		Epilepsy N=97	
	Male	Female	Male	Female
Germs***	2.25 (.24) 2.00	2.28 (.14) 2.00	1.50 (.60) 2.00	1.87 (.13) 2.00
Diet	2.32 (.23) 2.00	2.25 (.14) 2.00	2.21 (.24) 2.00	2.03 (.12) 2.00
Pollution	2.00 (.18) 2.00	2.14 (.15) 2.00	1.79 (.17) 2.00	1.77 (.11) 2.00
Genetic	2.36 (.21) 2.00	2.06 (.13) 2.00	1.86 (.21) 1.50	2.23 (.15) 2.00
By chance**	2.64 (.23) 3.00	2.90 (.17) 3.00	2.18 (.22) 2.00	2.32 (.14) 3.00
Stress cause	3.39 (.27) 3.50	3.17 (.17) 3.00	2.89 (.26) 3.00	3.03 (.17) 3.00
My own behaviour**	2.46 (.19) 2.00	2.70 (.17) 2.00	2.00 (.19) 2.50	2.23 (.14) 2.00
Other people's behaviour	3.00 (.24) 3.00	2.45 (.16) 2.00	2.32 (.19) 2.50	2.38 (.16) 2.00
My state of mind**	3.54 (.25) 4.00	2.96 (.18) 3.00	2.46 (.24) 2.50	2.36 (.15) 2.00

***<.001; **<.01

Stigma

In terms of Stigma, there were no significant differences between male and female patients in either diagnostic group. Mann-Whitney test results revealed that patients with PNEAD were more likely to feel stigmatized by their attacks than patients with epilepsy ($U=3636.50$, $p<0.01$) (Table 4.9).

Table 4.9:

Means (Std. Error) and Median of Stigma for PNEAD and Epilepsy in Male and Female Patients.

	Male		Female	
	Mean (Std. Error), Median		Mean (Std. Error), Median	
PNEAD N=97	1.96 (.17)	2.00	1.23 (.14)	2.00
Epilepsy N=97	1.36 (.21)	1.00	1.14 (.14)	1.00

Role-Emotional Limitations

There were significant differences between male and female patients in terms of Role-Emotional Limitations. In the PNEAD group female patients were less likely to report Limitations than male patients ($U=572.50$, $p<0.001$). In the epilepsy group males and females did not differ in this domain. Male patients with PNEAD were more likely to report Role-Emotional Limitations than male patients with epilepsy ($U=187.00$, $p<0.001$). There were no significant differences between females with PNEAD vs females with epilepsy regarding Role-Emotional Limitations. Patients with PNEAD were more likely to report Role-Emotional Limitations compared to patients with epilepsy ($U=3578.00$, $p<0.01$).

Mental Health

In terms of Mental Health, there were no differences between male and female patients in the epilepsy group. Male patients with PNEAD were more dysfunctional in terms of Mental Health than female patients ($U=572.00$, $p<0.01$). Male patients with PNEAD were more dysfunctional than male patients with epilepsy ($U=212.50$, $p<0.01$). Female patients with PNEAD were more dysfunctional than female with epilepsy ($U=604.50$, $p<0.001$). Patients with PNEAD (in general) were more dysfunctional from a Mental Health point of view than patients with epilepsy ($U=1678.50$, $p<0.001$).

General Health

In terms of General Health perceptions, there were no significant gender differences (PNEAD group), although there were significant differences between male and female with epilepsy. Male with epilepsy were more dysfunctional in terms of General Health perceptions than female with epilepsy ($U=687.00$, $p<0.05$). Female with PNEAD were more dysfunctional than females with epilepsy in terms of General Health perceptions ($U=1873.50$, $p<0.05$). In general, Mann-Whitney test results revealed that patients with PNEAD were more dysfunctional in terms of General Health perceptions than patients with epilepsy ($U=3740.00$, $p<0.05$). There were no significant differences between male patients across PNEAD vs epilepsy diagnostic groups.

Other SF-36 domains

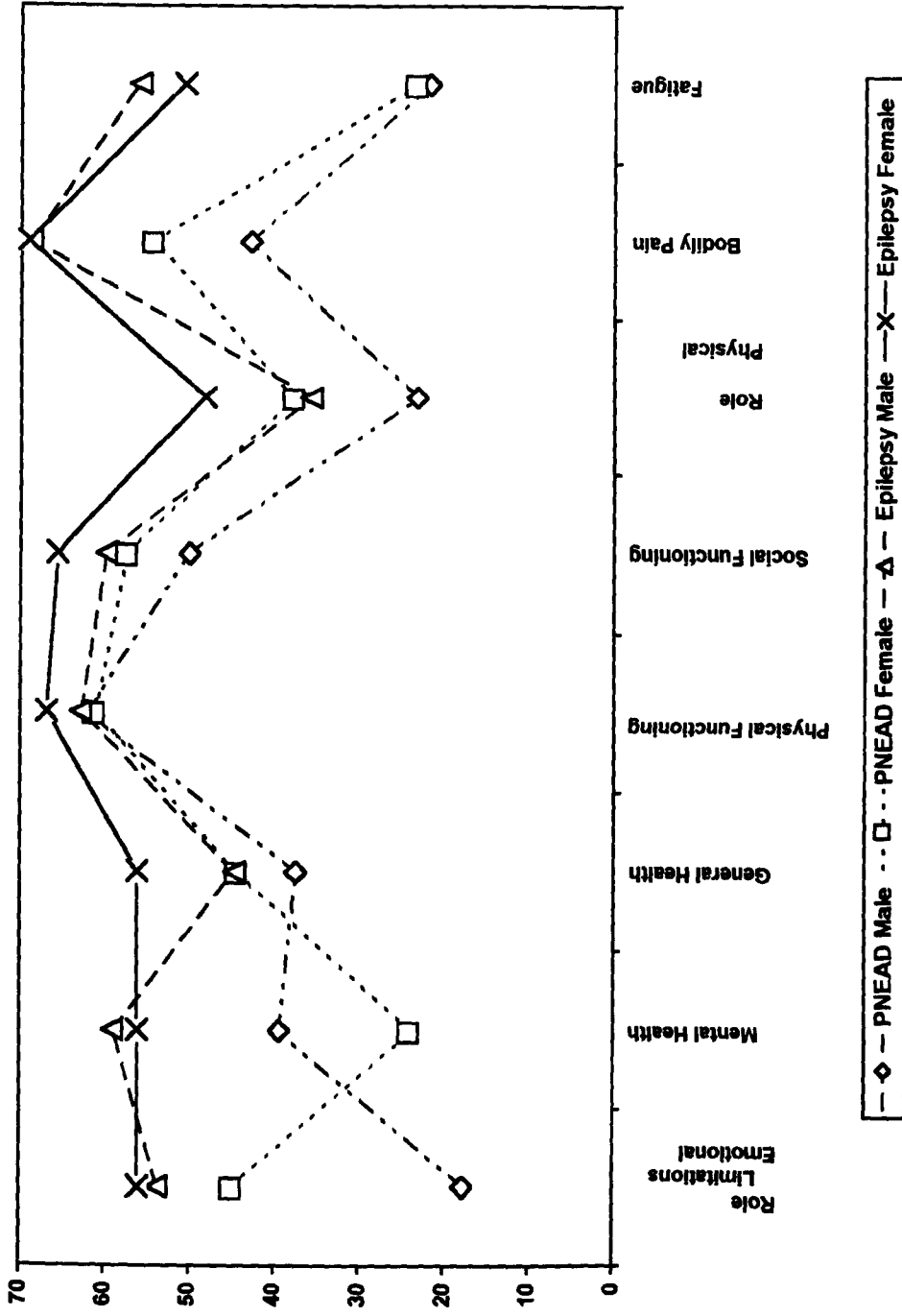
Male and female patients did not differ on other dimensions from the SF-36 scale-Physical Functioning, Social Functioning, Role-Physical, Bodily Pain, and Fatigue in either PNEAD or epilepsy groups. No significant differences were found between diagnostic groups for Physical, and Social Functioning domains. In terms of Physical Functioning, patients with PNEAD were more likely than patients with epilepsy to report poorer Social Functioning ($U=3908.50$, $p<0.05$). Patients with PNEAD were more dysfunctional than patients with epilepsy in terms of Bodily Pain ($U=3187.00$, $p<0.001$). Patients with PNEAD reported greater Fatigue than patients with epilepsy ($U=1255.50$, $p<0.001$) (Table 4.10, also see Figures 4.1).

Table 4.10:

Means (Std. Error) and Median of SF-36 Scales for PNEAD and Epilepsy in Male and Female Patients.

	PNEAD N=97		Epilepsy N=97	
	Male	Female	Male	Female
Role-Emotional Limitations	17.86 (6.30) .00	44.93 (4.81) 33.33	53.71 (7.34) 50.00	56.04 (4.99) 66.67
Mental Health	39.43 (4.25) 46.00	24.00 (2.57) 20.00	59.00 (4.50) 62.00	56.06 (2.32) 56.00
General Health	37.50 (5.01) 35.00	44.42 (3.77) 45.00	44.64 (4.85) 40.00	56.16 (2.84) 55.00
Physical Functioning	62.14 (5.64) 70.00	61.16 (3.75) 65.00	62.86 (5.84) 62.50	66.88 (3.65) 75.00
Social Functioning	50.00 (7.49) 50.00	57.25 (4.38) 75.00	59.82 (7.31) 62.50	65.58 (3.58) 75.00
Role-Physical	23.21 (4.97) 25.00	37.68 (5.15) 25.00	35.71 (6.48) 25.00	48.19 (4.74) 50.00
Bodily Pain	42.86 (4.97) 44.44	54.25 (3.79) 55.56	68.65 (6.16) 83.33	69.08 (3.49) 77.78
Fatigue	21.79 (2.96) 20.00	23.33 (1.62) 25.00	55.89 (3.93) 60.00	50.58 (2.58) 50.00

Figure 4.1: Mean Scores on SF-36. Comparison of Males vs Females in PNEAD vs Epilepsy



MOS Social Support

There were no significant differences between male and female patients on all Social Support Scales, in either diagnostic group. Patients with epilepsy were more likely to have Tangible Support than patients with PNEAD (U=2437.50, p<0.001). Patients with PNEAD reported less Emotional Support from family or friends compared with patients with epilepsy (U=2796.00, p<0.001), less positive Social Interaction (U=2885.00, p<0.001), and less Affectionate Support (U=2821.00, p<0.001). Patients with PNEAD reported less Overall Social Support from their families or relatives than patients with epilepsy (U=2428.50, p<0.001) (Table 4.11).

Table 4.11:

Means (Std. Error) and Median of MOS Social Support Scales for PNEAD and Epilepsy in Males and Females Patients.

	PNEAD N=97		Epilepsy N=97	
	Male	Female	Male	Female
Tangible Support	44.64 (5.14) 37.50	54.80 (3.94) 50.00	80.58 (3.93) 84.38	76.63 (2.52) 75.00
Affectionate Support	53.27 (5.71) 45.83	57.49 (3.27) 58.33	76.49 (3.86) 79.17	75.36 (2.66) 75.00
Positive Interaction	57.81 (4.89) 50.00	67.21 (3.14) 68.75	81.03 (3.19) 87.50	81.70 (2.08) 87.50
Emotional Support	57.92 (3.69) 57.81	64.54 (2.73) 68.75	78.79 (3.85) 82.81	76.99 (1.73) 81.25
Overall Social Support	53.90 (3.97) 47.37	61.52 (2.80) 65.79	78.76 (3.06) 78.95	78.01 (1.71) 76.31

4.4.4 Multiple Regressions

In the tests of collinearity, the minimum tolerance was 0.25 and the maximum condition index was 29.42. Therefore the variables did not show significant multicollinearity and were suitable for regression analysis.

Education was related to Impact and to several other variables. Therefore it was entered first, as block 1, in all analyses, so that the effects of variables entered subsequently controlled for this. The first analysis examined whether group (PNEAD vs epilepsy) predicted Impact. Significant predictor variables in this analysis were both education and group. In the final model, group was a significant and unique predictor of Impact, reflecting the fact that PNEAD patients scored higher on perceived Impact than patients with epilepsy. Education failed to reach significance when group was added (Table 4.12.A).

Table 4.12.A:

Summary of Multiple Regression Analyses: In this and following Tables, F-to-enter Refers to the Set of Variables Entered in one Block. R² refers to Complete Set of Variables Entered to that Point. β and b are Taken from the Final Model.

Dependent Variable: Impact

	β	b	Sig. of β	R ²	Sig. of R ²	F-to-enter (d.f.)	Sig. of F-to-enter
Education	-0.09	-2.11	> .05	.03	< .05	6.37 (1,192)	< .05
Group	-.45	-9.36	< .001	.23	< .001	48.36 (1,191)	< .001

A second analysis examined whether Clinical Characteristics of attacks explained differences in Impact. Clinical Characteristics (i.e. Seizure Severity (Percept), Seizure Severity (Ictal/Post-ictal), and Illness Identity) were entered in block 2, i.e. after education in block 1, followed by group in block 3. Each block was significant. The only significant Clinical Characteristic was Illness Identity (although it did not remain significant once Group was added). Seizure Severity (Percept), and Seizure Severity (Ictal/Post-ictal), failed to reach significance. Group emerged once again as a significant and unique predictor (Table 4.12.B).

Table 4.12.B:

	β	b	Sig. of β	R ²	Sig. of R ²	F-to-enter (d.f.)	Sig. of F-to-enter
Education	-.10	-2.33	> .05	.03	< .05	6.37 (1,192)	< .05
Clinical Characteristics							
Seizure Severity (Percept)	-	-	-				
Seizure Severity (Ictal/Post-ictal)	-	-	-	.12	< .001	19.54 (1,191)	< .01
Illness Identity	.11	.33	> .05				
Group	-.40	-8.23	< .001	.24	< .001	28.57 (1,190)	< .001

A third analysis examined the influence of Psychological Disturbance. Psychological disturbance (i.e. Anxiety, Depression, Role-Emotional Limitations, and Mental Health) was entered in block 3 (i.e. after education in block 1, and Clinical Characteristics in block 2), followed by Group. Each block was significant but Group was only marginally significant. Of the Psychological Disturbance variables, Anxiety, Role-Emotional Limitations and Mental Health were each significant. Thus in the final model Anxiety, Role-Emotional Limitations, and Group were significant predictors (Table 4.12.C).

Table 4.12.C:

	β	b	Sig. of β	R ²	Sig. of R ²	F-to-enter (d.f.)	Sig. of F-to-enter
Education	-.02	-.52	> .05	.03	< .05	6.37 (1,192)	< .05
Clinical Characteristic							
Seizure Severity (Percept)	-	-	-				
Seizure Severity (Ictal/Post-ictal)	-	-	-	.12	< .001	19.54 (1,191)	< .01
Illness Identity	.10	.31	> .05				
Psychological Disturbance							
Anxiety	.29	.56	< .001				
Depression	-	-	-	.41	< .001	30.92 (3,188)	< .001
Role-Emotion Limitations	-.27	-6.79	< .001				
Mental Health	-.11	-4.51	> .05				
Group	-.19	-3.98	< .05	.43	< .001	5.57 (1,187)	< .05

The fourth analysis examined whether adding Physical Problems could account for differences in Impact. Physical Problems, i.e. General Health, Physical-Functioning, Bodily pain, and Fatigue were entered in block 4, followed by Group in block 5. Physical Problems were significant, but only one of the variables, Fatigue, was significant. Group was no longer significant (Table 4.12.D).

Table 4.12.D:

	β	b	Sig. of β	R ²	Sig. of R ²	F-to-enter (d.f.)	Sig. of F-to-enter
Education	-.04	-.83	> .05	.03	< .05	6.37 (1,192)	< .05
Clinical Characteristic							
Seizure Severity (Percept)							
Seizure Severity (Ictal/Post-ictal)				.12	< .001	19.54 (1,191)	< .01
Illness Identity	.15	.44	< .05				
Psychological Disturbance							
Anxiety	.30	.58	< .001				
Depression	-	-	-	.41	< .001	30.92 (3,188)	< .001
Role-Emotion Limitations	-.26	-6.65	< .001				
Mental Health	-.16	-6.34	< .01				
Physical Problems							
General Health	-	-	-				
Physical-Functioning	-	-	-	.43	< .001	4.26 (1,187)	< .05
Bodily Pain	-	-	-				
Fatigue	-.13	-6.03	< .05				
Group*	-	-	-	-	-	-	-

*: Variable in this block was non significant

The fifth analysis examined the influence of Social Support. Therefore, Overall Social Support was included in block 5. Neither Social Support nor Group was significant.

The sixth analysis examined the role of Symptom Beliefs (Table 4.12.E). Symptom Beliefs (Stress and Concern) were entered in block 6. All blocks were significant except block 5 i.e. Social Support and block 7 (Group). Of the Beliefs, only Concern was significant. Thus in the final model, Clinical Characteristics (Illness Identity), Psychological Disturbance (Anxiety, Role-Emotional Limitations, and Mental Health), Physical Problems (Fatigue) and Symptoms Beliefs (Concern) were significant.

The final analysis examined the role of Consultation Satisfaction, which was included as block 7. Group was again included as the final block. Consultation Satisfaction and Group were non significant.

Table 4.12.E:

	β	b	Sig. of β	R ²	Sig. of R ²	F-to-enter (d.f.)	Sig. of F-to-enter
Education	-.05	-1.14	> .05	.03	< .05	6.37 (1,192)	< .05
Clinical Characteristic							
Seizure Severity (Percept)	-	-	-				
Seizure Severity (Ictal/Post-ictal)	-	-	-	.12	< .001	19.54 (1,191)	< .01
Illness Identity	.13	.40	< .05				
Psychological							
Disturbance	.28	.54	< .001				
Anxiety	-	-	-				
Depression	-.24	-6.15	< .001	.41	< .001	30.92 (3,188)	< .001
Role-Emotion Limitations Mental Health	-.15	-6.04	< .05				
Physical Problems							
General Health	-	-	-				
Physical Functioning	-	-	-	.43	< .001	4.26 (1,187)	< .05
Bodily Pain	-	-	-				
Fatigue	-.13	-5.99	< .05				
Social Support*	-	-	-	-	-	-	-
Symptoms Beliefs							
Stress	-	-	-	.45	< .001	7.62 (1,186)	< .05
Concern	.16	.88	< .01				

*: Variables in this block were all non significant.

4.5 Discussion

4.5.1 *Strengths of this Study*

- This is the only study, to the author's knowledge, that has examined in detail the quality of life of patients with PNEAD.
- The sample size was large and was carefully matched with a comparison group of people with epilepsy.
- The sample was large enough to allow statistical analysis of factors that influenced the overall impact of the illness.
- The measures were wide-ranging enough to capture the overall impact of this condition.
- Patients with PNEAD were all diagnosed at a centre with a proven excellence for diagnosis and management of epilepsy and PNEAD.

4.5.2 Main findings

4.5.2.1 Impact of the Two Conditions

Many of the results of this study showed the greater impact of illness in people with PNEAD than those with epilepsy that was suggested by the study in chapter 3. These differences included: greater report of long-term health problems; more severe description of attacks, both in frequency and severity; higher scores on symptom beliefs scales measuring concern about illness; higher scores on the perceived impact scale; higher levels of depression and anxiety; perception that the illness would last longer; greater illness identity. Greater impact of PNEAD was also seen on quality of life. Patients with PNEAD reported greater impairment on most of the SF-36 scales.

There was also evidence of greater impact on the family: family cohesion scores were lower in PNEAD, and they reported less overall social support from family and relatives than people with epilepsy. These differences were generally the same in males and females. Levels of consultation satisfaction were also lower in PNEAD, as found in chapter 3. Interestingly, PNEAD patients reported that they felt more stigmatised by their condition than those with epilepsy.

4.5.2.2 Patients' Explanations for PNEAD

Patients with PNEAD were more likely to attribute their illness to germs, and also to their own behaviour and thoughts. These results were not found in chapter 3, but the sample of that study was much smaller and they were newly diagnosed.

Perhaps the belief about their own behaviour and thoughts develops because people are searching for an explanation during the period after diagnosis. This belief might give clinicians a focus for psychological intervention. Cognitive-behaviour therapy might be used to help patients understand how to modify their behaviour and thoughts. PNEAD patients also believed more in the effects of chance. Perhaps this reflects their knowledge that their attacks are not caused by a physical disorder such as epilepsy. In the absence of any definite cause for the condition, they may feel that it is much less predictable. The absence of a physical cause may also help to explain why PNEAD patients felt more stigmatised than those with epilepsy. Perhaps this was because they believed that others thought that their attacks were because of mental illness.

4.5.2.3 Influences on Impact

The series of multiple regression analyses examined which variables were most important in explaining the difference in impact between the two conditions. Variables were added in sequence to the regression equation until the group difference was no longer significant. The difference in impact could not be explained by the clinical characteristics of the two conditions (including Seizure Severity and Illness Identity). Neither could the difference be completely explained by including psychological disturbance (Anxiety, Depression, Role-Emotional limitations) in the set of predictor variables. However, when physical problems (General Health, Physical-Functioning, Bodily Pain and Fatigue) were included, the group difference was no longer significant. This suggests that patient-perceived

physical health is a particularly significant factor in explaining the difference in perceived impact of the two conditions.

4.5.3 Clinical Implications

This study shows the importance of an early diagnosis and intervention to prevent the high level of impact developing that this study has shown. This study also has clear implications for how this condition should be managed. These include the following: (i) early detection is necessary; (ii) even though patients blame their PNEAD for their problems in life, the clinician should be aware of the underlying psychological problems that may be present; (iii) referral to an established multidisciplinary team who have expertise in managing this condition is necessary; (iv) to prevent patients with PNEAD feeling so stigmatised, the clinician must develop a good relationship which avoids challenging the patient; (v) patients need to be educated about the nature and causes of PNEAD.

4.5.4 Summary

The study shows that patients with PNEAD are very generally impaired, both physically and psychosocially. This is consistent with previous research where people with PNEAD have a high level of unexplained symptoms and health problems of different kinds (Reilly et al 1999; Moore and Baker 1997). In this study, they also perceived the impact of their condition as being even greater than people with epilepsy. The regression analyses suggest that the greater impairment

(particularly physical impairment) helps to explain why PNEAD patients perceive such a great impact of their condition.

It is well known that physical symptoms are often a way of expressing emotional distress (Murphy 1990; Miliora 1998). It has been shown previously that widespread physical symptoms and impairment reflect reported history of abuse. Therefore one explanation for the present findings is that this group of patients (with PNEAD) may attribute their widespread physical problems to their current disorder rather than to their history of abuse.

CHAPTER 5: CONCLUSION

Chapter 1 showed that PNEAD is a complex condition with relatively high incidence and prevalence. In clinical practice, PNEAD is difficult to manage because so little is known about the psychological and social factors associated with its development and maintenance. As a result, many patients with PNEAD are treated inappropriately. This inappropriate treatment therefore probably adds to their problems in many cases. There are several implications of inappropriate treatment and these include the following: misuse use of anti-epileptic medication and the dangers associated with the long term effects of these drugs; the use of limited health services resources; the failure to provide PNEAD patients with the help that they need.

The findings of this thesis can help in several ways. First, they help to understand the factors that cause and maintain PNEAD, and this information may be useful in supporting the diagnosis of the condition. It should also be part of a full assessment. For instance, clinicians should be aware that many patients with PNEAD have been abused as children, which has been suggested previously on the basis of smaller studies (Betts and Boden 1992; Harden 1997). Asking about abuse is therefore likely to be helpful in understanding how PNEAD might have developed. It may also help to decide what is the most appropriate treatment. For example, it may be necessary to refer abused patients for long-term psychotherapy. Dysfunction in the family of origin was also identified in Chapter 2 as a factor associated with PNEAD. In chapter 4, there was evidence that current family functioning was also impaired in PNEAD. For these patients, family therapy may

therefore be the appropriate treatment. Even if these treatments are not available, the clinician may be able to help patients to understand the relationship of abuse and past or present family functioning with their current symptoms.

The findings also help to understand that PNEAD has a severe impact on patients, despite the absence of a physical disease (Betts & Boden 1992; Gates and Erdahl 1993; Riaz et al 1998). In Chapter 3, the findings identified that, despite the absence of a physical disorder, diagnosis had a significant negative impact. This negative impact may reflect the absence of a clear explanation for the patient, and also the fear that it amounts to a mental illness. These findings highlight the importance of ensuring that the patient does not feel that their symptoms are being dismissed as part of a mental disorder. Patients need a plausible explanation of why this diagnosis was made. Perhaps patients need to understand firstly that their symptoms are not rare, particularly when there is a history of abuse. The success of 'normalising' the symptoms will have significant implications for how well the patient receives the diagnosis.

Chapter 4 showed that, by comparison with epilepsy, patients did not make a positive adjustment to their condition. Even 1-3 years after diagnosis, PNEAD patients were more severely impaired than were those with epilepsy. There could be a number of explanations for this, which include: the failure to accept that the diagnosis is correct; the lack of an appropriate alternative explanation; the failure to provide treatment that addresses the causal factors; the failure to provide treatment that addresses the severe distress and dysfunction associated with this condition.

The prognosis of patients with PNEAD has been evaluated in few controlled studies. The few studies that have been published show that the seizure and psychosocial prognosis is poor (Kristensen and Alving, 1992; Krumholz and Neidermeyer, 1983; McDade and Brown, 1992). The authors of these studies have recommended some important objectives in managing this condition. These include the following: early diagnosis of PNEAD; recognition of the underlying psychological problem; referral to a specialist epilepsy centre; treatment of the underlying problems by a multidisciplinary team with experience of managing this condition. Chapter 2 has shown the importance of identifying the underlying psychological problems, which is an essential aspect of managing PNEAD. Chapter 3 emphasized the importance of establishing a good relationship between the patients and the doctor, even at the time of diagnosis. Patients in the study clearly identified the need to have confidence in their diagnosis. This can only be achieved with good communication between the patients and the doctors. Prognosis has been shown to be good when PNEAD has been managed in a specialist multidisciplinary unit. Where there is a good relationship between the patient and clinicians, which is not confrontational. Proper management of this condition can result in fewer hospital admissions, less unnecessary use of medication and increased employment rates (McDade and Brown, 1992).

Reviews of the studies that have examined the prognosis of PNEAD have suggested that the following factors are likely to be associated with a good outcome: (i) a short duration of PNEAD; (ii) no significant psychiatric problem; (iii) an acute emotional trauma just before the onset. Poor prognosis is therefore associated with longer duration of illness, significant psychiatric problems and the

absence of a traumatic event just before the illness began (Walczak et al, 1995). The present studies found that many patients with PNEAD had a history of trauma in childhood. As yet, the author does not know whether these patients are likely to have a worse outcome than those with more recent traumas instead. This should be studied in future research.

Future research should attempt to replicate these studies and to test models of the ways that different variables link in leading to PNEAD. Although this thesis had larger samples that have been studied before, even larger samples would be needed for the statistical procedures that would be necessary to develop more complex models than those tested here. There also needs to be research that specifically addresses the treatment of PNEAD. A randomised clinical trial comparing different treatments is necessary to test the suggestions made in this thesis (Devinsky 1998). Until now, there is no evidence from large studies about the efficacy of treatment programmes for this condition. Such studies would have to be large to allow test of the possibility, suggested above, that different treatments might be appropriate for patients with different problems.

Ideally, in the future management of PNEAD, patients will undergo a full examination at presentation of their symptoms which would include both electrophysical investigations but also assessment of their previous and present psychological history. Such an approach would allow the clinical team not only to understand the development and maintenance of the condition but also to propose the most appropriate treatment. An early intervention may successfully prevent the

development of severe and chronic symptoms and improve the quality of life of people with PNEAD.

It is very important to make an accurate diagnosis of PNEAD as soon as possible and then provide an appropriate treatment. However, there is little evidence to support many of the treatments currently being provided for PNEAD, and further research should focus on systematically assessing different treatment approaches. This research clearly identified the importance of the role of abuse and the development and maintenance of PNEAD. Therefore, treatment programmes should clearly take into account this factor. This research has also shown the importance of recognizing both the immediate and longer-term impact of PNEAD on the quality of life of those individuals with the condition. This shows the importance of a multi-disciplinary input into management of these patients. The evidence about the role of beliefs suggests also a need for treatment to include an educational component about the nature of PNEAD.

In my own country, there is very little known about PNEAD or somatising disorders in general. It cannot be assumed that results from this study will generalize to the UAE. Ihezue et al (1994) reported that sociocultural factors play an important role in determining the nature of psychiatric morbidity and the pattern of utilization of mental health facilities in the United Arab Emirates. Therefore, appropriate research, taking into account the sociocultural differences, needs to be conducted in UAE. My intention is to return to UAE and establish a programme of research that will highlight the problems of somatisation, particularly in women. I

hope further to use some of the research skills I have gained through my thesis and apply them to this future research.

Future research would address the following questions:

- Whether the rate of PNEAD is similar between the UK and the UAE.
- Whether and how it is possible in the UAE to identify instances of abuse; whether there are similarities in terms of incidence and prevalence of abuse between the UK and the UAE.
- Whether the association between PNEAD and abuse is similar between my own country and the UK.
- Whether there are differences between the two countries in how patients with PNEAD perceived their physical functioning and mental states.

The research will, ultimately, show whether the treatment of PNEAD in the UAE should be similar to that in the UK, or whether the sociocultural differences between the two countries will require different treatment approaches.

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APPENDICES

Patient's Information Sheet

Each week patients are being asked to help our research by filling in a detailed questionnaire. This asks about illness and symptoms which you experience. Some questions ask about your relationships within the family. Other questions ask about personal experiences that might affect how you feel about your health.

Many questions will not necessarily apply to you. However, if our research is to be valid, it is important that all the questions are answered by as many patients as possible. Therefore we are asking whether you would be willing to complete our questionnaire. You do not have to do so. Whether or not you do will not affect your own treatment. If you do decide to take part, this would help us in improving the care we offer to patients in future.

If any question is unclear to you, please ask the researcher to explain it. If you find that you do not want to answer a particular question, please just go on to the next.

Information that we collect will be entirely anonymous and confidential. **PLEASE DO NOT WRITE YOUR NAME.** Your answers will not be disclosed to any of the hospital staff.

Thank you

Suad Al Marzooqi
Postgraduate Research
Associate

Appendix 2.2

QUESTIONNAIRE FOR STUDY 1

We do not need to know your name, but we need to know the following personal details:

1. **How old are you?** -----

2. **What is your sex?**

M or F

3. **Please tick ONE of the following...**

Single Divorced Widowed Married (or living with a partner) Other

4. a) **Please tick ONE of the following that best describes your employment.**

- Employed
- Unemployed
- Self-employed
- Housewife
- Retired
- Student

b) **If you do have a job tick the ONE of the following that best describes it.**

- Unskilled manual
- Skilled manual
- Shopwork/ clerical/ officework
- Skilled technical
- Professional/ managerial

5. **Please tick ONE of the following that best describes your religion.**

- | | | |
|---|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Church of England/Protestant | <input type="checkbox"/> Catholic | <input type="checkbox"/> Jewish |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Muslim | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> None | <input type="checkbox"/> Other | |

6. **Please tick ALL that you have.**

- | | |
|---|--|
| <input type="checkbox"/> O-levels or G.C.S.E. | <input type="checkbox"/> A-levels or equivalent |
| <input type="checkbox"/> University Degree | <input type="checkbox"/> Trade/Technical Qualification |
| <input type="checkbox"/> Professional qualification | <input type="checkbox"/> C.S.E. |
| <input type="checkbox"/> No formal qualifications. | |

Somatisation

How have you felt **DURING** the **PAST SEVEN DAYS** including today? For **EACH** symptom please circle the number which best describes how much it has bothered you during the past seven days.

0: Not at all; 1: A little; 2: Moderately; 3: Quite a bit; 4: Extremely

	Not at all			Extremely	
	0	1	2	3	4
Headaches.	0	1	2	3	4
Faintness or dizziness.	0	1	2	3	4
Pains in the heart or chest.	0	1	2	3	4
Feeling low in energy or showed down.	0	1	2	3	4
Pains in the lower part of your back.	0	1	2	3	4
Soreness of your muscles.	0	1	2	3	4
Trouble getting your breath.	0	1	2	3	4
Hot or cold spells.	0	1	2	3	4
Numbness or tingling in parts of your body.	0	1	2	3	4
A lump in your throat.	0	1	2	3	4
Weakness in parts of your body.	0	1	2	3	4
Heavy feelings in your arms or legs.	0	1	2	3	4

Parental Bonding

This lists various attitudes and behaviors of parents. For each question tick a box to show how much it applied to your **Mother** (or the main person who looked after you if this was not your mother) in your first 16 years.

	Very like	Moderately like	Moderately like	Very unlike
1. Spoke to me with a warm and friendly voice -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Did not help me as much as I needed -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Let me do those things I like doing -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Seemed emotionally cold to me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Appeared to understand my problems and worries -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was affectionate to me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Liked me to make my own decisions -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Did not want me to grow up -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Tried to control everything I did -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Invaded my privacy -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Enjoyed talking things over with me. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Frequently smiled at me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Tended to baby me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Did not seem to understand what I needed or wanted -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Let me decide things for myself -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Made me feel I wasn't wanted -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Could make me feel better when I was upset -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Did not talk with me very much -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Tried to make me dependent on her/him -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Felt I could not look after myself unless she/he was around -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Gave me as much freedom as I wanted -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Let me go out as often as I wanted -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Was overprotective of me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Did not praise me -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Let me dress in any way I pleased -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Illness Behaviour (Hypochondriasis)

Here are some questions about you and your illness. Please circle either **Yes** or **No** to answer each question.

- | | | |
|---|------------|-----------|
| 1. Do you think there is something seriously wrong with your body? | Yes | No |
| 2. Does your illness interfere with your life a great deal? | Yes | No |
| 3. If the doctor told you that he could find nothing wrong with you, would you believe him? | Yes | No |
| 4. If you feel ill and someone tells you that you are looking better, do you become annoyed? | Yes | No |
| 5. Are you more sensitive to pain than other people? | Yes | No |
| 6. Are you afraid of illness? | Yes | No |
| 7. Do you think that you worry about your health more than most people? | Yes | No |
| 8. Do you find that you get jealous of other people's good health? | Yes | No |
| 9. Do you ever have silly thoughts about your health which you can't get out of your mind, no matter how hard you try? | Yes | No |
| 10. Are you upset by the way people take your illness? | Yes | No |
| 11. Are you sleeping well? | Yes | No |
| 12. Do you often think that you might suddenly fall ill? | Yes | No |
| 13. If a disease is brought to your attention (through the radio, television, newspapers or someone you know) do you worry about getting it yourself? | Yes | No |
| 14. Do you find that you are bothered by many different symptoms? | Yes | No |
| 15. Do you find that you are often aware of various things happening in your body? | Yes | No |

Please ensure that you have circled each of the items.

Hospital Anxiety and Depression Scale

Please read each item and tick the box opposite 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 response is better than a long thought-out one.

Tick one box in each section.

I feel tense or 'wound up'

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

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- 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 like 'butterflies' in the stomach:

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

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

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 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

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

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

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- Not too often
- Very little

I look forward with enjoyment to things

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

I feel cheerful

- Never
- Not often
- Sometimes
- Most of the time

I get sudden feelings of panic

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

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

I can enjoy a good book or radio or television program

- Often
- Sometimes
- Not often
- Very seldom

**Drossman's Questionnaire of Sexual, Physical
and Psychological Abuse**

We now know that many people may have unwanted "sexual" or violent experiences as children or adults. Some of these are with playmates or friends, and some with relatives or acquaintances. These experiences may be so upsetting that they may not be discussed with anyone.

Sometimes they are been for long periods of time, and sometimes they are frequently brought to mind.

We would like you to help us understand these experiences that people may have. Please try to remember whether any of the following occurred to you.

For each of the following questions please answer (Yes) or (No) for you **Both** as a **CHILD** and as an **ADULT**.

- | | As a Child
13 and younger | | As an Adult
14 and above | |
|---|--------------------------------------|-----------------------------|-------------------------------------|-----------------------------|
| 1 a. Has anyone ever exposed the sex organs of their body to you when you didn't want it? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| b. Has anyone ever threatened to have sex with you when you didn't want this? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| c. Has anyone ever touched the sex organs of your body when you didn't want this? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| d. Has anyone ever made you touch the sex organs of their body when you didn't want this? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| e. Has anyone ever tried forcefully or succeeded to have sex with you when you didn't want this? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| f. Have you had any other unwanted sexual experiences not mentioned above? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

If you answer yes to the last question, please tell us what these were if you are happy to do so.

2. When you were a child, did an older person do the following:

a. Insult or humiliate you, or try to make you feel guilty?

Never

Seldom

Occasionally

Often

b. Hit, kick or beat you?

Never

Seldom

Occasionally

Often

3. Now, that you are an adult, does any other adult do the following?

a. Insult or humiliate you, or try to make you feel guilty?

Never

Seldom

Occasionally

Often

b. Hit, kick or beat you?

Never

Seldom

Occasionally

Often

**4. Have you ever discussed these experiences with anyone before
(relating to questions on this page and the one before)?**

Never

Yes, with a friend or acquaintance.

Yes, with a minister or lay counselor.

Yes, with a family member.

Yes, with a professional counselor (psychologist, physician).

5. Are you now seeing a counselor for these or any other emotional concerns?

Yes

No

Rosenberg's Self-esteem Scale

Here are some items to show how you feel about yourself. Please tick one box for each item.

	Strongly agree	Agree	Disagree	Strongly disagree
a. I feel that I'm a person of worth, at least on an equal plane with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I feel that I have a number of good qualities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. All in all, I am inclined to feel that I am a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I am able to do most things as well as most other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I feel I do not have much to be proud of.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I take a positive attitude toward myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. On the whole, I am satisfied with myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I wish I could have more respect for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I. I certainly feel useless at times.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. At times I think I am no good at all.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Family Environmental Scale

There are statements about families. Please decide which of these statements are **True** of your family and which are **False**. If you think the statement is **True** or mostly **True** of your family, **Please Circle T**. If you think the statement is **False** or mostly **False** of your family, **Please Circle F**.

- | | | |
|---|----------|----------|
| 1. Family members really help and support one another. | T | F |
| 2. Family members often keep their feelings to themselves. | T | F |
| 3. We fight a lot in our family. | T | F |
| 4. We don't do things on our own very often in our family. | T | F |
| 5. We feel it is important to be the best at whatever you do. | T | F |
| 6. We often talk about political and social problems. | T | F |
| 7. We spend most weekends and evenings at home. | T | F |
| 8. Family members attend church, synagogue,
or Sunday School fairly often. | T | F |
| 9. Activities in our family are pretty carefully planned. | T | F |
| 10. Family members are rarely ordered around. | T | F |
| 11. We often seem to be killing time at home. | T | F |
| 12. We say anything we want to around home. | T | F |
| 13. Family members rarely become openly angry. | T | F |
| 14. In our family, we are strongly encouraged to be independent. | T | F |
| 15. Getting ahead in life is very important in our family. | T | F |
| 16. We rarely go to lectures, plays or concerts. | T | F |
| 17. Friends often come over for dinner or to visit. | T | F |
| 18. We don't say prayers in our family. | T | F |
| 19. We are generally very neat and orderly. | T | F |

Please remember to circle a response for each of the items.

- | | | |
|--|---|---|
| 20. There are very few rules to follow in our family. | T | F |
| 21. We put a lot of energy into what we do at home. | T | F |
| 22. It's hard to "blow off steam" at home without upsetting somebody. | T | F |
| 23. Family members sometimes get so angry they throw things. | T | F |
| 24. We think things out for ourselves in our family. | T | F |
| 25. How much money a person makes is not very important to us. | T | F |
| 26. Learning about new and different things is very important in our family. | T | F |
| 27. Nobody in our family is active in sports, Little League, bowling, etc. | T | F |
| 28. We often talk about the religious meaning of Christmas, Passover, or other holidays. | T | F |
| 29. It's often hard to find things when you need them in our household. | T | F |
| 30. There is one family member who makes most of the decisions. | T | F |
| 31. There is a feeling of togetherness in our family. | T | F |
| 32. We tell each other about our personal problems. | T | F |
| 33. Family members hardly ever lose their tempers. | T | F |
| 34. We come and go as we want to in our family. | T | F |
| 35. We believe in competition and "may the best man win." | T | F |
| 36. We are not that interested in cultural activities. | T | F |
| 37. We often go to movies, sports events, camping, etc. | T | F |
| 38. We don't believe in heaven or hell. | T | F |
| 39. Being on time is very important in our family. | T | F |

Please remember to circle a response for each of the items.

40. There are set ways of doing things at home.	T	F
41. We rarely volunteer when something has to be done at home.	T	F
42. If we feel like doing something on the spur of the moment we often just pick up and go.	T	F
43. Family members often criticize each other.	T	F
44. There is very little privacy in our family.	T	F
45. We always strive to do things just a little better the next time.	T	F
46. We rarely have intellectual discussion.	T	F
47. Everyone in our family has a hobby or two.	T	F
48. Family members have strict ideas about what is right and wrong.	T	F
49. People change their minds often in our family.	T	F
50. There is a strong emphasis on following rules in our family.	T	F
51. Family members really back each other up.	T	F
52. Someone usually gets upset if you complain in our family.	T	F
53. Family members sometimes hit each other.	T	F
54. Family members almost always rely on themselves when a problem comes up.	T	F
55. Family members rarely worry about job promotions, school, grades, etc.	T	F
56. Someone in our family plays a musical instrument.	T	F
57. Family members are not very involved in recreational activities outside work or school.	T	F
58. We believe there are some things you just have to take on faith.	T	F

Please remember to circle a response for each of the items.

59. Family members make sure their rooms are neat.	T	F
60. Everyone has an equal say in family decisions.	T	F
61. There is very little group spirit in our family.	T	F
62. Money and paying bills is openly talked about in our family.	T	F
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	T	F
64. Family members strongly encourage each other to stand up for their rights.	T	F
65. In our family, we don't try that hard to succeed.	T	F
66. Family members often go to the library.	T	F
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).	T	F
68. In our family each person has different ideas about what is right and wrong.	T	F
69. Each person's duties are clearly defined in our family.	T	F
70. We can do whatever we want to in our family.	T	F
71. We really get along well with each other.	T	F
72. We are usually careful about what we say to each other.	T	F
73. Family members often try to one-up or out-do each other.	T	F
74. It's hard to be by yourself without hurting someone's feelings in our household.	T	F
75. "Work before play" is the rule in our family.	T	F
76. Watching TV is more important than reading in our family.	T	F
77. Family members go out a lot.	T	F

Please ensure that you have circled each of the items.

78. The Bible is a very important book in our home.	T	F
79. Money is not handled very carefully in our family.	T	F
80. Rules are pretty inflexible in our household.	T	F
81. There is plenty of time and attention for everyone in our family.	T	F
83. In our family, we believe you don't ever get anywhere by raising your voice.	T	F
84. We are not really encouraged to speak up for ourselves in our family.	T	F
85. Family members are often compared with others as to how well they are doing at work or school.	T	F
86. Family members really like music, art and literature.	T	F
87. Our main form of entertainment is watching TV or listening to the radio.	T	F
88. Family members believe that if you sin you will be punished.	T	F
89. Dishes are usually done immediately after eating.	T	F
90. You can't get away with much in our family.	T	F

Please remember to circle a response for each of the items.



THE UNIVERSITY
of LIVERPOOL

Thank you for filling in this questionnaire. Please feel free to ask me any questions that you may have about it.

Thank you for cooperation.

Patient's Information Sheet

We are asking people attending outpatients' clinics who suffer from attacks to help us in this follow-up study.

If you agree to take part, we will ask you to complete a questionnaire concerning how you cope with attacks, and how much you feel that your attacks affect your everyday life. It should take approximately 30-45 minutes to complete.

Your name and address do not appear anywhere in this questionnaire. The information you give us will not be used in any way that could identify you personally. No information will be passed to your GP or specialist or seen by anyone other than the staff involved in the research. If you decide you do not wish to answer the questionnaires, this will not affect your treatment.

Please feel free to ask any questions you may have before starting.

Thank you for cooperation

**Suad Al Marzooqi
Postgraduate Research
Associate**

QUESTIONNAIRE FOR STUDY 2

We do not need to know your name, but we need to know the following personal details:

1. **How old are you?** -----

2. **What is your sex?**

M or F

3. **Please tick ONE of the following...**

Single Divorced Widowed Married (or living with a partner) other

4. a) **Please tick ONE of the following that best describes your employment.**

- Employed
- Unemployed
- Self-employed
- Housewife
- Retired
- Student

b) **If you do have a job tick the ONE of the following that best describes it.**

- Unskilled manual
- Skilled manual
- Shopwork/ clerical/ officework
- Skilled technical
- Professional/ managerial

5. **Please tick ONE of the following that best describes your religion.**

- | | | |
|---|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Church of England/Protestant | <input type="checkbox"/> Catholic | <input type="checkbox"/> Jewish |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Muslim | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> None | <input type="checkbox"/> Other | |

6. **Please tick ALL that you have.**

- | | |
|---|--|
| <input type="checkbox"/> O-levels or G.C.S.E. | <input type="checkbox"/> A-levels or equivalent |
| <input type="checkbox"/> University Degree | <input type="checkbox"/> Trade/Technical Qualification |
| <input type="checkbox"/> Professional qualification | <input type="checkbox"/> C.S.E. |
| <input type="checkbox"/> No formal qualifications. | |

Features and Types of Attacks

Some questions about your attacks.

- 1. How old were you when you had your first attack? Years
 - 2. How old were you when you had your last attack? Years
 - 3. Have you ever had a period of at least 2 years when you were free of attacks? Yes
..... No
 - 4. Apart from your attacks, do you have any long-term problems with your health? Yes
..... No
 - 5. Did your mother or father or any of your brothers or sisters have attacks? Yes
..... No
 - 6. How many attacks have you had in the past year?
None.....
Less than one per month.....
One or more per month.....
-

7. Below are some descriptions of different kinds of attacks. Which of these descriptions matches the attacks you have?

(You may , of course, have more than one kind of attack. If so, please tick All the attacks that apply to you).

A grand mal attack. Unconsciousness with the body becoming stiff with jerking of all the limbs, and frothing at the mouth, possibly with difficulty breathing. Followed by a period sleepiness and confusion lasting for at least 5 minutes before a full recovery

A petit mal attack. A brief episode of no more than a few seconds with blankness without falling and possibly flickering of the eyelid

Attacks with a trance-like state, sometimes with lip-smacking, swallowing, gesturing or fidgeting, followed by confusion, usually with at least a minute before full recovery

Attacks of falling with brief loss of consciousness preceded by a feeling of light-headedness which comes on gradually, but which may be allowed by sweating and clamminess, shakiness and sickness.

Brief jerks of the arms and body (sometimes the legs) occurring usually within an hour or two of waking without any blackout

Some other kind of attacks.....
(Please describe)

Illness Perception Questionnaire

Please indicate how frequently you now experience each of the following symptoms as part of your attacks.

Symptom	All of the time	Frequently	Occasionally	Never
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Headaches				
Upset Stomach				
Sleep Difficulties				
Lack of Strength				

We are interested in how you see your attacks. Please indicate how much you Agree or Disagree with the following statements about your attacks by ticking the box that best describes how you see your attacks.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. A germ or virus caused my attacks.					
2. Diet played a major role in causing my attacks.					
3. Pollution of the environment caused my attacks.					
4. My attacks are hereditary- they run in my family.					
5. It was just by chance that I became ill.					
6. Stress is a major factor in causing my attacks.					
7. My attacks are largely due to my own behaviour					
8. Other people play a large role in causing my attacks.					
9. My state of mind plays a major part in causing my attacks.					
10. My attacks will stop in near future.					

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
11. I am always likely to have attacks.					
12. I will keep having attacks for a long time.					
13. My attacks are a serious condition.					
14. My attacks have had major consequences on my life.					
15. My attacks have become easier to live with.					
16. My attacks have not had much effect on my life.					
17. My attacks have strongly affected the way others see me.					
18. My attacks have serious economic and financial consequences.					
19. My attacks have strongly affected the way I see myself as a person.					
20. My attacks will improve in time.					
21. There is a lot which I can do to control my symptoms.					
22. There is very little that can be done to improve my attacks.					
23. My treatment will be effective in curing my attacks.					
24. Recovery from my attacks is largely dependent on chance or fate.					
25. What I do can determine whether my attacks get better or worse.					

Symptom Beliefs Questionnaire

Many people believe that their attacks can be caused by different things. For each of the following, tick the box to show whether you think it **Probably Does** or **Probably Does not help to cause your attack**.
(Please answer every item.)

	PROBABLY DOES HELP TO CAUSE	DON'T KNOW	PROBABLY DOES NOT HELP TO CAUSE
Over-work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A "weak spot" in my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My moods/emotions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Part of my body is inflamed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Demanding family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y job/housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working or living conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weak constitution/low resistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
"Nerves"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being rundown	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal, financial or domestic problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Here are statements about your attacks. For each set of 3 please tick the **ONE** statement which best applies to you.

1. I have not thought about what has caused my attacks.
- I have thought a little about what has caused my attacks.
- I have thought a lot about the cause of my attacks.
2. I have no idea of the reason for my attacks.
- I have some idea of the reason for my attacks.
- I think I know the reason for my attacks.
3. Whatever caused my attacks has **probably** been going on a long while.
- Whatever caused my attacks **may** have been going on a long while.
- Whatever caused my attacks had probably **not** been going on for long.

Seizure Severity Scale

Now some more detailed questions about the attacks you have.

Please take care to answer every question. (Tick the response that best describes your attacks)

1. How often have your attacks occurred at a particular time of day or night? will happen?

- always
- usually
- sometimes
- never-my attacks occur at any time

2. When you attacks have happened, how often have you been able to tell that they

- always
- usually
- sometimes
- never

3. How often have you been able to fight off your attacks?

- always
- usually
- sometimes
- never

4. How often have you had an aura or warning wit your attacks?

- always
- usually
- sometimes
- never

my attacks have only been auras or whamming

5. How much control do you feel you have over your attacks?

- very good control
- fairly good control
- little control
- no control

6. When you have had attacks, how often have they occurred together in clusters with quite long period between each cluster?

- always
- usually
- sometimes
- never

7. How often did your attacks occur when you were asleep?

- Always
- usually
- sometimes
- never

8. How many of the things you want to do have your attacks stopped you doing?

- all of them
- a lot of them
- a few of them
- none of them

9. Overall, how severe have your attacks been in the last year?

- very severe
- sever
- mild
- very mild

10. In the last year, have you bland out/lost consciousness during attacks? If yes, for how long?

- yes, for less than 1 minute
- yes, for between 1-2 minutes
- yes, for between 2-5 minutes
- yes, for more than 5 minutes
- no, I have not blanked out/lost

consciousness

11. When you have an attack do you smack your lips, fidget or behave in an unusual way?

- yes, always
- yes, usually
- yes, sometimes
- No, never

13. When you recovered from your attacks how confused did you feel?

- very confused
- fairly confused
- slightly confused
- not feel confused at all

15. When you recover from your attacks, how often do you have a headache?

- always
- usually
- sometimes
- never

17. When you recover from your attacks, how often do you find that tongue?

you had wet yourself?

- always
- usually
- sometimes
- never

19. When you recover from your attacks how often do you find that you have injured yourself (other than biting your tongue)?

- always
- usually
- sometimes
- never

12. When you recover from your attacks, do you feel confused? If yes, for how long?

- yes, for less than 1 minute
- yes, for between 1-5 minutes
- yes, for between 6 minutes-1 hour
- yes, for over 1 hour
- I do not know

14. When you have your attacks, how often do you fall to the ground?

- always
- usually
- sometimes
- never

16. When you recovered from your attacks, how often did you feel sleepy?

- always
- usually
- sometimes
- never

18. When you recover from your attacks, how often do you find that you have bitten your

- always
- usually
- sometimes
- never

20. When you have your attacks, how quickly can you usually return to what you were doing?

- less than 1 minute
- between 1-5 minutes
- between 6 minutes-1 hour
- over 1 hour

Short-Form 36 Health Survey

This questionnaire asks for your views about your health. Your disability is an important part of your health and you should take it into account when answering the questionnaire.

Answer every question by either ticking the box or circling the number that best describes your attacks. If you are unsure how to answer a question, please give the best answer you can.

1. In general would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

2. Compared to one year ago, how would you rate your health in general now?

- Much better now than one year ago
- A little better now than one year ago
- About the same
- A little worse than one year ago
- Much worse than one year ago

3. The following questions are about activities you might do during a typical day. Does your health limit you in these activities? (circle 1, 2 or 3 on each line.)

	Yes limited a lot	Yes limited a little	No, Not limited at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf.	1	2	3
c. Lifting or carrying groceries.	1	2	3
d. Climbing several flights of stairs.	1	2	3
e. Climbing one flight of stairs.	1	2	3
f. Bending, kneeling or stooping.	1	2	3
g. Walking more than a mile.	1	2	3
h. Walking less than a mile but more than 100 yards.	1	2	3
i. Walking about 100 yards.	1	2	3
j. Bathing and dressing yourself.	1	2	3

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your health? (Please answer YES or NO for each question by circling 1 or 2 on each line.)

	YES	NO
a. Have you had to cut down the amount of time you spent on or other activities.	1	2
b. Have you accomplished less than you would like.	1	2
c. Were you limited in the kind of work or other activities you could do.	1	2
d. Had you had difficulty performing the work or other activities (for example it took extra effort)	1	2

5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional problems** (such as feeling depressed or anxious)? Please answer YES or NO for each question by circling 1 or 2 on each line.

	YES	NO
a. Do you feel you have had to cut down the amount of time you spent on work or other activities.	1	2
b. Do you feel you have accomplished less than you would like.	1	2
c. Do you feel that you have not worked as carefully as usual.	1	2

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Tick one box)

- | | |
|------------|--------------------------|
| Not at all | <input type="checkbox"/> |
| Slightly | <input type="checkbox"/> |
| Moderately | <input type="checkbox"/> |
| Quit a bit | <input type="checkbox"/> |
| Extremely | <input type="checkbox"/> |
-

7. How much bodily pain have you had during the **past 4 weeks**?

(Tick one box)

- | | |
|-------------|--------------------------|
| None | <input type="checkbox"/> |
| Very mild | <input type="checkbox"/> |
| Mild | <input type="checkbox"/> |
| Moderate | <input type="checkbox"/> |
| Severe | <input type="checkbox"/> |
| Very severe | <input type="checkbox"/> |

8. During the past 4 weeks, how much did the pain interfere with your normal work (including work both outside the home and housework)?

(Tick one box)

- | | |
|-------------|--------------------------|
| Not at all | <input type="checkbox"/> |
| Very mild | <input type="checkbox"/> |
| Moderately | <input type="checkbox"/> |
| Quite a bit | <input type="checkbox"/> |
| Extremely | <input type="checkbox"/> |

9. These questions are about **how you feel and how things have been with you during the past month**. For each question, please tick one answer that comes closest to the way you have been feeling.

How much of the time during the **Past month**....

(Tick one box on each line)

	All of the Time	Most of the Time	A Good bit of the Time	Some of the Time	A little of the Time	None of the Time
a. Did you feel full of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you felt fed up.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt fed up.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Have you felt calm and peaceful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you have a lot of energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Have you been happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Did you feel worn out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Have you been happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did you feel tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Has your health limited your social life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Please choose the answer that best describes how **True** or **False** each of the following statements in for you is about your health in general.

(tick one box on each line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
a. I seem to suffer with my health more than most people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My health is as good as most peoples.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I do not think that my health is going to improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In general my health is excellent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hospital Anxiety and Depression Scale

Please read each item and tick the box opposite 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 response is better than a long thought-out one.

Tick one box in each section.

I feel tense or 'wound up'

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

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- 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 like 'butterflies' in the stomach:

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

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

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 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

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

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

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- Not too often
- Very little

I look forward with enjoyment to things

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

I feel cheerful

- Never
- Not often
- Sometimes
- Most of the time

I get sudden feelings of panic

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

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

I can enjoy a good book or radio or television program

- Often
- Sometimes
- Not often
- Very seldom

Cohesion Sub-scale of the Family Environmental Scale

Here are statements about your family (this means the family that you live with). For each one please decide whether it is **True** of your family or **False**. If you think the statement is **True** or mostly **True** of your family, please circle **T**. If you think the statement is **False** or mostly **False** of your family, please Circle **F**.

- | | | |
|--|----------|----------|
| 1. Family members really help and support one another. | T | F |
| 2. We often seem to be killing time at home. | T | F |
| 3. We put a lot of energy into what we do at home. | T | F |
| 4. There is a feeling of togetherness in our family. | T | F |
| 5. We rarely volunteer when something has to be done at home. | T | F |
| 6. Family members really back each other up. | T | F |
| 7. There is very little group spirit in our family. | T | F |
| 8. We really get along well with each other. | T | F |
| 9. There is plenty of time and attention for everyone in our family. | T | F |

Please fill in the other coloured sheets after SEEING THE CONSULTANT.

Consultation Satisfaction Scale

The following questions ask you **what you think of your today's visit to the doctor**. Please circle the answer that is closest to what you think. "Neutral" means you have no feelings either way.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. I am totally satisfied with my visit to this doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This doctor was very careful to check everything when examining me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I will follow this doctor's advice because I think he/she is absolutely right.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt able to tell this doctor about very personal things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The time I was able to spend with the doctor was not long enough to deal with everything I wanted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. This doctor told me everything about my treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Some things about my consultation with the doctor could have been better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. There are some things this doctor does not know about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. The doctor examined me very thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I thought this doctor took notice of me as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The time I was allowed to spend with the doctor was not long enough to deal with everything I wanted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I understand my illness much better after seeing this doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. This doctor was interested in me as a person, not just my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. This doctor knows all about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I felt this doctor really knew what I was thinking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I wish it had been possible to spend a little longer with the doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am not completely satisfied with my visit to the doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I would find it difficult to tell this doctor about some private things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Attitudes Towards Diagnosis Scale

For each question, please tick one box that describes your views.

1. What is **your family's** view of the doctor's diagnosis?

- Certainly correct
- Probably correct
- Unsure
- Probably wrong
- Certainly wrong

2. Does **your family** believe that more tests should be carried out to check the diagnosis?

- Certainly
- Probably
- Unsure
- Probably not
- Certainly not

3. Does **your family** believe that a second opinion is needed?

- Certainly
- Probably
- Unsure
- Probably not
- Certainly not

4. What is **your view** of the doctor's diagnosis

- Certainly correct
- Probably correct
- Unsure
- Probably wrong
- Certainly wrong

5. Do **you believe** that more tests should be carried out to check the diagnosis?

- Certainly correct
- Probably correct
- Unsure
- Probably wrong
- Certainly wrong

6. Do **you believe** that a second opinion is needed?

- Certainly
- Probably
- Unsure
- Probably not
- Certainly not

Thank you for filling in this questionnaire. Please feel free to ask me any questions that you may have about it.

Please check that you have answered all the questions....

Thank you for co-operation.

Letter to Patient

Dear...

Three months ago you were kind enough to complete a questionnaire for us on living with attacks. I enclose the follow up questionnaire for you complete and a stamped addressed envelope for its return.

many thanks for your help

Yours sincerely

Suad Al Marzooqi

Postgraduate Research Associate

Under the supervision of:

Dr. Gus A. Baker

Senior Lecturer in Clinical Neuropsychology

Consultant Clinical Neuropsychologist

Patient's Information Sheet

We are asking people attending outpatients' clinics who suffer from attacks to help us.

If you agree to take part, we will ask you to complete a questionnaire concerning how you cope with attacks, and how much you feel that your attacks affect your everyday life. It should take approximately 30-45 minutes to complete.

Your name and address do not appear anywhere in this questionnaire. The information you give us will not be used in any way that could identify you personally. No information will be passed to your GP or specialist or seen by anyone other than the staff involved in the research. If you decide you do not wish to answer the questionnaires, this will not affect your treatment.

Please feel free to ask any questions you may have before starting.

Thank you for cooperation

**Suad Al Marzooqi
Postgraduate Research
Associate**

QUESTIONNAIRE FOR STUDY 3

We do not need to know your name, But we need to know the following personal details:

1. **How old are you?** -----

2. **What is your sex?**

M or F

3. **Please tick ONE of the following...**

Single Divorced Widowed Married (or living with a partner) other

4. a) **Please tick ONE of the following that best describes your employment.**

- Employed
- Unemployed
- Self-employed
- Housewife
- Retired
- Student

b) **If you do have a job tick the ONE of the following that best describes it.**

- Unskilled manual
- Skilled manual
- Shopwork/ clerical/ officework
- Skilled technical
- Professional/ managerial

5. **Please tick ONE of the following that best describes your religion.**

- | | | |
|---|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Church of England/Protestant | <input type="checkbox"/> Catholic | <input type="checkbox"/> Jewish |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Muslim | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> None | <input type="checkbox"/> Other | |

6. **Please tick ALL that you have.**

- | | |
|---|--|
| <input type="checkbox"/> O-levels or G.C.S.E. | <input type="checkbox"/> A-levels or equivalent |
| <input type="checkbox"/> University Degree | <input type="checkbox"/> Trade/Technical Qualification |
| <input type="checkbox"/> Professional qualification | <input type="checkbox"/> C.S.E. |
| <input type="checkbox"/> No formal qualifications. | |

Features and Types of Attacks

Some questions about your attacks.

1. How old were you when you had your first attack? Years
 2. How old were you when you had your last attack? Years
 3. Have you ever had a period of at least 2 years when you were free of attacks? Yes
..... No
 4. Apart from your attacks, do you have any long-term problems with your health? Yes
..... No
 5. Did your mother or father or any of your brothers or sisters have attacks? Yes
..... No
 6. How many attacks have you had in the past year?
None.....
Less than one per month.....
One or more per month.....
-

7. Below are some descriptions of different kinds of attacks. Which of these descriptions matches the attacks you have?

(You may, of course, have more than one kind of attack. If so, please tick All the attacks that apply to you).

A grand mal attack. Unconsciousness with the body becoming stiff with jerking of all the limbs, and frothing at the mouth, possibly with difficulty breathing. Followed by a period sleepiness and confusion lasting for at least 5 minutes before a full recovery

A petit mal attack. A brief episode of no more than a few seconds with blankness without falling and possibly flickering of the eyelid

Attacks with a trance-like state, sometimes with lip-smacking, swallowing, gesturing or fidgeting, followed by confusion, usually with at least a minute before full recovery

Attacks of falling with brief loss of consciousness preceded by a feeling of light-headedness which comes on gradually, but which may be allowed by sweating and clamminess, shakiness and sickness.

Brief jerks of the arms and body (sometimes the legs) occurring usually within an hour or two of waking without any blackout

Some other kind of attacks.....
(Please describe)

Illness Perception Questionnaire

Please indicate how **frequently** you now experience **each** of the following symptoms as part of **your attacks**.

Symptom	All of the time	Frequently	Occasionally	Never
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Headaches				
Upset Stomach				
Sleep Difficulties				
Lack of Strength				

We are interested in **how you see your attacks**. Please indicate how much you **Agree** or **Disagree** with the following statements about your attacks by ticking the box that best describes how you see your attacks.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. A germ or virus caused my attacks.					
2. Diet played a major role in causing my attacks.					
3. Pollution of the environment caused my attacks.					
4. My attacks are hereditary- they run in my family.					
5. It was just by chance that I became ill.					
6. Stress is a major factor in causing my attacks.					
7. My attacks are largely due to my own behaviour					
8. Other people play a large role in causing my attacks.					
9. My state of mind plays a major part in causing my attacks.					
10. My attacks will stop in near future.					

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
11. I am always likely to have attacks.					
12. I will keep having attacks for a long time.					
13. My attacks are a serious condition.					
14. My attacks have had major consequences on my life.					
15. My attacks have become easier to live with.					
16. My attacks have not had much effect on my life.					
17. My attacks have strongly affected the way others see me.					
18. My attacks have serious economic and financial consequences.					
19. My attacks have strongly affected the way I see myself as a person.					
20. My attacks will improve in time.					
21. There is a lot which I can do to control my symptoms.					
22. There is very little that can be done to improve my attacks.					
23. My treatment will be effective in curing my attacks.					
24. Recovery from my attacks is largely dependent on chance or fate.					
25. What I do can determine whether my attacks get better or worse.					

Symptom Beliefs Questionnaire

Many people believe that their attacks can be caused by different things. For each of the following, tick the box to show whether you think it **Probably Does** or **Probably Does not help to cause your attack**.
(Please answer every item.)

	PROBABLY DOES HELP TO CAUSE	DON'T KNOW	PROBABLY DOES NOT HELP TO CAUSE
Over-work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A "weak spot" in my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My moods/emotions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Part of my body is inflamed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Demanding family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y job/housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working or living conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weak constitution/low resistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
"Nerves"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being rundown	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal, financial or domestic problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Here are statements about your attacks. For each set of 3 please tick the **ONE** statement which best applies to you.

1. I have not thought about what has caused my attacks.
 I have thought a little about what has caused my attacks.
 I have thought a lot about the cause of my attacks.
2. I have no idea of the reason for my attacks.
 I have some idea of the reason for my attacks.
 I think I know the reason for my attacks.
3. Whatever caused my attacks has **probably** been going on a long while.
 Whatever caused my attacks **may** have been going on a long while.
 Whatever caused my attacks had probably **not** been going on for long.

Seizure Severity Scale

Now some more detailed questions about the attacks you have.

Please take care to answer every question. (Tick the response that best describes your attacks)

1. How often have your attacks occurred at a particular time of day or night? will happen?

- always
- usually
- sometimes
- never-my attacks occur at any time

2. When you attacks have happened, how often have you been able to tell that they

- always
- usually
- sometimes
- never

3. How often have you been able to fight off your attacks?

- always
- usually
- sometimes
- never

4. How often have you had an aura or warning with your attacks?

- always
- usually
- sometimes
- never
- my attacks have only been auras or whamming

5. How much control do you feel you they have over your attacks?

- very good control
- fairly good control
- little control
- no control

6. When you have had attacks, how often have occurred together in clusters with quite long period between each cluster?

- always
- usually
- sometimes
- never

7. How often did your attacks occur your when you were asleep?

- Always
- usually
- sometimes
- never

8. How many of the things you want to do have attacks stopped you doing?

- all of them
- a lot of them
- a few of them
- none of them

9. Overall, how severe have your attacks been in the last year?

- very severe
- sever
- mild
- very mild

10. In the last year, have you blanked out/lost consciousness during attacks? If yes, for how long?

- yes, for less than 1 minute
- yes, for between 1-2 minutes
- yes, for between 2-5 minutes
- yes, for more than 5 minutes
- no, I have not blanked out/lost consciousness

11. When you have an attack do you feel smack your lips, fidget or behave in an usual way?

- yes, always
- yes, usually
- yes, sometimes
- No, never

12. When you recover from your attacks, do you confused? If yes, for how long?

- yes, for less than 1 minute
- yes, for between 1-5 minutes
- yes, for between 6 minutes-1 hour
- yes, for over 1 hour
- I do not know

13. When you recovered from your attacks how confused did you feel?

- very confused
- fairly confused
- slightly confused
- not feel confused at all

14. When you have your attacks, how often do you fall to the ground?

- always
- usually
- sometimes
- never

15. When you recover from your attacks, how often do you have a headache?

- always
- usually
- sometimes
- never

16. When you recovered from your attacks, how often did you feel sleepy?

- always
- usually
- sometimes
- never

17. When you recover from your attacks, how often do you find that you had wet yourself?

- always
- usually
- sometimes
- never

18. When you recover from your attacks, how often do you find that you have bitten your tongue?

- always
- usually
- sometimes
- never

19. When you recover from your attacks how often do you find that you have injured yourself (other than biting your tongue)?

- always
- usually
- sometimes
- never

20. When you have your attacks, how quickly can you usually return to what you were doing?

- less than 1 minute
- between 1-5 minutes
- between 6 minutes-1 hour
- over 1 hour

Stigma Scale and Impact of Epilepsy Scale

Are you currently taking any drugs to control your attacks? Yes.....[Go to (a)]
 No..... [Go to (b)]

a). Which of the following are you taking?

- | | | | |
|---------------------------------|--------------------------|----------------------------------|--------------------------|
| Carbamazepine or Tegretol | <input type="checkbox"/> | Phenobarbitone or Prominal | <input type="checkbox"/> |
| Calobazam or Frisium | <input type="checkbox"/> | Primidone or Mysoline | <input type="checkbox"/> |
| Clonazepam or Rivotril | <input type="checkbox"/> | Sodium Valproate or Epilim | <input type="checkbox"/> |
| Lamotrigine or Iomictal | <input type="checkbox"/> | Vigabatrin or Sabril | <input type="checkbox"/> |
| Phenytoin or Epanutin | <input type="checkbox"/> | Ethosuximide or Zarontin | <input type="checkbox"/> |

b). During the **last year**, how many times have you consulted your GP (family doctor) or another doctor in the same practice? (That is, actually seen the doctor, not just collected a repeat prescription)?

Not at all.....
 Number of times (please write in).....

Below are some statements about how you feel with or towards other people. For each statement, if your answer is **Yes**, ring 1; if **No**, ring 0 .

Because of my attacks:	YES	NO
a) I feel that some people are uncomfortable with me	1	0
b) I feel some people treat me like an inferior person	1	0
c) I feel some people would prefer to avoid me	1	0

We would like to know how much you feel your attacks and their treatment affect your everyday life. For each item listed, **please tick the response which shows best how you feel.**

Do your attacks and its treatment affect:

	A lot	Some	A little	Not at all	Not applicable
1. Your relationship with your spouse/partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Your relationship with other members of your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Your social life and social activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Whether or not you are able to work in paid employment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The kind of paid work you can do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Your health overall?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Your relationship with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The way you feel about yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Your future plans and ambitions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Your standard of living?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Short-Form 36 Health Survey

This questionnaire asks for your views about your health. Your disability is an important part of your health and you should take it into account when answering the questionnaire.

Answer every question by either ticking the box or circling the number that best describes your attacks. If you are unsure how to answer a question, please give the best answer you can.

1. In general would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

2. Compared to one year ago, how would you rate your health in general now?

- Much better now than one year ago
- A little better now than one year ago
- About the same
- A little worse than one year ago
- Much worse than one year ago

3. The following questions are about activities you might do during a typical day. Does your health limit you in these activities? (circle 1, 2 or 3 on each line.)

limited	Yes limited a lot	Yes limited a little	No, Not at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf.	1	2	3
c. Lifting or carrying groceries.	1	2	3
d. Climbing several flights of stairs.	1	2	3
e. Climbing one flight of stairs.	1	2	3
f. Bending, kneeling or stooping.	1	2	3
g. Walking more than a mile.	1	2	3
h. Walking less than a mile but more than 100 yards.	1	2	3
i. Walking about 100 yards.	1	2	3
j. Bathing and dressing yourself.	1	2	3

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your health? (Please answer YES or NO for each question by circling 1 or 2 on each line.)

	YES	NO
a. Have you had to cut down the amount of time you spent on or other activities.	1	2
b. Have you accomplished less than you would like.	1	2
c. Were you limited in the kind of work or other activities you could do.	1	2
d. Had you had difficulty performing the work or other activities (for example it took extra effort)	1	2

5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional problems** (such as feeling depressed or anxious)? Please answer YES or NO for each question by circling 1 or 2 on each line.

	YES	NO
a. Do you feel you have had to cut down the amount of time you spent on work or other activities.	1	2
b. Do you feel you have accomplished less than you would like.	1	2
c. Do you feel that you have not worked as carefully as usual.	1	2

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Tick one box)

- Not at all
 - Slightly
 - Moderately
 - Quit a bit
 - Extremely
-

7. How much bodily pain have you had during the **past 4 weeks**?

(Tick one box)

- None
- Very mild
- Mild
- Moderate
- Severe
- Very severe

8. During the past 4 weeks, how much did the pain interfere with your normal work (including work both outside the home and housework)?

(Tick one box)

- Not at all
- Very mild
- Moderately
- Quite a bit
- Extremely

9. These questions are about **how you feel and how things have been with you during the past month**. For each question, please tick one answer that comes closest to the way you have been feeling.

How much of the time during the **Past month**....

(Tick one box on each line)

	All of the Time	Most of the Time	A Good bit of the Time	Some of the Time	A little of the Time	None of the Time
a. Did you feel full of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Have you felt fed up.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Have you felt fed up.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Have you felt calm and peaceful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you have a lot of energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Have you been happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Did you feel worn out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Have you been happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did you feel tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Has your health limited your social life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Please choose the answer that best describes how **True** or **False** each of the following statements in for you is about your health in general.

(tick one box on each line)

	Definitely True	Mostly True	Not Sure	Mostly False	False
a. I seem to suffer with my health more than most people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My health is as good as most peoples.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I do not think that my health is going to improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In general my health is excellent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hospital Anxiety and Depression Scale

Please read each item and tick the box opposite 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 response is better than a long thought-out one.

Tick one box in each section.

I feel tense or 'wound up'

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

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- 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 like 'butterflies' in the stomach:

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

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

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 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

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

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

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- Not too often
- Very little

I look forward with enjoyment to things

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

I feel cheerful

- Never
- Not often
- Sometimes
- Most of the time

I get sudden feelings of panic

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

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

I can enjoy a good book or radio or television program

- Often
- Sometimes
- Not often
- Very seldom

Cohesion Sub-scale of the Family Environmental Scale

Here are statements about your family (this means the family that you live with). For each one please decide whether it is **True** of your family or **False**. If you think the statement is **True** or mostly **True** of your family, please circle **T**. If you think the statement is **False** or mostly **False** of your family, please Circle **F**.

- | | | |
|--|----------|----------|
| 1. Family members really help and support one another. | T | F |
| 2. We often seem to be killing time at home. | T | F |
| 3. We put a lot of energy into what we do at home. | T | F |
| 4. There is a feeling of togetherness in our family. | T | F |
| 5. We rarely volunteer when something has to be done at home. | T | F |
| 6. Family members really back each other up. | T | F |
| 7. There is very little group spirit in our family. | T | F |
| 8. We really get along well with each other. | T | F |
| 9. There is plenty of time and attention for everyone in our family. | T | F |

Social Support Scale

There are some questions about the support that is available to you.

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

Write in number of close friends and close relatives

--	--

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?(Please, Tick one box)

None A little Some Most All

	of the time	of the time	of the time	of the time	of the time
2. Someone to help you if you were confined to bed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Someone you can count on to listen to you when you need to talk.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Someone to give you good advice about a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Someone to take you to the doctor if you needed it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Someone who shows you love and affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Someone to have a good time with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Someone to give you information to help you understand a situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Someone to confide in or talk to about yourself or your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Someone who hugs you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Someone to get together with for relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Someone to prepare your meals if you were unable to do it yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Someone whose advice you really want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Someone to do things with, to help you get your mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Someone to help with daily chores if you were sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Someone to share your most private worries and fears with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Someone to turn to for suggestions about how to deal with a personal problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Someone to do something enjoyable with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Someone who understands your problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Someone to love and make you feel wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Consultation Satisfaction Scale

The following questions ask you **what you think of your today's visit to the doctor**. Please circle the answer that is closest to what you think. "Neutral" means you have no feelings either way.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. I am totally satisfied with my visit to this doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This doctor was very careful to check everything when examining me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I will follow this doctor's advice because I think he/she is absolutely right.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt able to tell this doctor about very personal things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The time I was able to spend with the doctor was not long enough to deal with everything I wanted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. This doctor told me everything about my treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Some things about my consultation with the doctor could have been better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. There are some things this doctor does not know about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. The doctor examined me very thoroughly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I thought this doctor took notice of me as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The time I was allowed to spend with the doctor was not long enough to deal with everything I wanted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I understand my illness much better after seeing this doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. This doctor was interested in me as a person, not just my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. This doctor knows all about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I felt this doctor really knew what I was thinking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I wish it had been possible to spend a little longer with the doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am not completely satisfied with my visit to the doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I would find it difficult to tell this doctor about some private things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



THE UNIVERSITY
of LIVERPOOL

Thank you for filling in this questionnaire. Please feel free to ask me any questions that you may have about it.

Please check that you have answered all the questions...

Thank you for cooperation.

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