THE UNIVERSITY OF HULL

An exploration of epileptic and nonepileptic seizures: an interpretative phenomenological analytic study

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by

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An exploration of accounts of seizures: an interpretative phenomenological study.

Background

Differentiating epileptic seizures from non epileptic seizures (NES) has always been difficult. Seizures can look very similar, substantial physical injury and incontinence can occur in both conditions and people can have both conditions simultaneously. Treatment for each condition is very different however, epilepsy needing anti epileptic medication whereas NES is a psychologically rooted condition.

Aims

- To develop previous work
- To document a number of detailed seizures descriptions and to analyse these using Interpretative Phenomenological Analysis (IPA)
- To identify linguistic markers to differentiate NES from epilepsy

Methodology

This project used IPA as a more expansive method of 'history taking' being completely patient led. The approach and its theoretical antecedents have been described in depth in the thesis.

Four newly referred patients with uncertain diagnoses were interviewed once, three twice. There was additional, contextual data.

Results

The interpretation illustrated that subjective seizure experiences using IPA can contribute to previous work:

- It heralded the potential beginnings of the development of an alternative 'seizure discourse' for lay and professionals.
- It had the potential to contribute to patient information material and a screening tool.
- It offered new ideas for clinical practice and research.

Discussion

As an approach, IPA has the potential to combine its findings with those in the field of neurophenomenology in terms of expanding knowledge of corresponding subjective experiences.

Conclusions

Given that subjective experiences of people can help locate seizure foci, IPA has the potential for establishing itself as a qualitative scientific research approach in the area of seizure experiences.

Key words: Interpretative Phenomenological analysis, epilepsy, nonepileptic seizures, differential diagnosis

An exploration of accounts of epileptic and nonepileptic seizures: an interpretative phenomenological analytic study.

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1 Courting confusion: If it's not epilepsy then what is it?

"Happy families are all alike; every unhappy family is unhappy in its own way" (Tolstoy 1989)(p1)[1]

This chapter will outline the issues associated with differentiating between epileptic seizures and nonepileptic seizures (NES). It will illustrate how important it is clinically and psychologically to define between the two seizure types (Bodde, Brooks et al. 2009). It will also describe the difficulties in differentiating between them notwithstanding the technology available and that both seizure types can occur concurrently. The consequences of being diagnosed with both conditions are given before a focus on NES in chapter 1.1 and as a functional syndrome (FS) in chapter 1.2.

'If it's not epilepsy' ... then 'what is it?' (Langfitt 2007)(p8).

Not everyone referred to a neurology clinic has epilepsy. The neurologist where this study is located sees around 1500 newly referred patients each year, of which around 300 – 400 have 'epilepsy/blackouts/funny do's'. Only around a third of newly referred patients in this context will have epilepsy (personal communication, A.M., 2007). [2] Other estimates cited suggest that, of people presenting to neurology with blackouts, 57% will have epilepsy, 22% faints and 18% have seizures which are non-epileptic (Kotsopoulos, de Krom et al. 2003). A further recent estimate was that between 15% and 30% of people seen in epilepsy centres do not have epilepsy but have NES (Bodde, Brooks et al. 2009). Incident rates across studies are difficult to interpret and may be under

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[1] Epileptic behaviour is stereotyped and the same behaviours happen in people whatever their socio economic background, PNES on the other hand 'are almost infinitely heterogeneous' and differ from person to person. (p229). Sirven, J. I. and D. S. Glosser (1998). "Psychogenic nonepileptic seizures: Theoretic and clinical considerations." <u>Neuropsychiatry, Neuropsychology, & Behavioral Neurology</u> 11(4): 225 - 235.

[2] A.M., is the neurologist who supported this study.

estimated with rates of between one person per 30,000 to 50,000 and 3 – 4.6 per 100, 000 people being suggested (Bodde, Brooks et al. 2009).

Epilepsy can be defined as:

> 'A sudden, involuntary, time-limited alteration in behaviour, motor activity, autonomic function, consciousness, or sensation, accompanied by an abnormal electro-graphic pattern (EEG).' (Thompson, Osorio et al. 2005)(p71).

NES are very common also but different in that they:

> 'are paroxysmal changes in behaviour that resemble epileptic seizures, have no electrophysiological correlate or clinical evidence for epilepsy, whereas there is positive evidence for psychogenic factors that may have caused the seizure.' (Bodde, Brooks et al. 2009)(p2).

Because both epilepsy and NES can involve impaired consciousness and exaggerated involuntary movements of the body (Sharpe and Faye 2006), NES can mimic any type of epileptic seizures, minor or major (Bodde, Brooks et al. 2009) and are difficult to distinguish between for patients, and their lay and professional carers. Moreover, many NES are preceded by epilepsy (Reuber 2008i). People with NES can involuntarily lose their motor function and/or their consciousness (Prigatano, Stonnington et al. 2002) which can manifest as partial complex or generalised seizures (LaFrance, Gates et al. 2008). However, making the distinction between epilepsy and NES is not impossible, video-EEG (VEEG) for many years has shown NES to be very different from epileptic ones, one early study reporting differences in facial muscle movements (Sirven and Glosser 1998).

Still further to court confusion, [3] between 3.6% to 58% of people can have both conditions, one series of patients suggesting that 58/329 of NES patients could be thus diagnosed (Reuber 2008i). In addition to this, some people have a past

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[3] The title of this chapter is from a comment made by a walking friend, J.L., March 2009.

history of epileptic seizures (Bodde, Brooks et al. 2009). Confusion is deepened in that some behaviour indicating NES, may actually be simple partial epileptic seizures, these often only producing EEG changes in only 10% - 20% of cases. The complex semiology/manifestations of Complex Partial (CP) epileptic seizures adds to the confusion, as these are not always associated with scalp EEG changes and thus can be mistaken for NES (Reuber 2008). NES which simulate CP epileptic seizures are particularly difficult to differentiate from frontal seizures (Bodde, Brooks et al. 2009). Magnetic resonance imaging (MRI) abnormalities and EEG changes have been found in people with NES but no patterns have emerged thus far which link these together (Reuber 2008).

The main attributes of epileptic seizures have been mapped and are usually recognisable by the attributes of each, see box 1 for a formulation of these aimed at non-clinicians (Baxendale 2006). Epilepsy is an evolving condition and people can move from one type to another (Engel 2001). Classification is based on various signs and symptoms which focus on predominant features occurring in a seizure in four spheres, sensorial, consciousness, motor and autonomic (Noachtar and Peters 2009).

'Loss of consciousness and 'impairment of consciousness' are the criteria used to distinguish between simple and complex seizures (Cavanna, Mula et al. 2008)(p184). In view of the increasing understanding of the 'pathophysiological and anatomic substrates of epileptic seizures and disorders' resulting in new descriptions of epileptic syndromes, classifying the epilepsies is a continuing, evolving process undertaken by the International League Against Epilepsy (ILEA)(Engel 2001)(p316). However, and this issue will be expanded upon later in the thesis, the ILEA definition does not fully account for 'alterations in the subjective content of ictal [seizure] consciousness' (Cavanna, Mula et al. 2008)(p184). Indeed, a person's conscious state is often assessed from witness descriptions and individual vocabularies and thus may not illustrate the 'vividness' of phenomenological seizure experiences (ibid)(p185). This could seriously limit our understanding and definitions of ictal states

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relating to consciousness given the lack of a vocabulary available to people attempting to describe these phenomena (Petitmengin 2006).

Box 1

Names and descriptions of different epileptic seizures for non clinicians (Adapted from Baxendale, 2006)

Partial (focal or local) seizures	Both clinical and EEG measured changes show a 'disruption of a system of neurons limited to one cerebral hemisphere' and sub divided into simple partial seizures (SPS) and complex partial seizures (CPS). Both can spread from one brain area to another (EpilepsyAction 2005)
Simple partial seizures	Consciousness is not impaired and, depending on the brain area affected, the subjective experience varies. Involuntary movements can occur; people can experience unusual tastes, smells or epigastric feelings. They can experience déjà vu, jamais vu (feelings of unfamiliarity) and feelings of intense ecstasy, anger or fear. SPS can act as warnings (auras) for the onset of a complex partial or generalised seizure.
Complex partial seizures	Consciousness is impaired, depending on which part of the brain is affected there can be either no symptoms or, dramatic ones such as 'shouting or posturing'. People are in danger of not responding to traffic, they are not affected by water or heat and may not respond to pain. They will not remember what happened to them during their seizure.
Generalised seizures	Generalised seizures can be convulsive or non convulsive, involve both brain hemispheres and can comprise of absences, (staring, blinking) myocolonic, (short, jerking movements of body parts), Tonic-clonic (going stiff, falling and convulsing), Tonic (going stiff, falling but without convulsions) and Atonic (flopping to the ground) (EpilepsyAction 2005) and which can leave them tired and aching.
Unclassified seizures	Those which cannot be classified because there is not enough clinical or other information and some do not fit comfortably within any of the ones described above.
Status epilepticus	When a seizure does not stop. This can be fatal in 8 - 10 % of cases and can cause permanent brain damage if a seizure lasts longer than 30 minutes. Urgent medical help should be sought if a seizure does not cease after 10 minutes.

Upon examining a wide literature between 1997 and 2007, I found an array of descriptions (notable for a paucity of first person accounts) about how NES are manifested. These and a significant number of additional studies have now been reviewed in terms of the 'epidemiology, semiology, clinical context,

treatment and prognosis of NES' (Reuber 2008)(p622). The behavioural manifestations of NES are examined in terms of the 'commonest semiology', along with a number of subjective symptoms. A recent review (covering English, German and Dutch studies over a period of 26 years) critically reviewed diagnostic procedures and identified very detailed seizure characteristics and etiology (Bodde, Brooks et al. 2009). Some examples of differences and similarities in the semiology of epilepsy and NES are in table 1 below. Important as these characteristics are, however, what can be just as important are the psychological or psychogenic factors which could have caused the seizures and/or the psychological mechanisms which transfer emotions into physical manifestations and other co-morbidities (Bodde, Brooks et al. 2009).

There is a distinct lack in the literature on the subjective or mental states of patients with NES (Reuber 2008) and this is one aspect of NES this thesis begins to address. Models to explain NES are being developed and include those which distinguish between levels of factors found in NES including, 'psychological etiology' as causal factors, predisposing factors rendering a person 'vulnerable' to NES, 'shaping factors' such as relative with epilepsy and on which behaviour is modelled, 'triggering factors' which can include circumstances or situations, mechanisms such as dissociation (see chapter 1.2) and, 'prolongation factors', that is, those which offer some explanations of why seizure behaviour is maintained (Bodde, Brooks et al. 2009)(p7).

Table 1.

Examples of differences and similarities in the semiology of NES and epilepsy. Adapted from (Reuber 2008) unless otherwise referenced

NES	Epilepsy
Rare in children under 10 years old (Bodde, Brooks et al. 2009.	There are various childhood epilepsies.
Seizure onset is more gradual.	Seizure onset is sudden.
Seizure symptoms vary considerably and virtually impossible to classify into specific patterns or (Bodde, Brooks et al. 2009).	Stereotyped behaviour is characteristic (see box 1 above).
When consciousness is impaired, 48% of patients can follow simple instructions during a seizure.	People with epilepsy cannot usually do this.
Duration - seizures been reported as lasting from 20 to 805 seconds, many for more than 120 seconds. Seizures lasting 1 to 30 minutes have been noted (Gene-Cos and Ring 2005)	Tonic clonic seizures last around 50-92 seconds. Frontal lobe complex partial seizures can last only 60 seconds and can be confused with NES (Chabolla and Shih 2006).
Motor activity is less vigorous and can wax and wane and any shaking is often asynchronous or asymmetrical, Muscle twitching varies in amplitude. Our of phase limb movements and thrashing movements of the entire body (Bodde, Brooks et al. 2009).	In tonic clonic seizures there is a gradual decline in limb jerk frequency during the seizures.
Post ictal recovery is either very rapid or very slow, and 'temporary neurological deficits' are not as common.	Post ictal recovery is associated with temporary neurological deficits post seizure.
People can be confused post ictally, with an individual experiencing headaches, exhaustion and needing sleep (Russell 2006).	Confusion, extreme tiredness after seizures (Featherstone 2004) (Baxendale 2006).
EEG abnormalities are present in about 16% of people having NES (De Timary, Fouchet et al. 2002). 27% had interictal EEG changes (Reuber 2008i).	Epileptic seizures are always accompanied by an abnormal EEG. (Thompson, Osorio et al. 2005)
Patients are more likely to have fluctuating but continuing levels of consciousness without memory gaps (Bodde, Brooks et al. 2009) and to remember ictal experiences.	Patients are less likely to remember ictal experiences.
Childhood physical and sexual abuse and family dysfunction are associated with NES.	Lesser instances of various abuses are recorded in patients with epilepsy.
Pelvis thrusting seen more often than in epilepsy (although one study refutes this saying that pelvic thrusting is seen in only 17% of NES patients) (Chabolla and Shih 2006).	Pelvis thrusting occurs in complex partial seizures too (Chabolla and Shih 2006).
Significantly more females than males have NES. The prevalence of men with NES could be underreported however (Bodde, Brooks et al. 2009).	There are more males with epilepsy than females (Kotsopoulos de Krom., Kessels et al. 2005).
Seizures can be provoked by various means [4] in the majority of patients (Reuber 2008i).	Very few seizures can be provoked in people with epilepsy (Reuber 2008i).

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[4] Provocation methods include, administering 'placebos', the use of 'physiologically challenging stimuli', 'stimulation or tilt testing' and 'a psychiatric interview and hypnosis'. Reuber (2008i)(p157).

NES is as serious a condition as epilepsy

Because NES are not the result of abnormal brain activity (Krebs 2007) they do not require treatment with anti epileptic drugs (AEDs), indeed these can result in serious side effects and can even exacerbate seizures (Bodde, Brooks et al. 2009). Since people can have both conditions, this complicates things still further, as epileptic seizures can be managed with AEDs and this can result in the NES also ceasing (Reuber 2008i) in that the medication may act as a placebo (Bowman and Markand 1996). NES can remain or people with NES can have a past history of epilepsy which implies a modelling of their epileptic behaviour (Bodde, Brooks et al., 2009).

Differentiating between epilepsy and NES has, historically, been a complex and difficult task for clinicians. As late as the 1990's there were no standards or clinical guidelines for diagnosing NES, epilepsy had to be definitely excluded but a diagnosis of non epileptic seizures was, even then, never absolutely certain (Kuyk, Leijten et al. 1997). It is still the case that no one, single, clinical or historical feature can pinpoint that seizures are non epileptic. However, the more features of the person's clinical history that are not characteristic of epileptic seizures, the more the diagnosis of NES can be suspected (Alsaadi and Marquez 2005). Any patient whose seizures are not responding to AEDs could, potentially, be experiencing NES (De Timary, Fouchet et al. 2002).

Symptoms previously identified as being associated exclusively with epilepsy, such as physical injury, and thought to differentiate between NES and epilepsy, have since been found to be of limited diagnostic value (LaFrance, Gates et al. 2008). For example, people with epilepsy or NES can experience incontinence (Russell 2006). In terms of self injury, carpet burns are almost exclusive to NES (Brown and Trimble 2000) whereas other burn types are almost always exclusive to epilepsy (Voermans, Zwarts et al. 2005). One patient finally diagnosed with NES, sustained skull based fractures and other injuries which necessitated craniotomy following his falls (Voermans, Zwarts et al. 2005). It is

not uncommon to see fractures in NES patients and this level of self injury could be due to dissociation which contributes to pain tolerance (Bodde, Brooks et al. 2009). Such injuries have also been viewed as approximate to suicide (Peguero, Abou-Khalil et al. 1995) although attempted suicide occurs in both NES and epilepsy (Russell 2006) suicidality in people with epilepsy being significantly more frequent than in the general population (Kanner 2009).

Medical techniques for differential diagnosis of seizures

The prolonged in-patient video-EEG (VEEG) technique introduced in the 1970's is now the gold standard for differentiating between epileptic and non epileptic seizures (Krebs, 2007). Patients' EEG rhythms are recorded for a period of time, [5] while their 'neurobehaviour' is recorded on video, and the two pieces of information are analysed - in many cases an 'absence of ictal patterns during the behavioural event' giving a 'reliable diagnostic correlate' for NES (La France, Gates et al. 2008)(p320). [6]

However, it is expensive, not available everywhere [7] and only around a third of people with NES actually have a seizure during the procedure (Reuber and Elger 2003). The chances of a seizure occurring during this procedure however, can increase up to 75% using various provocation techniques, such as sleep deprivation (Langfitt 2007), placebo injections and hypnosis (Reuber 2008i). These techniques can help establish a diagnosis of NES as well as shortening evaluation time and in-patient stays (Benbadis 2009). Ethical issues relating to

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[5] This may need several days and up to two weeks in hospital. Langfitt, J., T (2007). "A Systems Perspective on Mind-Body Disorders: A Case Example of Psychogenic Non-Epileptic Attacks (PNEA)." The Family Psychologist 23(1): 4 - 6.

[6] However, epileptiform activity can be present in asymptomatic people and it does need an expert in epilepsy to interpret findings. Dekkers, W. and P. van Domburg (2000). "The role of doctor and patient in the construction of the pseudo-epileptic attack disorder." Medicine, Health Care and Philosophy 3: 29 - 38.

[7] This unavailablility is not restricted to the UK, it is also the case in other European countries. Gonzáles-Goizueta, E., B. Martinez-Pérez, et al. (2000). "Crisis psicógenas no epiléptical." Revista de Neurologia 35(10): 954 - 959.

provocation techniques being used are outweighed by the counter argument that it is more unethical not to obtain a definitive diagnosis given the chance to do so and the grave consequences associated with being given the wrong diagnosis (Benbadis 2009). People with NES misdiagnosed with epilepsy, can receive treatments and procedures such as repeated invasive diagnostic tests, parenteral treatment with toxic medications and emergency intubation which are unnecessary, expensive and dangerous (La France and Benbadis 2006i; La France, Gates et al. 2008).

If a seizure does occur with V EEG, then it must be agreed with patients and witnesses that it is a typical example (Russell 2006), with inaccuracies in witness reports being, potentially problematic (Rugg-Gunn, Harrison et al. 2001; Mannan and Wieshmann 2003). Moreover, there may be EEG alterations in patients with NES. In short, the diagnostic value of this procedure is by no means certain and a 'worrisome' outcome in many studies (Bodde, Brooks et al. 2009)(p5).

Notwithstanding that NES have been known about since the 19th century, the situation today is that diagnosis can take up to between 7 and 16 years, the higher figure being associated with a co-existence of epilepsy and NES (De Timary, Fouchet et al. 2002; Reuber, Fernández et al. 2002a). These factors underscore the need for early diagnosis of both seizure types which will then trigger appropriate management and treatments.

Furthermore the social and economic cost of misdiagnosing and treating NES as epilepsy is enormous, for patients, their families, the medical system and society and delay in diagnosis worsens the prognosis for people with NES (La France and Benbadis 2006i; La France, Gates et al. 2008). Seizure related costs can be reduced by 84% following a diagnosis of NES. For these reasons alone, the differential diagnosis of NES and epilepsy should be given more 'scientific' attention (Bodde, Brooks et al. 2009)(p2).

History taking as a method of diagnosis

Another method used towards diagnosing conditions is that of a Bayes Theorum analysis which works by collecting clusters of medical and other information. Bayes theorem can calculate the probabilities of certain diagnoses from published data (prior probability and likelihood ratios (Summerton 2008). Through a process of elimination this will give a probability measure of whether a patient has a certain condition. This can result in history taking being a 'diagnostic technology' in itself, resulting in patients being less likely to be subjected to diagnostic tests and procedures (Summerton 2008)(p273)

Diagnostic reference frames for epileptologists covering most seizure types using this calculation with patients' and doctors' opinions of seizure symptoms are soon to be tested for their appropriate use in day to day clinical practice (van Ast, Renier et al. 2006). Such a technique could potentially help in eliminating epilepsy as a diagnosis in some patients – a main route to diagnosing NES. [8]

The following sections will examine some of the issues pertaining to being diagnosed with either epilepsy or NES. Once given, a diagnosis of epilepsy is difficult to remove (Cuthill and Espie 2005). However, a diagnosis of NES, a condition 'not explainable from a medical-biological and rational-scientific point of view' (Dekkers and van Domburg 2000)(p33) can have significant personal and social implications.

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[8] Because there are no specific descriptions of signs and symptoms relating to each and every epileptic seizure type experts across the globe are building up diagnostic reference frames (DRFs) for distinguishing frequently occurring characteristics in various seizure types. Beginning by gaining feedback on signs and symptoms occurring in six seizure types, they then determined how reliable these were. For example, more specialists were needed to confirm the descriptions of Atypical Absence seizures. They then went onto explore whether specialists chose discriminative sets of frequently occurring symptoms and found that sufficient agreement occurred in 75% of cases. A second part to the study concluded that seizure descriptions by a number or experts can discriminate between a number of seizure types but not for aggregated seizure types such as primary generalised seizures. Authors suggest that a list of seizure manifestations could be included alongside ILEA lists of ictal phenomena. Finally, they calculated the probability of patient manifestations occurring in order to classify seizures and tested these against known seizure types. 66 patients and their carers were involved in this study. 91% of seizures were correctly classified using this method when tested in a clinical setting.

Epilepsy

The term 'epilepsy' refers to a group of central nervous system disorders manifesting in seizures (Baxendale 2006). The etymology of the Greek term depicting epilepsy is epi-lambanein - meaning to surprise. However the idea of suddenness is not completely accurate and has hindered research in this area somewhat as people can have warnings prior to a seizure and these are important to identify (Petitmengin 2006). Considering 'epilepsy' as an umbrella term used for a condition which has various seizure manifestations (Petitmengin 2006), epileptic seizure behaviour can be seen as, a stereotyped response to 'unconditional neural stimuli', usually being 'self limited', lasting less than five minutes (Baxendale 2006)(p174) and common to any socio economic class of person. It is one of the most common serious chronic central nervous system neurological disorders in the UK (Rajpura and Sethi 2004) affecting almost 1% of the population (Elwyn, Todd et al. 2003). There are about 30,000 new cases per year in the UK (Duncan 2004). That, is, in the UK, in 2003, in a population of nearly 60 million, nearly half a million people had epilepsy (JEP 2005)

The language of epilepsy (Lebrun 1992)

> "Epilepsy is the devil; it destroys your brain cells" (Person with epilepsy, Epilepsy Action Conference, 2006)

Epileptic seizures have a historical association with religion and spirit possession (Carrazana, DeToledo et al. 1999). People with epilepsy have themselves used terminology such as their epilepsy being an unclean spirit, evil, a craziness or mental illness (Schneider and Conrad 1981)(p217). Studies examining social attitudes towards epilepsy globally uncovered generalisations and beliefs about the condition and which included epilepsy as being a punishment for sinning, involving possession or bewitchment, connotations of contagion persist and that it is a brain disease (Andermann 2000). Euphemisms such as, 'the falling illness' or 'falling sickness' were created to

describe the condition, as the term 'epilepsy' was often taboo (Lebrun 1992). Terms related to le mal (the disease) grand mal and petit mal seizures are still used by lay and professional people (ibid). The word seizure remains common parlance in lay and neurological settings as does ictus (for seizure, meaning a blow or a stroke) persisting in medical literature describing the temporality of seizures (Baxendale 2006).

Epilepsy and the media

The language of epilepsy continues to mirror these views and misconceptions. The manner in which epilepsy is portrayed in the English lay print media can serve to reinforce such historical misconceptions and biases about the condition to the general public. Epileptologists (Krauss, Gondek et al. 2000) categorised 210 stories in various newspapers and magazines from the UK, the United States and other English speaking countries world wide, in terms of whether reporting of scientific advances and treatments was accurate, whether they stigmatised epilepsy and if they over-exaggerated the risks associated with the condition.

They examined metaphor and terminology used in stories and reports finding that around 70% of reporting was accurate in terms of social and medical issues, new therapies and scientific advances. The remaining 30% however, served as a barrier to altering prevalent stereotypes, maintained the imagery of epilepsy as a mystical brain disease, seizures being described in 'demonic or deathly imagery' or as life threatening. There were exaggerated claims about treatment and research - not substantiated by reporters (Krauss, Gondek et al. 2000)(p1898).

Epilepsy and the law

Some stigmatising legislation related to people with epilepsy has only been repealed relatively recently. As late as 1956, 18 states in America provided for

the sterilisation of people with epilepsy on eugenic grounds. World wide, epilepsy has been viewed as a reason for annulling and prohibiting marriages. The law in the UK prohibiting people with epilepsy from marrying was only repealed in 1970. Seventeen states in America prohibited people with epilepsy to marry, the final state to repealing this particular law only doing so in 1980. In some parts of India in the 1990's, a marriage could be voided if one of the partners was found to have been epileptic before the marriage but had not divulged this, as it was believed epilepsy was hereditary (Lebrun 1992).

Epilepsy is not a condition which a person can take personal responsibility for having (Galvin 2002). Ancient English law has only been recently reviewed in terms of the ramifications caused should people with epilepsy commit a crime as they come out of a seizure, but which they do not remember committing. The philosophical arguments about identity, autonomy and responsibility are relevant here. That is, whether there is a deficit in a person's ontology following a seizure which can absolve a person from being culpable, the brain overriding existing behavioural patterns (Dekkers and van Domburg 2000).

The McNaughten Rules, created in 1843, do not differentiate between epilepsy and insanity, and crimes carried out by people with epilepsy (although rare) could result in them facing the choice of, a) pleading guilty to an offence they cannot remember committing, and thus then gaining a criminal record and facing possible imprisonment or, b) entering a plea of not guilty by reason of insanity (NGBRI) with the possibility of being sent to a psychiatric hospital and the law recording them as insane with all the implications of this label. In 1992, following the enactment of the 1991 Insanity and Unfitness to plead act, judges could exercise more control over what happened to such people, many sentenced to community work rather than imprisonment, but the label of insanity still stuck (Reuber and Mackay 2008ii).

More recently, the Domestic Violence, Crime and Victims Act (2004) allows for people pleading NGBRI not to be hospitalised unless they require in-patient

treatment (Fox 2008). A case series study of criminal cases of pleas of NGBRI between 1975 and 2001, counted 13 cases identified as being carried out by people with epilepsy. Although difficult to establish retrospectively, it was considered that most of the defendants carried out their offences post ictally. Behaviour in this period can be aggressive and ictal behaviour can consist of many, complicated automatisms which would inhibit self-directed action. Of the 13 cases, and before the 1991 act came into force, five of these people were sentenced to mandatory, indefinite hospitalisation (one for murder). Of the remaining eight (offending *after* this date) six gained mainly supervisory and treatment orders and two, absolute discharges even though the offences were not minor (Reuber and Mackay 2008ii).

There is also a recent call for the terms 'insane' or 'sane', to be removed from categories of insane automatism (sleep walking), sane automatism (sudden arousal from sleep in a non-sleep walker) and automatism due to epilepsy, and that an international, standardised diagnostic protocol be applied to people suspected of having sleep or epilepsy automatisms. The plea, 'not guilty by reason of sleep disorder', was rejected recently by the House of Lords for cases of automatism due to epilepsy and this rejection also seems equally likely for sleepwalkers (Ebrahim and Fenwick 2008).

Further implications of being diagnosed with epilepsy

Involving altered brain states, epilepsy can be a difficult condition to deal with as both patients and lay and professional carers try and make sense of its manifestations (Cregeen 1996). 25% of people with epilepsy and nearly 50% of people experiencing complex partial seizures have psychosis, depression, anxiety, personality disorders and other behavioural problems (Mendez, Engebrit et al. 1996). Having epilepsy does not affect everyone in the same way (Faircloth 1998) epileptic discharges being expressed through a range of behavioural symptoms including hallucinations, sudden emotional outbursts, and other psychopathology (Griffiths 1990). Close surveillance is required on

the part of individuals and significant others to constantly accommodate the condition in an attempt to manage and minimise its disruptive influence and keep people physically safe (Featherstone 2004; Baxendale 2006). As adults, between one third and one half of people with epilepsy experience some social maladjustment (Kanner 2003). Unemployment amongst people with epilepsy is double that of other disabling conditions (Bawden 2009).

Not being able to drive is a major concern for people with epilepsy. DVLA regulations relating to epilepsy and seizures are very clear; a single attack whilst awake disqualifies a person from driving until they have been seizure free for a year, whereupon a three year licence will be issued (i.e., the person may still have epilepsy but is seizure free). Loss of consciousness or altered awareness with no clinical evidence that a first seizure is epilepsy, disqualifies a person from driving for six months after which the licence may be returned (DVLA 2008). Patients have been known to lie to their general practitioners and employers about seizure occurrence to ensure they can still drive and/or work (personal communications from, J.D., 9/8/04 & C.J., 21/9/04).

'The Cognitive maze of epilepsy' (Krämer 2003)(p18)

People with well-managed epilepsy have positive psychological profiles and generally do not suffer significant intellectual decline (Moore and Baker 2002). However, one review of the world literature did find relationships between seizures and adverse cognitive change (Dodrill 2002) and other studies have argued that epilepsy can be an ongoing process in terms of developing other conditions (Trimble 2001) [9] or a progression in terms of cognitive deficits (Devinsky 2003). One author cited figures of around 30% of people with epilepsy as having additional neurological disorders (Baxendale 2006). In terms of life stages, there is evidence that continuing seizures can result in reducing the mental abilities of developing children and adolescents and that

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[9] For example, epilepsy and psychiatric illness are closely linked and it has been discovered that suppressing seizures can aid in the development of severe psychopathology. (Trimble, 2001)

AEDs can contribute to this loss (Dodrill 2002). The onset of childhood temporal lobe epilepsy can be particularly detrimental to ongoing cognition (Hermann, Seidenberg et al. 2002) and neuropsychological impairment can be associated with chronic epilepsy (Hermann and Seidenberg 2007). Ageing affects how medicines work within the body and AEDs can react negatively with other medications taken potentially contributing to 'central nervous system related adverse events' in older people (Krämer 2003)(p20).

Depression is a common psychiatric disorder in people with epilepsy, compared to the prevalence of 8.7% in the general population,16% in people with asthma,17% in people with diabetes, it rises to 29% in people with epilepsy (Kanner 2003) often being linked directly to seizure attacks and to which seizure suppression medication may contribute (Stefan and Pauli 2002), the effect being potentially, cumulative (Kanner 2003). Population based studies have shown a bi-directional relationship between epilepsy and depression and there is a possibility 'that the pathophysiology that leads to depression may lower the seizure threshold as well.' (ibid)(p4).

While there is hope that eventually, epilepsy can be prevented rather than managed, research at present is at a very fledgling stage (Spinney 2004) therefore the main issue is to treat and manage it. First line treatment for epilepsy is anti-epileptic drug therapy and sometimes, surgery (Ryvlin 2003). However, Cognitive Behavioural Therapy helps with strategies to reduce seizure frequency, to lessen the impact of epilepsy on daily life (Goldstein, McAlpine et al. 2003) and for stress and seizure management. Biofeedback can help with depression and patient locus of control (Uhlmann and Froscher 2001). The aim of all treatments is to limit seizure occurrence, adverse events and to manage and treat any co-morbid conditions. Although the fear, uncertainty and unpredictability of seizures occurring is often cited by people with epilepsy as being the worse aspect of the condition (Fisher, Vickrey et al. 2000), others argue that seizures are only the tip of the iceberg in terms of treatment

considerations (Kanner 2003) and 'the burden of the illness is experienced even when the disease is not severe' (Levisohn 2002)(p489).

1.1 Courting confusion: Nonepileptic seizures

NES have been defined as:

> 'episodes of paroxysmal impairment of self-control associated with a range of motor, sensory, and mental manifestations, which represent an experiential or behavioural response to emotional or social distress' (Reuber 2008)(p622)

That is they are, unlike epilepsy, 'primarily unrelated to medically explained structural changes, functional states or conditions' (Reuber 2008i)(p155). Considered a public health problem by some (Sirven and Glosser 1998; Bazil, Legros et al. 2003) many patients with NES comprising a significant share of the workload of neurologists, emergency and general physicians (Reuber and Elger 2003). Although around 75% of people are given AEDs initially (ibid), the treatment for non epileptic seizures is not AEDs or indeed, any other neurological treatment (Taylor 2001).

Prevalence and incidence of NES

The prevalence of NES varies depending on patient populations, study settings and methods so can appear confusing and contradictory. The prevalence of NES in community samples has not yet been fully researched (Gomes, Kropf et al. 2002) although incidence in the general population has been estimated at 1.5 per 100,000 people per year, this being approximately 4% of the incidence of epilepsy (Bodde, Brooks et al. 2009). In Northern Ireland for example this year, 3000 people diagnosed with epilepsy do not have this condition but are receiving treatment for epilepsy (EpilepsyAction 2009). Given these variations, estimates of between 2 to 33 per 100,000 people having NES have been suggested (Benbadis, O'Neill et al. 2004). Some people with NES may never present to services because they manage their seizure occurrences themselves. Figures for people having NES, therefore, may be underestimated (Reuber 2008i).

Our current knowledge of NES seizure manifestations is extremely well documented and found repeatedly across studies, many features indicating the potential for different types of NES (Reuber 2008). For example, people scoring high on neuroticism exhibit a wider range of symptoms and there are suggestions that two broad types of NES could encompass two different types of dissociation [10] (Lawton and Baker 2008). However, there may be no such a thing as *typical* NES as there are for epilepsy.

Because of some of the many 'grey areas' described above, many NES are commonly mistaken as epilepsy, and given a neurologic explanation in clinical practice. Most features of NES semiology can be seen in the various epileptic seizures, however, whatever the combination of symptoms and behaviours, they are not 'explained by epileptic activation or disinhibition of centres of neural networks in the brain' (Reuber 2008i)(p157).

A patient presenting, for example in an Accident & Emergency Department with 'vigorous motor activity' (a common scenario) [11] is very likely to be diagnosed with epilepsy (Russell 2006). The patient may then be labelled, 'known epileptic' which opens the door for future, invasive procedures to be instigated (such as intubation), and for AEDs to be prescribed erroneously (Russell 2006)(p65). It is very difficult to remove a diagnosis of epilepsy and if this is a misdiagnosis there could be grave clinical and psychological repercussions (Cuthill and Espie 2005). A diagnosis of 'known epileptic' should *always* be questioned by physicians as inappropriate medical interventions aimed at epilepsy can be fatal for people with NES (Reuber, Baker et al. 2004; LaFrance, Gates et al. 2008).

How seizures were defined originally is important, that is, whether with VEEG (Jeffries, Krumbolz et al. 2003) and whether the clinician making the assessment is an epilepsy expert (Russell 2006). The high cost and scarcity of

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[10] The concept of dissociation is discussed in chapter 1.2.
[11] It is possible, if a doctor has a thorough knowledge of psychodynamic theory and epileptology, to diagnose and end safely pseudo-status epilepticus (PSE). Kütemeyer et al, 2005.

the medical diagnostic techniques mentioned above, as well as a lack of clinician expertise, have contributed to the misdiagnosis of seizures since the 1950's (Rugg-Gunn, Harrison et al. 2001) and still do (Russell 2006) and physicians, particularly less experienced ones, tend to err on the side of caution diagnosing epilepsy rather than NES (Reuber 2008i). However, some studies report that NES is diagnosed more than epilepsy (Bodde, Brooks et al. 2009).

Links between NES and abuse

Some of the physical manifestations of non epileptic seizures containing for example, pelvic thrusting (termed abreactive seizures) mimicking sexual intercourse, have contributed historically to people such as Freud relating these physical experiences and the subsequent unconscious processing of sexual abuse (Sharpe and Faye 2006). The process itself has been related to the concepts of conversion and dissociation [12] (Reuber 2008i).

The higher rates of women reporting sexual trauma links to Post Traumatic Stress Disorder (Reuber, Mitchell et al. 2007 iv). One study suggested that childhood abuse could put people at risk of post traumatic stress disorder (PTSD) in adult life (Kendall-Tackett 2002). Child sexual abuse has been argued by some, particularly by those in the epilepsy community, to be strongly associated with NES (Sharpe and Faye 2006). It has been found that patients with NES had statistically significantly higher rates of PTSD and Childhood Sexual Abuse (CSA) and higher Dissociative Experiences Scale (DES) scores than patients with epilepsy. No differences were found between *women* with NES and epilepsy for histories of PTSD or CSA. Thus although this indicated that PTSD, dissociation and CSA may be common among women presenting with both epilepsy and NES, neither a positive history of CSA nor a history of PTSD is evidence against epilepsy (Dikel, Fennell et al. 2003).

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[12] The concept of dissociation is discussed below

However, one comparative study found that, although all NES patients and 85% of epilepsy patients also reported trauma, only the NES patients met the *criteria* for a PTSD diagnosis. Given that child abuse can lead to PTSD and PTSD to NES, there has emerged a significant relationship between childhood sexual abuse and NES (Rosenberg, Rosenberg et al. 2000). Case reports suggest that traumatic events are an important risk factor for developing NES (Fiszman, Alves-Leon et al. 2004) and trauma per se, is seen as the root of many NES (Kalogjera-Sackellares 2004). A review of studies examining the prevalence of traumatic events, including abuse and posttraumatic stress disorder (PTSD) in NES patients, argued that childhood abuse was an etiological factor in only a small number of NES patients (Sharpe and Faye 2006). More recently, broader categories of trauma including physical abuse, loss, and psychological abuse have been implicated in NES, and the level of reporting of sexual and physical childhood abuse is significantly higher in NES patients, particularly women, than in those with epilepsy. Such experiences can affect brain development which could 'reduce resilience to stress in later life' including symptoms such as NES (Reuber 2008i)(p163).

Classification of NES

NES are classified into physiologic [13] and psychogenic seizures, the latter being the ones considered in this thesis and defined as ones which are not related to

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[13] Physiologic seizures can stem from causes such as; syncope, migraine, tension headaches, hyperventilation, transient ischemic attacks (when the blood supply to the brain is severely reduced), hypoglycaemia (when a person with diabetes has injected too much insulin, eaten to little or exercised without extra food intake), benign Myoclonus, (a twitching of muscles), myasthenia gravis, (an auto-immune disorder where the neuro-muscular junction is damaged and muscles become weak after even slight exertion), paroxysmal choreoathethosis, (involuntary movements of the limbs mainly with strange sweeping motions), cardiac arrhythmias (if the heart temporarily stops beating, seizures can occur due to a lack of oxygen), and one of the parasomnias. Also dysautonomia (associated with automonic nervous system diseases such as brain stem disorders, hypothalamic disease, spinal cord diseases and also those in the peripheral nervous system), drug intoxication or withdrawal (alcohol, benzodiazepines, overdoses of prescribed medications such as tricyclic anti-depressants), movement disorders (seizure like movements); panic attacks (which can be mistaken for seizures (children can induce anoxic seizures if they hold their breath for example) and, vestibular symptoms (for example the dizziness in Meniere's disease can resemble a seizure). Alsaadi, T. M. and A. V. Marquez (2005). "Psychgenic Nonepileptic Seizures." American Family Physician 72(5) with explanations from PC (personal communication).

'medically explained structural changes, functional states or conditions' (Reuber 2008i). These are those, 'affecting the brain through a reaction to mental distress or a learned response' being a reaction to psychogenic factors including trauma and conflict (Reuber 2008i)(p155).

People with NES are caught between the disciplines of neurology and psychiatry (La France, Alper et al. 2006) often being diagnosed as having 'dissociative convulsions' [14] - a recognised psychiatric condition (Brown and Trimble 2000)(p286), defined in the ICD-10, as being 'a partial or complete loss of the normal integration between memories of the past, awareness of identity and immediate sensation, and control of body movements' (ICD-10 p151) in (Brown and Trimble 2000)(p285). There are thoughts as to whether NES should be classified as an individual condition within psychiatry (Reuber 2008i).

Etiology of NES

NES are most likely to begin when a person is between 15 and 35 years old (Krebs 2007) women representing significantly more cases than males (Kotsopoulos de Krom., Kessels et al. 2005; Sharpe and Faye 2006; Reuber 2008). Although this is not in the case in children or the elderly - the latter often being found to have a physiological basis to their seizures anyway (Russell 2006) and there may be different reasons why men and women develop NES. For example, two studies found that men presenting with the condition had employment problems, and women had histories of sexual and physical abuse (Reuber 2008i). Another concluded that men with NES have significantly worse patterns of emotional adjustment, as measured by the MMPI, than women with NES or subjects of either gender with epilepsy (Holmes 2001). One study examining men and women with NES and epilepsy (confirmed with VEEG) found differences in gender that were not statistically significant but offered insights into how NES may be caused. Men were more likely to attribute

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[14] The concepts of dissociation and conversion related to this diagnosis are discussed in chapter 1.2.

their NES to a predisposing factor, women reported sexual abuse eight times more than men and the carers and family of men with NES said they were three times less likely to accept the diagnosis of NES (Oto, Conway et al. 2005).

There are various precipitating and predisposing factors one or more of which are present in most people with NES, including rape, physical abuse, childbirth, family bereavement/discord/separation, job loss, road traffic accidents and physical health problems (Reuber 2008i). Reuber proposes 'a Multifactorial Etiologic model for PNES' [15] (Reuber 2008i)(p153) which would identify predisposing, precipitating and perpetuating factors. Biological factors, early life experiences, ongoing stress may interact in 'causing' NES, or a single one may be the protagonist. High rates of sexual trauma are reported by women as is family and social discord, breakdown and stress, whereas men report more hypochondria and concerns about their health. However, these may relate to gender differences generally in what men and women view as important to report in medical consultations. Illness representations of patients (which include, examining symptoms and labelling the condition, considerations of the causes and consequences of it, its development and duration and how controllable or curable it is) may also be an etiological factor contributing to NES (Reuber 2008i).

The implications of being diagnosed with NES

> 'People with NES are difficult to treat within the 'bounds of rational
> medical treatment' (Dekkers and van Domburg 2000)(p29)

A diagnosis of NES has been known to cause conflict between some doctors and patients (Dekkers and van Domburg 2000) even when the diagnoses has been reached by gold standard prolonged video-EEG. [16] People with NES, however,

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[15] Psychogenic Non-epileptic Seizures, another form of terminology for NES.
[16] This is understandable in that some video EEG recordings show that 'electric epileptiform activity occurs in about two per cent of the asymptomatic population' (p33) and, people can have concurrent epilepsy and non epileptic seizures. Dekkers, W. and P. van Domburg (2000). "The role of doctor and patient in the construction of the pseudo-epileptic attack disorder."

are not usually faking their symptoms (Russell 2006) although it has been known (Dekkers and van Domburg 2000), when a patient is conscious of making gains from having seizures [17] (Sharpe and Faye 2006) such as increased attention from others or financial gain, perhaps in the form of social security benefits (Langfitt 2007). People with NES being more likely to be claiming these benefits than people with similarly severe epileptic seizures, thus this gain may play a role in perpetuating NES (Reuber 2008i). People with NES also have a lot at stake regarding the driving issue, it being questionable that anyone with periods of unconsciousness, organic or not, should be driving (Langfitt 2007).

The earlier people are diagnosed with NES, the better for everyone (Bodde, Brooks et al. 2009). Financially, correct diagnosis could reduce seizure-related costs such as assessment, emergency and in-patient stays. One study cited remission rates of between 25 and 56% following a diagnosis (Langfitt 2007). Paradoxically, a small number of short term studies show good outcomes regarding seizure cessation, whereas the longer term outcome appears to be poor, with only 16% of people becoming free of seizures (which is only a good marker if people do not have concomitant epilepsy) and in paid employment. However, this is another area ripe for research in order to establish the reasons for this, although it is posited that this could be put down to individual differences in patients, such as relapse, developing other health problems and individual etiologies (Reuber 2008i). Many people with NES retire through ill health and others are unemployed at a relatively young age (Reuber 2008i). Factors which improve prognosis include, fast recognition of the condition, onset at a younger age, higher IQ and higher socio-economic status (Reuber 2008i).

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[17] One study found evidence that a man was simulating seizures in order to be able to leave the army. Van Merode, T., M. De Krom, C T F M, et al. (1997). "Gender-related differences in non-epileptic attacks: a study of patients' cases in the literature." Seizure 6: 311 - 315.

Historical views on NES

Hysteria (a condition in which people appear to mimic epileptic convulsions and other neurological attributes) (Faber 1997) has always been associated historically with women [18] the condition being seen predominantly in 19th and 20th century neurology settings (Brown and Trimble 2000). Landouzy, and later Charcot, in the mid 19th century, were early neurologists who attempted a formal tentative, diagnostic criteria which would help clinicians differentiate between epilepsy and hysteria using the case histories of hundreds of patients and acknowledging that the two conditions can co-exist (Faber 1997). People having NES were thought to have a separate condition which had special capacities including evil powers, their seizures being perceived as expressions of powerful emotions, imitating and malingering (Dekkers and van Domburg 2000).

One study retrospectively examined the histories of 43 well known historical figures, were considered to have epilepsy, including Pythagoras and the actor Richard Burton (Dekkers and van Domburg 2000). Approximately 21 of them were 're-diagnosed' as having had anxiety/psychogenic seizures and approximately 12 as experiencing alcohol withdrawal seizures, with none of the remaining people thought to have had epilepsy at all. Dostoevsky was known to have struggled to differentiate his epileptic fits from other types he experienced and which were diagnosed by Freud as severe hysteria at the time (Dekkers and van Domburg 2000) - that is, he was diagnosed as having both epileptic and NES.

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[18] The fact that more females present with NES is not fully explained for example, by higher instances of sexual abuse reported by women, and alternative explanations of learned expressions of anger, fear or helplessness and biological differences have been proffered as an explanation for this gender difference. Reuber, M. (2008i). Are Psychogenic Non-epileptic Seizures an Expression of "Neurologic" Pathology? Psychiatric Controversies in Epilepsy. M. Reuber, Elsevier.
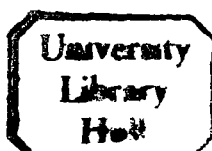
Terminology for NES

Historically, various terms and labels for NES have been used by neurologists and in the literature, being imbued with various meanings and eliciting varying reactions from patients (see box 2, below). More recently, terms used to describe experiences in seizure patients have been found to include fits, blackouts and seizures and the use of these terms has been found to differentiate between NES and epilepsy patients (Plug, Sharrack et al. 2009).

Box 2

Historical terms and labels used for NES

- From the 19th century term, 'hystéro-épilepsie', the terms, 'hysterical seizure' and 'pseudoseizures', imply psychiatric based causes which often offends patients (Stone, Campbell et al. 2003)
- 'Epileptic equivalents' - this term was coined to clarify the relationship between similar physical manifestations in NES and epilepsy Berrios (1984), in (Dekkers and van Domburg 2000).
- 'Pseudoepileptic seizure' defines patients as experiencing real seizures which were not epileptic (Kuyk and Leijten 1997).
- 'Non epileptic attack disorder', (NEAD), being, 'non judgemental' describes a problem without implying a cause (Scull 1997) and covers, 'organic, pathological non epileptic conditions', such as some 'cerebrovascular and neurological syndromes' which can cause epileptic type seizures (Dekkers and van Domburg 2000)(p32).
- 'Pseudo-epileptic attack disorder' (PEAD) recognises seizures as being 'an involuntary, paroxysmally occurring pattern of behaviour' similar to epilepsy but without its organic roots (ibid).
- 'Non organic seizures', 'psychological attacks', 'dissociative seizures', or 'conversion disorder' are additional terms suggested for clinicians to consider (Stone, Campbell et al. 2003).
- 'Non epileptic seizures', (NES) describes the problem without implying a particular cause (Russell 2006).

Treatment

Treatment for NES needs to be considered separately from that of epilepsy (Kato 2006). It requires a multi disciplinary approach (Gonzáles-Goizueta, Martinez-Pérez et al. 2000) which can include, a family systems perspective [19] (Langfitt 2007), CBT, biofeedback, (Uhlmann and Froscher 2001), pilots of 'individualized brief integrative therapy' (Reuber 2008)(p628), and group therapy (Barry, Wittenburg et al. 2009).

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[19] Mind/body patterns of behaviour with diagnostic criteria of symptoms have been used previously in relation to people with NES. Their symptoms were found to be related, in the main, to dysfunctional family systems and the people concerned mainly diagnosed with conversion disorders. Griffiths, J. L. (1990). "The Mind/Body Problem Revisited: Pseudoseizure Patients." Family Systems Medicine 8(1): 71 - 89.

Vital to treating NES is a patient being presented with and accepting their diagnosis. Many patients do not fully understand their condition, are unsure what precipitates it, and find a diagnosis of NES confusing. Few attend very long for psychological follow-up. Improving these understandings has implications for developing more tailored treatment approaches (Carton, Thompson et al. 2003). For patients whose diagnosis is successfully presented and accepted, this can result in their becoming seizure free (Hall-Patch, Brown et al. 2010).

In terms of implications for both treatment and diagnostic practices, in a comparison of the use of the terms, 'fit', 'blackout', 'attack' and 'seizure', epilepsy patients preferred 'seizure' and other epilepsy-related terminology, whereas people with NES actively avoided the term seizure, preferring 'fit' and in particular, 'blackout', notwithstanding being previously exposed to epilepsy terminology (Plug, Sharrack et al. 2009).

Informing patients of the link between abuse (as trauma), and NES is a controversial and ethical issue. For some people this may help them come to terms with their diagnosis, others may not remember any trauma, and NES can occur in the absence of any trauma (Thompson, Isaac et al. 2009).

Some patients find it difficult to accept that there is no organic cause for their physical symptoms (Reuber 2008) although a sensitive communication of the diagnosis can reduce seizure occurrence in some. Some may be angry with this diagnosis (Reuber 2008), given that they may have been diagnosed with epilepsy previously with all the implications of this diagnosis.

Conclusion

Correctly diagnosing people with seizures is important for patients and their lay and professionals carers, their condition and prognosis can then be explained to them in terms of their organic or psychological nature. Diagnosing people with NES will enable them to be given their correct treatment as early as possible, and would have the benefit of freeing up neurology clinic time for people with epilepsy who need these services long term. Differential diagnosis can be ascertained with video-EEG when the circumstances are right. [20] One study found that, over a period of 20 years, only 33 studies described predominantly medically based diagnostic techniques, other than EEG video telemetry, all of which could be useful as complementary techniques for differentiating NES from epilepsy (Russell 2006). Chapter 2 shows that there are linguistic hints that clinicians can be aware of which may indicate one or another diagnosis. Also suggested, as an additional part of the diagnostic process, is that the illness representations of patients should be considered in the etiology of NES (Reuber 2008i) as they can offer some clues as to the difficulty people with NES have in understanding the process and mechanisms of their condition (Green, Payne et al. 2004).

Notwithstanding that NES have been classified as a psychiatric disorder, little attention has been given to it from researchers in general (Bodde, Brooks et al. 2009), and from psychologists in particular given that it results from psychological processes (Reuber 2008) and that it could be as prevalent as multiple sclerosis (Sharpe and Faye 2006).

Chapter 1.2 will explain NES as a functional symptom (FS), the theories behind this concept and whether NES, as a distinct FS, could be identified by specific

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[20] Alternative diagnostic approaches have been used in the past including; demographic and medical history variables, seizure semiology, provocative testing, prolactin levels, single photon emission computed tomography, psychological testing, and neuropsychological testing but have not been found to give the accuracy of EEG. Cragar Dona, E., D. T. R. Berry, et al. (2002). "A Review of Diagnostic Techniques in the Differential Diagnosis of Epileptic and Nonepileptic Seizures." Neuropsychology Review 12(1): 31 - 64.

predisposing, precipitating, perpetuating and triggering factors which are seizure related and based on an individual patient's etiology (Reuber 2008i).

1.2 Functional symptoms (FS) as an explanation for NES

'Somatoform and dissociative disorders, including NES straddle the interface between neurology and psychiatry: body and mind.' (Reuber 2008i)(p168)

When there are no medically objective explanations for a patient's subjective experiences, these are termed variously, 'somatisation', 'somatoform disorders', medically unexplained symptoms' (MUS) or 'functional somatic symptoms' (Reuber, Mitchell et al. 2007 iv). A functional symptom is, 'one that, after appropriate medical assessment, cannot be explained in terms of a conventionally defined medical disease' (Wessely, Nimnuan et al. 1999)(p936). Functional symptoms (FS) will be the main term used here as many patients with NES prefer this terminology (Stone, Campbell et al. 2003) (Reuber, Mitchell et al. 2007 iv). This term is useful in that it offers patients a positive interpretation of their symptoms, i.e., "there is not damage of nerve cells but a disruption of function", (Reuber, Mitchell et al. 2007 iv)(p309).

Symptoms are considered as medically unexplainable if functional disability or distress is clinically significant and cannot be 'solely attributable to anxiety, depression, hypochondrias, or psychosis' (Brown 2004)(p794), being classified in the DSM-1v as:

> 'according to the nature, number, and duration of the symptoms in question' which are not 'accounted for by identifiable physical pathology... including musculoskeletal pain, (being of the highest prevalence) and other 'pain, fatigue, general malaise.' (Brown 2004)(p793).

FS are at the lower end of a hierarchy between 'medically explained' and 'medically unexplained symptoms' (Nettleton, O'Malley et al. 2004). Patients are often extremely disabled (Wessely and White 2004), presenting with incapacitating symptoms which have no obvious physiological basis and for which their doctors are powerless to treat with conventional medical solutions

(Nettleton, O'Malley et al. 2004). People consulting about FS comprise around 20% of all UK primary care consultations, and in medical outpatients around 35% (Wessely, Nimnuan et al. 1999).

FS can include complaints of chronic pelvic pain, presented in gynaecology, irritable bowel syndrome presented in gastroenterology, and fibromyalgia presented in rheumatology (Wessely, Nimnuan et al. 1999; Wessely and White 2004). In neurology outpatient settings, 10-30% of patients will present symptoms which have no 'pathophysiological explanation' (Reuber, Mitchell et al. 2007 iv)(p307), such as pseudoseizures and pseudohallucinations (Brown 2004) while in another study, 9% of 4470 neurology inpatients were found to have neurologically unexplained symptoms (Reuber, Mitchell et al. 2007 iv)(p311).

FS are difficult territory for doctors and patients, people's distress levels are not always accurately reflected in their demeanour and their physiological experiences differ (Kirmayer, Groleau et al. 2004). Patients can be difficult to help (LaFrance, Gates et al. 2008), and often less than happy with their medical consultations (Wessely, Nimnuan et al. 1999). Although patients may offer clues about the roots of their symptoms in what may be chaotic narratives (Nettleton, O'Malley et al. 2004), these are not always picked up by clinicians, who may not be comfortable working with patients with FS (Reuber, Mitchell et al. 2007 iv). Physicians may focus on biomedical issues because a), they work in that tradition, and b), because some patients search for this level of explanation as it can absolve them of responsibility for their condition and treatment and elicits concern from others (Kirmayer, Groleau et al. 2004). This discomfort was expressed by the neurologist involved in this study:

> 'most of us are far more comfortable dealing with hard physical disease,
> it's when it's non physical that we actually struggle.' A.M., (115) [21]

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[21] Please see file C in the thesis appendices.

The etiology of FSs is best understood as an interaction between predisposing, precipitating, perpetuating factors, psychiatric disorders and personality traits. A biopsychosocial model would encompass dimensions of an individual's past and present life, their personal biography, including any past experience of trauma or abuse for example, biological factors, including gender, psychological attributes, such as dissociative episodes, social aspects of their life, for example isolation, and their illness beliefs (Reuber, Mitchell et al. 2007 iv) and representations (Reuber 2008i).

These psychological factors may operate at different levels, as triggers, i.e., the role for a stressor is implicated here, such as past abuse, they may predispose a person to have these experiences (for example, individual personality types) or they may act to maintain them (family dynamics) i.e., various background factors may be associated with the seizures but these may not be apparent as and when the seizures are manifested (Goldstein and Mellers 2006).

FS can also be 'explained' up to a point in terms of psycho-physiological and socio-physiological models whereby the central nervous system (CNS) mediates and interacts with psychological and social factors. This makes it difficult, for example, to differentiate between organic pain associated with real injury and pain caused by 'CNS activity that may be associated with emotional distress or social conflict' (Kirmayer, Groleau et al. 2004)(p666). In some NES patients behaviour can correlate with measurable, physiological change and dysfunction in the CNS (Griffiths 1990).

Changes in brain physiology lend support to the theory that many FS share similar mechanisms (Wessely, Nimnuan et al. 1999)(p937). It has been suggested for example, that Chronic Fatigue Syndrome (CFS) may be due to a disregulation in a person's stress response and this may explain why a patient feels genuinely ill. Functional brain imaging studies are beginning to offer insights into the physiology of conditions such as conversion disorder (see section below) (Kirmayer, Groleau et al. 2004), NES being classified as such a

disorder (LaFrance, Gates et al. 2008). In one single case study, a patient with FS was found to have dysfunction in an area of the brain which may have been implicated in the regulation of 'intentional motor behaviour' (Kirmayer, Groleau et al. 2004)(p666).

Connections between NES and other FS

The condition of NES as a FS, appears to be closely associated with other medically unexplained conditions already mentioned above, including CFS, another condition with no obvious physiological explanations (Dickson, Knussen et al. 2008) but which now has inclusion and exclusion criteria of specific physical and mental symptoms which help formally define the condition (Sharpe and Faye 2006). Also, Fibromyalgia - 'widespread musculoskeletal aches and pains' – and hardly acknowledged as a diagnosis twenty years ago (Kirmayer, Groleau et al. 2004)(p664) is accepted now as a discrete, diagnosable, functional symptom and considered part of the symptoms included in a diagnosis of CFS. Such conditions lack the elements which constitute a 'true' disease, i.e., 'a natural cause, specific pathophysiological abnormalities and specific clinical findings' (Dekkers and van Domburg 2000)(p36).

Many FS however, remain 'unnamed' (Nettleton, O'Malley et al. 2004) because they share 'core or diagnostic features' suggesting that, rather than representing 'specific diagnostic entities' in different medical specialities, each may be part of one and the same syndrome (Wessely, Nimnuan et al. 1999)(p937) (Wessely and White 2004). There is some support for similar treatments being effective across a range of FS, given that symptoms are shared across conditions. This begs the question of whether 'different' FSs should be treated in discrete, particular, individual, medical specialities. For NES for example, there remains the variations in behavioural presentations, and psychological and etiological correlates of the condition, and symptom manifestation which supports an argument for an appropriate, specialist management of the condition (Larson 2006).

Numerous studies are reaching conclusions about the incidence of other FS in patients experiencing seizures, which may help differentiate between NES and epileptic seizures. For example, the presence of 'an antecedent diagnosis of fibromyalgia or chronic pain, and the occurrence of a seizure occurring in the clinic', constitute what are termed red flags and have been recognised informally by epileptologists as implying a diagnosis of refractory NES (Benbadis 2005)(p2)(Russell 2006). If risk factors for epilepsy are not present, and a patient has a history of other FS and childhood abuse experiences, then NES should be positively considered (Russell 2006).

The history of the concept of dissociation

Dissociation occurs in a number of both neurological and psychiatric disorders including temporal lobe epilepsy and NES and 'is both a mechanism and a disorder', dissociation in NES often being mistaken as epileptic unconsciousness (La France, Gates et al. 2008)(p317). The World Health Organisation (WHO) diagnostic criterion suggests that as a mechanism, this is related to 'trauma, insoluble or intolerable problems or disturbed relationships'. WHO (1992) in (ibid)(p318). The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) defines dissociation as, " a disruption in the usually integrated functions of consciousness, memory, identity or the perception of the environment" DSM IV (p477), in (Lawton and Baker 2008)(p333).

Dissociation used to be considered 'a heterogeneous group of psychiatric conditions previously subsumed within the broader construct of hysteria', which, in the 19th century, began to explain FS in the many patients who presented with this almost exclusively in neurology settings (Brown and Trimble 2000)(p295). Briquet, a professor of legal medicine in Paris in the 19th century, was probably the earliest proponent of the idea that hysterical symptoms occur as a result of trauma, including childhood sexual, physical and emotional abuse (Browne 1990). 'Briquet's syndrome', is a chronic somatisation disorder (polysymptomatic hysteria) in the DSM-1v, whereby people can

present with a number of somatic complaints, various neurological symptoms and a past history of abnormal illness behaviour (Brown 2004; LaFrance, Gates et al. 2008).

The psychiatrist and philosopher Janet's early theory of dissociation (still influential today in the field of dissociative disorders) perceived 'hysterical' patients when threatened with traumatic events, as instinctively averting their attention from these, so that their memories were not consciously integrated into their present life (Kuyk 1996). People had no control over when and under what circumstances the old, traumatic memories may be activated however, be it by internal or external triggers, and these often manifested in the form of unexplained physical symptoms. Some of these memories may have been inhibited at the time of the original experience and could be traumatic for an individual if they appeared later (Browne 1990).

Features of dissociation include, dissociative amnesia, fugue, identity disorder and depersonalisation disorder (Lawton and Baker 2008), memory disturbances, 'derealization, a discontinuity of personal existence, hallucinatory phenomena' and a 'contraction of the field of consciousness' (Meares 1999)(p1850), and 'autoscopy' (out of body experiences) whereby a person can feel as if they are looking down on themselves (LaFrance, Gates et al. 2008)(p318).

Hughlings Jackson's theory of dissociation, the breaking down of parallel concomitance, is also useful here (Meares 1999). The concept of parallel concomitance was developed from a particular concept of the self arising from brain function integrating with different evolutionary levels of memory and consciousness (which develop during childhood) to the highest, pre frontal activity, termed 'concomitant parallelism' (Meares 1999)(p1851). Functions developing later, and which are implicated in reflection, 'are the most fragile and are first lost' (ibid)(p1852). The highest level of consciousness is 'doubling' (op cit)(p1851), for example, when one can hold models of the past and present

in one's mind. Jackson gave the example of smelling a rose as an adult and being able to remember where and when one first did this as a child (Meares 1999). Dissociation occurs when later, evolving functions are disrupted resulting in an 'uncoupling of consciousness' or 'dissolution' (Meares 1999)(p1851), that is, the breaking down of parallel concomitance. The implication of this argument is that brain states influence a person's mind and that psychological trauma can cause similar insult to the mind/brain as that caused by chemical trauma (Meares 1999). Jackson's 'dreamy state' occurs when a person unconsciously engages in complex behaviours and does not remember this behaviour. To Jackson, this can be a result of 'neuronal exhaustion', prior trauma during development or previous head injuries.

Although memories related to these traumas were not *consciously* attended to, they were still processed *unconsciously* (Brown 2004). Painful memories or processes are thus being denied from coming into a person's conscious awareness (Harden 1997; Wolf, Schöndienst et al. 2000). As Browne points out, traumatic or other experiences for that matter are not experienced or attended to all at once, they can be processed unconsciously, over a period of hours, days, months, even years before they becomes an integral part of self. This 'involves neurophysiological and somatic work on the part of the person to whom the experience happens' (Browne 1990)(p21).

Thus NES, as a dissociative mechanism, can defend against extraordinary levels of arousal and limit the 'coding' of an experience in specific ways. Linguistic pathways and expressions could be reduced in use (Gülich, Schöndienst et al. 2003) and subsumed under sensorimotor ones such as NES (Gülich and Schöndienst 1999).

In the ICD-10, dissociation is defined as, 'a partial or complete loss of the normal integration between memories of the past, awareness of identity and immediate sensation, and control of body movements' ICD-10 (p151) in (Brown and Trimble 2000)(p285). Because the main characteristic of NES is a bodily

function disturbance, rather than a cerebral one (Harden 1997), some symptoms within this are classified within the somatoform disorders of the ICD-10. As a theoretical explanation, dissociation is a mechanism whereby psychological factors are associated with causing, in the case of NES, 'impaired voluntary control over neurological function' (Goldstein and Mellers 2006)(p616).

Neodissociation theory argues that dissociation is a normal, systematic, cognitive, psychological defence mechanism which everyone has, and which is mediated by 'autonomous but interconnected cognitive control systems' which are hierarchically organised, and activated without an individual having to attend to them consciously. Dissociation as a system however, can become overused and maladaptive, resulting in unexplained symptoms manifesting themselves (Brown 2004).

A general population study on 'the clinical profile' of people with NES found that dissociation and anxiety disorders were significant diagnoses in these cases (Gomes, Kropf et al. 2002)(p716). However, again confusion lurks, since dissociation is not a diagnostic feature exclusive to NES. Jackson's 'dreamy state' can also occur in medial temporal epilepsy (Meares 1999) in people with complex partial epilepsy (Alper 1997) [22] and aspects of dissociation can also be found in people with temporal lobe epilepsy (LaFrance, Gates et al. 2008), where transient amnesia may be the only apparent symptom (Kuyk, Spinhoven et al. 1999).

However dissociation is no longer considered a 'unidirectional construct' with two qualitatively different phenomena being identified within this and within NES and epilepsy (Lawton and Baker 2008). Detachment involves 'an altered

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[22] One early study found three people who were thought to have had complex partial seizures being rediagnosed with pseudo complex partial seizures following lengthy further in-patient assessment. Ramchandani, D. and B. A. Schindler (1992). "Distinguishing features of pseudocomplex partial seizures." Bulletin Of The Menninger Clinic 56(4): 479 - 486.

state of consciousness characterised by a sense of separation from aspects of everyday experience' and common in epilepsy. 'Compartmentalism' on the other hand is 'a reversible deficit in the deliberate control of processes that would normally be amenable to such control, and that are objectively intact despite subjective experience to the contrary' (ibid)(p334). There is the potential for these two constructs to be able to differentiate between types of dissociation and their symptoms occurring in NES and epilepsy rather than those used in measures which lack the specificity to differentiate between these and, therefore, between the two conditions (ibid).

Conversion theory

Conversion theory extends the concept of dissociation as a defence mechanism and suggests that the recollection of traumatic memories are repressed but, in order to maintain brain homeostasis, and to ensure that a person is protected from these past traumas, they have to be expressed in other ways. They are converted into, and expressed as, symptoms present in the original scenario, or symbolically in the form of seizures. This way of expressing symptoms, reduces a person's anxiety, they do not have to address underlying psychic conflicts and, can elicit concern from others (Langfitt 2007). Increased dissociative traits are present in conversion disorder which often presents as conversion NES (and again, confusingly can present in complex partial epilepsy) although obviously, 'the etiologic basis' of the dissociation diverges between these two groups (Alper 1997)(p991).

Where to next?

Whilst acknowledging that much progress has been made in terms of differentiating NES from epileptic seizures, knowledge about them remains limited. Until more is known about the subjective experiences and mental states of patients with NES, when and where their seizures happen, whether certain subjective psychological/states link with any motor or autonomic

physical seizure manifestations and how the biographies of individuals affect their seizures, this could remain the case (Reuber 2008). Reuber also argues for the use of neuroimaging techniques, (which have contributed to knowledge about posttraumatic stress disorder for example) neuropsychological studies and psychogenetics for a potential contribution to the development of a future, biopsychosocial model of NES (Reuber 2008).

2 Introduction to Conversation analysis. CA and history taking as a diagnostic method

In addition to VEEG and the potential for statistically based history taking methods to identify, and/or eliminate epilepsy/NES, new, innovative ways of diagnosing seizures through linguistics are now contributing to this. In-depth history taking has long been recognised as important in epilepsy in particular, medical, social and psychiatric histories being, potentially, as useful as seizure descriptions in differentiating seizure types (Bodde, Brooks et al. 2009).

In an attempt to differentiate specifically between NES and epilepsy, a project begun over ten years ago has gone beyond what is traditionally advocated in the clinic. A history taking method drawing on insights from Conversation Analysis (CA), has been developed by German researchers and linguists, under the umbrella of a German project, (the 'Bethel Project' [23]), and which is currently being added to with work being done in the UK contributing significantly to differential diagnosis (Plug, Sharrack et al. 2009; Reuber, Monzoni et al. 2009).

This project has identified that people with NES and epilepsy talk very differently about their seizure experiences and these differences can be analysed linguistically. By way of illustrating the potential of this approach to differential diagnosis, a striking study (Stauder 1996) cited by Gülich (2003), showed that an analysis of clinical interviews using a CA approach could successfully differentiate between functional circulatory imbalance and coronary heart

[23] The project Linguistic Differential-typology of Epileptic and other Seizure Disorders – Diagnostic and Therapeutic Issues was subsidised by the German Research Association from 1.3.1999. This project was conducted at the Mara I Clinic, Epilepsy Centre Bethel (Chief Consultant: Prof. Dr. Peter Wolf). Members of the project were: Ingrid Furchner, Elisabeth Gülich, Martin Schöndienst, Meike Schwabe, Nicolas Tsapos. In 1996 and 1997 this project was called Formulation Patterns in Illness Narratives of Patients who suffer from Seizures and supported by the University of Bielefeld. A corpus of transcripts was thus developed. Research into NES has been extended in the UK with Dr Markus Reuber and Leendert Plug, NEST (Non-Epileptic Seizures Treatment) Group 2006. nest@sheffield.ac.uk

conditions. This study involved patients with angina who described their symptoms in a semi-structured interview as part of an in-depth diagnostic process. It was possible to differentiate linguistically between a coronary heart condition (a serious condition) and functional circulatory imbalance (not so serious) and this diagnosis held true in 80% of patients after a coronary angiogram (diagnostically sure) was performed following the interview (Gülich 2003). [24]

Brief introduction to Conversation Analysis (CA)

Conversation Analysis (CA) is briefly described here in terms of its history, objectives, theoretical roots, philosophy and technical method. How it works in relation to the studies in this synthesis and the way in which the authors in the Bethel Project have shifted from CA's original conceptions, will be explained throughout the synthesis following this introduction.

The objective of CA

'to identify socially organised competences which underlie intersubjectivity and mutual intelligibility in talk-in-interaction' (Maynard and Heritage 2005)(p78).

CA has developed over the last 30 years, being established by Sacks, along with collaborators Schegloff and Jefferson (Atkinson and Heritage 1984). Sacks was a sociologist working in the ethnomethodology tradition, and suggested that the ways in which people conduct their social life are methodical, describable and reproducible (Atkinson and Heritage 1984; Sacks 1984). CA's main objective is

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[24] German work about pain experience is being undertaken using a similar linguistic analysis, mainly focusing on lexicon, metaphors, metonymies, paraphrases, reformulations, and strategies used by people and is helping to, 'develop an empirically founded systematic description of the procedures which German-speaking patients actually use in order to describe pain of different kinds and quality'. Menz, F., J. Lalouschek, et al. (2005). The representation of Pain and Illness Narratives: Questions of Orality, Gender and Transformation. A discourse analytic and medical semiotic study Institut fur Sprachwissenschaft der Universitat Wien

to understand how people negotiate social tasks in every day life, with the assumption that there are regular procedures in conversations which can be identified and described and which illustrate the skills people share and use in order to understand, manage and orient themselves towards each other's behaviour (Atkinson and Heritage 1984). The approach attempts to separate participants' intersubjective understanding of the course of conversation as it evolves moment by moment (Arminen 1999).

The 'natural laboratory' of CA (Atkinson and Heritage 1984)(p3)

Traditionally, 'pure' CA analysis use recordings of naturally occurring everyday, conversations within a wide range of situations (Atkinson and Heritage 1984) and are not, traditionally, manipulated by experimental interventions or with the use of interview schedules. Examples of work being done recently within Health Psychology include recordings of telephone conversations to a Birth Crisis help line, (Kitzinger and Kitzinger 2007), conversations between a woman with Alzheimer's and her family (Kitzinger and Kitzinger 2007i), teenage girls' telephone conversations (Stockhill 2007), calls to the NSPCC (Hepburn 2004) with others undertaking video analysis, (Lerner and Zimmerman 2003; Lerner, Zimmerman et al. Forthcoming). Video analysis being a different endeavour to one of a linguistic analysis only and one which could offer an analysis of bodily expressions, involving other additional subjective dynamics with the attention on 'expressive bodily gestures' (Finlay 2006)(p23).

CA does not refer to information outside of the conversation being studied, working with actions, preferences, sequences and implications but never with thoughts (personal communication, PC). The linguistic behaviour of the participants is the only information needed to analyse what is happening (Atkinson and Heritage 1984). What people say and how they say it, is not assumed to be determined by their mental states (Drew 1995). This is in direct contrast to the IPA method used in this study. CA is an approach, a technology

Chapter 2. Introduction to Conversation analysis: History taking as a diagnostic method.

and an analytical stance, the boundaries of which are explained below.

The theoretical roots of CA

In terms of its relation to the Human Sciences (Arminen 1999) CA is considered a 'kind of sociology' and was not, initially a study of language per se (Ten Have 1999)(p9). It is practiced by different disciplines who justify their different conceptualisations and use of CA (ibid). Working alongside the ethnomethodological tradition (ibid) a part of phenomenological sociology which reifies, above all else, the phenomena identified by a participant [25], CA aims to give information about what is actually occurring in a human society Sacks (1984) in (Atkinson and Heritage 1984). Ethnomethodology and CA see society as containing order at different levels and, by examining closely people's talk, it can make sense of how they negotiate everyday tasks and social relationships in the particular, social milieu they inhabit (ibid).

Underpinning CA thought is that, far from being random, people's personal conversations reflect a reflexive, internalised process that they, as members of a society, have undergone in reaching a common understanding of this society, in terms of everyday run of the mill conversations. Language may not always be what it first appears to be; underneath these everyday conversations are details, meanings, typicalities and conventions which go beyond what is actually spoken Sacks (1984) in (Atkinson and Heritage 1984). Without a detailed analysis of such conversations these could remain unearthed.

This social action in CA is understood by 'co-locutors' in terms of being a part of the same 'culture' or 'social' group (Arminen 1999). Rather than imposing researchers' own ideas on what is studied which could result in missing important aspects of what is being said, a conversation analyst will wait and see what people *choose* to talk about. That is, an 'unmotivated examination' of what

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[25] This element of the approach is similar to IPA, the proposed approach for this study.

is there, can bring up unexpected findings which can then be explored and built upon, Sacks (1984) in (Atkinson and Heritage 1984). [26] If the analyst is a member of the 'society' their conversation partner belongs to, (in the case of the Bethel project both conversations partners had knowledge of seizures for instance) analysis will not present any problems, if they are not, it could be argued that an ethnographic knowledge of that society would be beneficial [27] (Arminen 1999).

The technicalities of conversation and how a CA works

CA is based on the premise that talk is organised (Drew 1995) and provides evidence for people's understandings their own and other's 'moves' as they take turns in inferring what the other person means. CA conversations are always recorded and transcribed in detail, so that others researchers can access and re analysed conversations at a later date (Atkinson and Heritage 1984). The transcriptions of audio and video recorded conversations are always notated in various levels of detail, symbolising verbal and non verbal activities (Maynard and Heritage 2005). According to the needs of an analysis, interactional detail may include, people talking over one another, hesitations and breaks in sentences leading to new beginnings. Overlapping speech, lengths of breaks in conversations, silences, intonations in speech, when people breathe in and out, emphasis or lengthening of words or syllables and if things are difficult to hear are also noted (Surmann 2002). [28]

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[26] The Bethel Project began to alter this fundamental tenet from its inception (i.e., departing from the unmotivated examination that Sacks first envisaged) in that something specific was being looked for and manipulating how this was found. This fundamentally alters the basic tenets of CA in that the work done was driven by hypotheses, this is further discussed in the synthesis. Schwabe, M., S. J. Howell, et al. (2007). "Differential diagnosis of Seizure disorders: a conversation analytic approach " Social Science & Medicine 65(4): 712 - 724.

[27] The linguists in the Bethel project were not initially, it could be argued, part of the 'culture' of seizures, but later became familiar with it.

[28] This method was originated by, Jefferson, G. (2004). Glossary of trenscript symbols with an introduction. . Conversation Analysis: Studies from the first generation. G. Lerner, H. Amsterdam, John Benjamins: 13 - 34.

Chapter 2. Introduction to Conversation analysis: History taking as a diagnostic method.

CA does not analyse solitary sentences or utterances but sequences of talk and turns (Atkinson and Heritage 1984) systematically examining dynamics and, detailed interactive talk (Friedland and Penn 2003). This process of, 'the next turn procedure' is one of the main tools in CA' (Arminen 1999)(p251), when a verbal action by one speaker will prompt a further action. How a person has understood the previous move of a co-locutor is shown in their subsequent reply. If one person does not perceive that the other person has understood a previous utterance they made as they intended it to be understood, they can endeavour to repair this misunderstanding in their next or later utterances (Maynard and Heritage 2005). Thus these repairs, turn taking and managing the topic are examined for evidence of understandings or misunderstandings between people (Friedland and Penn 2003). 'Recipient design' (ibid)(p13), is a characteristic which gives clues to 'co-interactants' (ibid)(p14), and an interpretation of other people's utterances. A person's response to these and their subsequent utterances, are clues as the conversation progresses. Where utterances are placed in the sequence of the conversation as a whole (a particularly important aspect in the studies below) and how people allocate their turns can be analysed.

Commonplace utterances are 'social objects' (Maynard and Heritage 2005)(p249), which accomplish social actions and activities without this being explicit. For example, saying 'Isn't it cold in here' can be seen as a comment which is understood as a request to turn on the heating (Maynard and Heritage 2005). Silences and gestures are also considered integral to the analysis and can, in themselves, achieve actions by the other person. The example of a parent remaining silent when their doctor does not want to give their child antibiotics, can result in the doctor altering his decision and prescribing them after all (Maynard and Heritage 2005). Thus a conversation is fluid but with a demonstrable structure, the sequences of people's actions as they communicate being 'doubly contextual' (Maynard and Heritage 2005), i.e., it is both context dependent and context renewing - a fundamental concept in CA.

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Like other qualitative approaches, CA also takes into account 'deviant' cases. An example of how this works is again given by (Maynard and Heritage 2005). HIV 'bad news' diagnoses were found to be given in a fashion which went against the conventional ones (designed to pacify and minimise the bad news). Unlike the pacifying style, the deviant cases were done in a much more forthright fashion, resulting in precipitating a discussion, in real time, about urgent issues relating to the diagnosis which needed this immediate engagement. That is, technically, an utterance can both alter and shift the context, in this example, from breaking bad news to asking urgent questions about prognosis (Maynard and Heritage 2005).

An accumulation of individual cases using CA can be used to identify and build up patterns, sequences and issues occurring about the same phenomena over numerous conversations. This is essentially a case by case analysis resulting in the accumulation of instances of a practice (Maynard and Heritage 2005) i.e., some generalisations can be made as to the properties of the phenomena in question (Drew 1995). This is what the Bethel project has done and a systematic qualitative narrative synthesis of this work is below.

Chapter 3 will give an introduction to the narrative synthesis, and the particular methodology used to examine and synthesise the studies from this project. Following this, in chapter 3.1, the synthesis question and methods used will be introduced. There will be an overview of the findings in chapter 3.2, and in chapter 3.3, a 'conceptual expression of the synthesis' (Pope, Mays et al. 2007)(p82). This is an interpretation of what the development of CA research to date has offered the differentiation of seizures using a linguistic analysis. It is to these findings that this study hopes to add.

3 An introduction to the narrative synthesis

There has been an 'epistemological shift' which recognises that qualitative research contributes important knowledge to the evidence base which is rooted in its iterative research processes (Dixon-Woods, Bonas et al. 2006). This is reflected in the scope of systematic reviews by the recently established Campbell Collaboration which has been widened to encompass more social and educational interventions and a substantial number of systematic qualitative reviews and syntheses have now been published (CampbellCollaboration 2008).

However, just how appropriate it is to dismantle individual studies and attempt to synthesise their findings into a 'whole' interpretation (Britten, Campbell et al. 2002; Zimmer 2006) and whether this is an appropriate intellectual endeavour, is disputed (Pope, Mays et al. 2007). Extreme relativists argue that this has the potential to lose valuable analyses unique to studies conducted in particular contexts by researchers with different backgrounds which affect their individual interpretations (Pope, Mays et al. 2007). Qualitative researchers however, work with similar methodological guidelines and have a mutual understanding of how findings are reached which enables them to understand the processes involved in synthesising work (Britten, Campbell et al. 2002). There remains a significant gap in reviews of qualitative research studies generally, which could hinder the progress of future work in an area. Authors in the same field do not always cite other relevant papers and a synthesis would address this problem (Pope, Mays et al. 2007).

This synthesis borrows concepts from meta synthesis and meta ethnography and is conceptual in its nature (Pope, Mays et al. 2007). It examines study findings, comparing and translating these across studies to reach a new interpretation which incorporates and 'distils the meanings of constituent studies' (Zimmer 2006)(p312). It is narrow in scope (Britten, Campbell et al. 2002) being an interpretation of findings in studies in the same

topic area selected because they are relevant to addressing a particular research question (Zimmer 2006). A resultant synthesis should go beyond what narrative and systematic literature reviews can offer (Britten, Campbell et al. 2002).

By examining agreements, contradictions and patterns in studies, a synthesis can reach a higher level of theory (Zimmer 2006) than that in single studies and can produce something which is not in the original papers, whereby the parts are more than the whole (Campbell, Pound et al. 2003). It involves a double hermeneutic in that the reviewer interprets the findings of the original research (Pope, Mays et al. 2007). This mirrors the approach of Interpretative Phenomenological Analysis (IPA) the approach used in this study. In the case of this synthesis, however, translating of German articles produced a triple hermeneutic in that this initial translation was one interpretation, i.e., the translation of authors' findings by a person other than the researcher who then interpreted these translations further.

It is important to consider individual papers in terms of what it can offer to the synthesis (Pope, Mays et al. 2007), papers here have similar philosophies and methods. Syntheses can include refutational studies, which can result in a refutational synthesis, (Campbell, Pound et al. 2003), can contribute to theory development but do not usually address different theoretical perspectives (Pope, Mays et al. 2007) and, importantly, can help build up a cumulative evidence base (Pope, Mays et al. 2007).

Qualitative synthesis is, essentially, a qualitative study in miniature (Zimmer 2006) and the methods for this are still fledgling, tending to be rooted in research study methods and analytic techniques, mirroring the qualitative research process itself although the way in which syntheses are undertaken vary. In some cases they can be seen as formally testing, 'the feasibility of synthesising using qualitative methodology including a formative evaluation of criteria for assessing the research to be synthesised' (Campbell, Pound et al.

2003)(p671). Synthesisers can utilise techniques of mapping ideas and arguments in order to reach what can be accepted as a reasonable synthesis of findings (Hart 1998) given the context of individual syntheses (Pope, Mays et al. 2007). Generally, synthesisers use the published findings of other authors (Campbell, Pound et al. 2003) staying close to their material and reasoning (Hart 1998).

The work synthesised here was undertaken by a small number of researchers, very aware of each other's work as they attempted to build up a theory based on a growing corpus of data. The synthesis will attempt to draw this together at two levels, the first offering an overview of the empirical findings while the second is a more conceptual expression of the synthesis findings.

Meta ethnography

The synthesis benefits from ideas in meta ethnography which is an approach used for the process of synthesising qualitative or interpretative research and is used as a basis for this synthesis. This approach, involves examining concepts present across studies and synthesising these in order to produce something which is inclusive, but which also has the potential to develop theory beyond that in any individual study (Zimmer 2006). It allows findings and meanings from within individual studies to be merged, whilst taking care not to lose the details of how these were arrived at and by whom.

One way to do this is to use researchers' and participants' own terms and phrases verbatim (Britten, Campbell et al. 2002). This is important in this particular synthesis because describing seizures can be difficult for patients and they manage this in individual, idiosyncratic ways. The studies in this synthesis used CA based *approaches* to analysis, albeit in slightly different ways and contexts, gradually developing the approach beyond 'pure' CA. Later work was underpinned by early developmental work thus giving studies the same theoretical base and a continuation and development of mutual ideas. This

rendered the synthesis more robust than if attempting one across studies using different methodologies (Zimmer 2006).

3.1 A narrative synthesis: Question and methods

Synthesis question

"How far do Conversation Analytic derived approaches identify that the nature of the language used by people to describe their seizures has implications for differential diagnosis of epileptic and non epileptic seizures?"

This synthesis was an activity benefitting from various personal experiences of the author including a background of extensive training in qualitative research methodology, undertaking original research and a knowledge of the general epilepsy/NES literature. It drew upon the work and methods in various qualitative syntheses already undertaken and includes an element of 'conceptual innovation' (Campbell, Pound et al. 2003)(p672).

Literature search

The rules of synthesis mean that studies have to contain commonalities in that findings can be found across studies notwithstanding context and time. The synthesis in this thesis contained such studies from Beilefeld University in Germany [29] and others which continued this work in the UK under the umbrella of the Bethel project. In terms of the quality and appraisal of studies, most of the ones contained in this synthesis were peer reviewed and accepted without further appraisal.

Studies to be included in the synthesis were those dating from 1992 to 2008 [30] and which used a CA approach in searching for attributes pertaining to seizure accounts. The main search for articles began, not with a traditional literature

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[29] (University of Bielefeld, in the faculty for Linguistics and Literary Studies. Prof Elisabeth Gülich and the Epilepsy Center Bethel (Dr Martin Schöndienst and Prof Peter Wolf). www.uni-bielefeld.de/lili/projekte/epiling.

[30] Some papers were in press at the time and references have thus been updated.

search, but by a serendipitous meeting with a German scholar of metaphor, (R.S., personal communication, 2005) who recommended two book chapters in the field of language and seizures as being perhaps worthy of translation, having reviewed them (Schmitt 2002). These were both subsequently translated.

This led to the author approaching authors in the field given that the Bethel Group had already come to many tentative conclusions relating to differential diagnosis and language. Maintaining a continual dialogue with researchers in the UK, and in Germany over an extended period of time at meetings and electronically as the synthesis progressed produced further up to date studies, studies in press and unpublished studies.

Following up references, accessing the web sites of major authors in the field for unpublished papers, conference papers, abstracts and talks in both the German and English languages ensured that most of the literature was captured. Some elements of 'Berrypicking' Bates (1989) cited in (Barroso, Gollop et al. 2003) were used. This is a directed search which also allows for an iterative and creative searching process to take place including subject searches in bibliographies, footnote chasing and tracking and searching citations. Abstracts from articles in other languages were examined to ensure no work on CA was excluded. Three studies were found but none of them were using a CA approach although their contents are noted below. [31] Notwithstanding this effort, some

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[31] One paper identified ictal motor patterns from patient charts which may help identify NES in the clinic, Giménes-Roldán, S., D. Hipola, et al. (1998). "Fenomenología crítica motora en pacientes no epilépticos con crisis psicógenas (Phenomenology of motor crisis in Non-epileptic patients with psychogenic crises)." Revista de Neurologia 27(157): 395 - 400.
    A second study lists items in patients' histories likely to provoke NES, and which were considered in both psychological terms, i.e., memories they recalled, and medically, i.e., history as recounted by the patient. These were divided into, family and marital problems, physical trauma and drug abuse. Vojtech, Z. (2000). "Nase zkusenosti s pseudozáchvaty (neepileptickáými psychologenními (Our experience with pseudoseizures (Non-epileptic Psychgenic Seizures)." Ceska-a-Slovenska-Neurologie-a-Neurochirurgie 63/96(3): 152 - 161.
    A third emphasised the importance of history taking to identify stressors. It also acknowledged that some epilepsies can imitate symptoms of NES. If NES is diagnosed, the diagnosis needs to be presented with care in order to aid the efficacy of therapy. Ganzález-Goizueta, B. M.-P., et al. (2002). "Crisis psicógenas no epilépticas (Non-Epileptic Psychogenic Seizures)." Revista de Neurologia 35(10): 954 - 959.

journal articles sought by this author and one of the Bethel authors appeared to be unobtainable. [32]

Given that this is a relatively new and small area of study which began in Germany, many of the references retrieved were in this language. Articles and abstracts of these and book chapter titles were translated in order to decide which of these were most relevant. Two book chapters and one article were finally fully translated by a German speaking academic researcher [33] and these translations are in the thesis appendices. One dissertation (Surmann 2005) was not translated in whole or part because the author had made significant published, contributions to the Bethel work in his specialist field of metaphoric conceptualisations in seizure descriptions. There were multiple articles by the same authors as they developed their ideas.

Some conference papers which represented pilot studies or a different perspective of concepts already arrived at, were examined in order to ensure that the developing thoughts of researchers were recorded and to render the synthesis more robust. Articles excluded were ones which did not examine conversations with adults.

Two formal literature searches were undertaken during the ad hoc search to ensure that papers had not been missed. The terms 'seizures' and 'diagnosis' 'conversation analysis' 'narratives and seizure and descriptions'; 'language and seizures' and 'language and epilepsy' were used across several data bases [34] from 1992 to June 2008. This yielded two conference abstracts over and above what

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[32] Gülich, Schöndienst & Surmann, 2002. Wie Anfälle zur sprache kommen (As accumulations to the language come). Psychotherpaie und Sozialwissenschaft. Zeitschrift für qualitative Forschung. 4,4.
Gülich, Schöndienst & Surmann, (2003). Schmerzen erzahlen Geschichten - Geschichten erzahlen Schmerzen (Pain that tells a story - stories that tell of pain). Psychotherapie und Sozialwissenschaftg. 5,3, 220 - 249.
[33] A.P., Clinical Psychologist, Manchester, UK.
[34] Ovid SP, Journals@Ovid Full Text, Your journals@ Ovid, Books@Ovid, International bibliography of the Social Sciences, Ovid MEDLINE® In-process & Other Non-Indexed Citations and Ovid MEDLINE ® to present. Ovid MEDLINE Daily update. Psych articles, Psych Info and Pub Med

had already been found. One pilot study (Reuber, Schwabe et al. 2007vi) was later written up as a published paper (Schwabe, Howell et al. 2007) and the other (Reuber and Plug 2007i) about metaphor was later undertaken as a full study (Plug, Sharrack et al. 2009i). A second search undertaken when the synthesis was complete, using the same data bases and the same terms did not yield any more relevant references.

All work finally selected is by researchers closely linked to each other in that their work stemmed from that done originally in Germany. There does not appear to be any other work in this area being undertaken. Because the studies were so closely related to each other, and written by combinations of the same authors, similar attributes were often present in conversations and pseudonyms were often used for patients. Advice was thus sought from some authors in order to clarify which, if any, study populations or particular individuals' analyses were replicated in different studies.

In some cases e.g., Surman (2002), it was difficult to separate patients out as he was working with the same, original corpus accumulated by Gülich and Schöndienst (1999) and some pseudonyms were the same. However, his analysis was mainly metaphorical, so this new analysis of the original corpus was treated as a separate one, it being acceptable in CA to re-analyse conversations (Atkinson and Heritage 1984).

The same applies to the work of Furchner, (2002), who examined levels of consciousness in Bethel patients. Similarly, Wolf, Schöndienst et al., (2000), referred to one of the patients in Gülich and Schöndienst (1999), (Mrs R) but added more findings to this patient's analysis. The final references included nine peer reviewed papers, (1 translated from German) three book chapters, (two translated from German) and 2 conference abstracts and these are listed in box 3, page 60. Where articles or chapters have been translated, the titles are in German and English. Brief résumés and further details of studies are in the

thesis appendices. [35]

Methods

This synthesis employed various activities during the working of the synthesis and these raw workings are in the thesis appendices and are referenced in the process below. The concept of ordered interpretations, (Pope, Mays et al. 2007) that is, the 1st order being the participants' words, the 2nd order being the author's, and the 3rd order being the synthesis itself was rendered somewhat askew in this work. Work that had been translated had already undergone an interpretation by the translator and, obviously, there were only excerpts of patients' transcripts in studies. Utilising the meta ethnographic approach, which moves from single accounts to identifying analogies *between* accounts whilst preserving the 'sense' of accounts by picking out their key organising concepts, authors' own words were highlighted and used for the initial workings, sometimes using them verbatim in the synthesis, (although they can be translated, as long as their original meaning is preserved) to both collect and to represent these key issues. These concepts were then translated *into* each other becoming the 'form' of the synthesis (Noblitt and Hare 1988)(p13).

Preserving original words, phrases and ideas as they were either originally spoken by participants or coined by authors ensured that the synthesis was rooted in constituent studies and the ideas therein (Hart 1998; Walter, Emery et al. 2004). Examples of these were, 'limited self consciousness' in (Furchner 2002), or pertaining specifically to NES, 'their peculiar conversation behaviour' in (Schoendienst, Surmann et al. 2005). This process also ensured that, first, given the increasing familiarity with the field, the researcher's own codes or concepts were not imposed onto the work, unless there was evidence for these in the original works of the authors. Secondly, because describing seizures is a difficult task for patients, their descriptions were idiosyncratic and varied from

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[35] See 'Workings' of synthesis file, documents 1(extensive details of studies) and 1a (brief details of studies).

person to person depending on many things including their level of articulation and imagination. Thirdly, it was noted that some patient descriptions may be useful for use in a future seizure discourse.

Initially general information was collected from each study; such as their underlying rational, methods, the numbers of conversations included, how they were conducted, by whom and in what setting, concepts, theories and hypotheses in the study, whether it was exploratory, or a specific study examining reformulation or metaphor for example, and findings and comments and ideas for further research were recorded. [36] This process began by first notating individual studies and progressed into a more detailed, structured working document [37] and a similar first stage to that used in IPA.

Second stage in the synthesis

Recording individual study themes and attributes of seizure descriptions

Since most of the authors in early studies were working on the same corpus which often resulted in one researcher expanding the analysis of a patient mentioned in another study I tracked individual fragments of transcripts belonging to the same participants between studies. [38] At a subsequent reading, each study was examined for concepts within them (O'Neill, Jinks et al. 2007). Given the emphasis on individual epilepsies in the early studies these were scoured for the attributes identified by these authors, the early identifiers in speech expanded upon in (Gülich and Kotschi 1995) and later ones gathered by

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[36] See document 1(extensive details of studies) in the file entitled 'Workings' of synthesis in the appendices
[37] See document 2 (breakdown of study components) in the file entitled 'Workings' of synthesis in the appendices
[38] The analysis of one patient (Mrs Reifen) for example, in Gülich and Schondienst, (1999) was further expanded on in; Wolf, P., M. Schöndienst, et al. (2000). Experiential auras. Epileptic Seizures: Pathophysiology and clinical semiology. H. Lüders, O and S. Noachta. New York., Churchhill Livingstone. 336 - 48.

subsequent authors, for example whether or not people focussed on their seizures experiences. These were mapped against each epilepsy and NES (see table 2, p 69 in the synthesis overview).

Interpretations were then constructed from these in that the themes or concepts already identified above had explanations for them. For example, there was a concern about the lack of systematic studies in that medical diagnostics had usurped patients' verbal descriptions. The theme that best described this concern in this paper was the importance of subjective symptoms (Gülich and Schöndienst 1999). As the work was developing, themes in the papers were added, such as participants' use of metaphor and later still, how significant the use of this linguistic resource was. All papers were examined in chronological order, themes within them were entered into an excel sheet, with relevant phrases or terms from each study being entered under the appropriate theme. Some studies had more or less under each theme depending on the focus of the paper and where it stood in the development of the work. In order not to miss any relevant information when 'expressing' the synthesis, separate excel pages were joined together, covered in overlay and laid out so that every theme with explanations, words and phrases, or statistical inferences, could be considered and clearly struck through when expressed in the synthesis. [39]

Representation of conversational attributes

In addition to this process, inextricably linked to the themes above and to ensure no information was excluded, each paper was examined for what the authors had found in terms of differential diagnosis in particular. They were examined for common and uncommon attributes which the authors had analysed as being related to a differential diagnosis of epilepsy and NES. This was done both by noting each author's conclusions and by examining the extracts of conversations given. Again these were noted for each single paper,

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[39] This process is illustrated in the thesis appendices, 'Workings' of synthesis file, documents 2 - 8.

and these attributes were again listed. [40]

The Bethel Project developed a model which analysed patients' verbal reports of their seizure experiences and this technique is contributing significantly towards differential diagnosis of different epileptic and nonepileptic seizures. The overview will describe the first four studies in terms of different linguistic formulations and efforts of people with NES and different epilepsies (see table 2) before moving on to the second level of the interpretation. This depicts the major NES/epilepsy distinctions in the final ten studies (see tables 3 - 6) in various areas of language use.

The conceptual expression of the work thus far illustrates how hypotheses in later studies were developed from early work, how the CA approach to the analysis changed such that the term, CA, was no longer appropriate and a new one, 'Epilepsy Discourse conversations' is suggested. Finally, a rationale for an additional analysis (IPA) of the language used by seizure patients will be put forward. The fourteen studies included in the synthesis are in box 3 below, with translations of titles where appropriate.

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[40] This process is illustrated in the thesis appendices, 'Workings' of synthesis file, documents 2 - 8.

Box 3. Studies included in the synthesis

1 (Gülich and Schöndienst 1999) Das ist unheimlich schwer zu beschreiben.'"This is terribly difficult to describe". Formulierungsmuster in Krankheitsbeschreibungen anfallskranker Patienten. Formulating Patterns of Epileptic Patients Describing their Attacks: Differential diagnostische und therapeutische Aspekte. Differential diagnostic and therapeutic aspects. Psychotherapie und Sozialwissenschaft. Zeitschrift für qualitative Forschung. In Psychotherapy and Social Sciences, Journal of qualitative research. Göttingen: Vandenhoeck und Ruprecht, Band 1, Heft 3, 199-227.

2 (Wolf, Schöndienst et al. 2000). Experiential Auras. In H.O. Luder & S. Noachtar. (Editors) Epileptic Seizures: Pathophysiology and Clinical Sociology. New York. Churchill Livingstone.

3 (Surmann 2002). "Wenn der Anfall kommt". Bildhafte Ausdrücke und metaphorische Konzepte im Sprechen anfallskranker Menschen. "When the seizure comes"1 - vivid expressions and metaphorical concepts in the language of people who suffer from convulsive illnesses. In Brünner & Gülich (Hrsg.). (2002) Krankheit verstehen. Interdisziplinäre Beiträge zur Sprache in Krankheitsdarstellungen. Understanding Illness. Interdisciplinary Writings regarding the language in the description of illnesses Bielefelder Schriften zu Linguistik und Literaturwissenschaft, Bielefeld Writings towards Linguistics and Literature Sciences Band 18, 95-120. Bielefeld: Aisthesis.

4 (Furchner 2002) "keine absence gleicht der anderen". Die Darstellung von Bewusstseinslücken in Anfallsbeschreibungen. "no absence resembles the other". The depiction of gaps in consciousness in seizure descriptions. In Brünner & Gülich (Hrsg.). (2002) Krankheit verstehen. Interdisziplinäre Beiträge zur Sprache in Krankheitsdarstellungen. Understanding Illness. Interdisciplinary Writings regarding the language in the description of illnesses Bielefelder Schriften zu Linguistik und Literaturwissenschaft, Bielefeld Writings towards Linguistics and Literature Sciences Band 18, 121 - 141. Bielefeld: Aisthesis.

5 (Gülich 2003i). Conversational techniques used in transferring knowledge between medical experts and non-experts. Discourse Studies. 5, 2, 235-263.

6 (Schoendienst, Surmann et al. 2005). Conversation Analysis Might Add to the Differentiation of Non-epileptic from epileptic seizures. 26th International Congress. Epilepsia. Conference proceedings.

7 (Schwabe, Howell et al. 2007). Differential diagnosis of seizure disorders: a conversation analytic approach. Social Science and Medicine. 65, 4, 712-724.

8 (Reuber and Plug 2007 ii). Getting more out of the history: Interactional, topical and linguistic features in clinical encounters with patients with epilepsy and psychogenic non-epileptic seizures. AES Conference Proceedings. Annual meeting of the American Epilepsy society. Philadelphia. Epilepsia. 48, (S6) 1 - 410. 1.057. Conference proceedings.

9 (Reuber and Plug 2007iii). Conversant in epilepsy. Listening better to people with seizures. Epilepsy Professional. Issue 5, 10-14.

10 (Schwabe, Reuber et al. 2008) Listening to people with seizures: How can linguistic analysis help in the differential diagnosis of seizure disorders? Communications and Medicine. 5, 1, 59 – 62

11 (Plug, Sharrack et al. 2008i) Conversation analysis can help to distinguish between epilepsy and non-epileptic seizures disorders: A case comparison. Seizure. European Journal of Epilepsy 18, 1, 43 – 50.

12 (Plug and Reuber 2008ii) Making the diagnosis in patients with blackouts - it's all in the history. Practical Neurology. 9, 4 – 15.

13 (Plug, Sharrack et al. 2009i) Seizure metaphors differ in patients' accounts of epileptic and psychogenic non-epileptic seizures. Epilepsia. 50, 5, 994 - 1000

14 (Plug, Sharrack et al. 2010) Seizure, fit or attack? The use of diagnostic labels by patients with epileptic or non-epileptic seizures. Applied Linguistics. 31, 1, 94 - 114

3.2 Conversation analysis and differential diagnosis of seizures. A narrative synthesis of the literature: An overview

This overview examined how the Bethel studies have built up a cumulative evidence base which is contributing to the differential diagnosis of seizures. The Bethel team recognised the significant lack of studies which systematically studied the phenomena of subjective seizure symptoms, being concerned that patient's accounts were being eclipsed in deference to more medically focussed diagnostic procedures (Gülich and Schöndienst 1999; Wolf, Schöndienst et al. 2000) and given that a typical seizure is not always witnessed during VEEG monitoring (Schwabe, Howell et al. 2007).

Treating patients as biomedical experts in their own conditions, albeit in possession of different sources of knowledge to those of their doctors (Tuckett, Boulton et al. 1985) was recognised by the Bethel team as important (Gülich, 2003; Schwabe, Howell & Reuber, 2007). Given the opportunity, it has been suggested that patients will indicate their attitudes towards illness and how they are coping (Gülich, 2003). This also has the potential to guide a diagnosis (Reuber 2008i). [41]

The early Bethel work attempted to differentiate between many different epilepsies and NES, [42] examining over 60 transcripts of differing epilepsies and NES. This overview examined studies one to four - those which focus on different epilepsies and NES (see table 2) before moving onto the second level of the interpretation, which depicts the major NES/epilepsy distinctions in the

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[41] This concern that patients' subjective experiences are of fundamental importance but, nonetheless, undervalued, has been addressed in the condition of schizophrenia. Noting patients' altering subjective experiences has been found to help in the early detection of people at risk of this condition. Parnas, J., P. Møller, et al. (2005). "EASE: Examination of Anomalous Self:Experience." Psychopathology 38: 236 -258.

[42] Gulich (1999), focal epilepsy left temporal (2 patients), idiopathic generalised with absences (1 patient) focal epilepsy and generalised signs (1 patient). Wolf (2000), cryptogenic right temporal lobe epilepsy with complex automatisms and rare generalised TCS, and Surmann (2002), generalised epilepsy, focal epilepsy, left temporal.

final ten studies (see tables 3 - 6). [43] Distinctions between different epilepsies
are considered again in later studies.

Terms for describing the indescribable

Formative work by Gülich and Kotschi, [44] had developed a model which would
evaluate metadiscursive comments and formulations in speech (Gülich and
Schöndienst 1999). It was this work which initially guided the Bethel
researchers on which elements of conversations to look out for in the context of
differential diagnosis, containing specific and relatively easy to observe
conversation attributes. These included; whether formulations were initiated by
patients or another person, the stages of, and various reformulation they went
through including 'hesitations', 'meta-discursive comments', 'adversative
structures' and the use of 'pre existing expressions'. See box 4 below, for
examples of these.

[43] One study which describes the progress of the Bethel work so far is not included in the
synthesis as it confirmed findings of previous studies. However, ideas and recommendations for
further work in this study are considered in the main findings section. Schwabe, M., M. Reuber,
et al. (2008). "Listening to people with seizures: How can linguistic analysis help in the
differential diagnosis of seizure disorders." Communication and Medicine 5(1): 59 -72.

[44] Gulich and Kotschi, Th (1995). 'Discourse Production in Oral Communication: A Study
Based on French' in U.M. Quasthoff (ed). Aspects of Oral communication. 30 - 66. Berlin: de
Gruyter.

Chapter 3.2. Conversation analysis and differential diagnosis of seizures.
A narrative synthesis: An overview

Box 4.

Examples of linguistic methods to describe seizures

'**Meta discursive comments**' - 'that's always very hard to describe, err'.

'**Vagueness indicators**' - 'so to speak' or, 'If I may express it that way'

'**Adversative structures**' are expressions to describe 'conflicting sensations' that is, phrases containing contradictory parts, for example,
I can still see everything' is connected by an '**adversative connector**' such as, 'but', followed by ' I'm not really there anymore'

Reformulation.

An example of the 3 stage reformulation processes is:

1) the patient beginning with a reference expression, for example, 'I hear, err, words and sounds all wrong', then
2) giving a reformulation indicator such as, 'well', followed by
3) a reformulation expression, such as, 'I wouldn't be able to understand you then'.

NES
'**Existing preformed expressions**' - 'to make the most of it really' or 'to be seizure free as much as possible'.

(Gülich and Schöndienst 1999)(p218)

Mental diplopia - Illusions of derealisation and depersonalization, double visual perception

(Wolf, Schöndienst et al. 2000)

Early work on conversational attributes pertaining to differentiating between different epilepsy seizure types and NES.

The work done by Gülich and Schöndienst (1999) used existing clinical, pre recorded interviews. However the subsequent findings and insights of researchers stemming from these required that additional interviews were recorded specifically for the Bethel project. The work at this stage was exploratory and the 'phased CA interview pattern' used in later studies (see box 5, page 86) was not formally established at this stage. This idea did not develop

until it was realised that certain events were happening at certain points in the conversations (Gülich and Schöndienst 1999).

In addition to attempting to distinguish between NES and epilepsy, researchers were also attempting at this point to search for complex correlations between anatomy, psychology and psychopathology, whether people's descriptions would alter depending on which hemisphere the aura or seizure started in and, whether people with NES differed from those with partial epileptic seizures - given that dissociative symptoms are also present in people with this type of epilepsy (Gülich and Schöndienst 1999; Wolf, Schöndienst et al. 2000). Also, models of memory and psychoanalytic perspectives on conversations, (that is, paying attention to *how* things were communicated over and above *what* is said (ibid)(p203). The use of metaphor and patients' experiences of consciousness were already being mooted for future hypotheses.

The importance of patients' talking in a therapeutic context, and how a conversation as it developed could give access to an individual's traumatic experiences was acknowledged. Having seizures was such an experience and comparisons were made between the 'distinctions and criteria that patients themselves formulated' (Gülich and Schöndienst 1999)(p203). This particular analysis used illustrations from five female patients, one of whom had NES. People with epilepsy exhibited intense efforts to formulate their experiences to the doctor, sometimes at a certain point in the conversation. Some descriptions were very specific and personal depending on the epileptic foci and personal experiences. Two patients with focal epilepsy showed similar reformulations giving cohesive accounts of their seizures (Gülich and Schöndienst 1999)(p203).

In describing seizures, people are attempting to remember and explain experiences which are uncommon to most other people, the temporal course of seizures being particularly difficult to put across given that people may spend some of this time experiencing differing levels of consciousness (Furchner

2002). Early studies using cortical stimulation had highlighted to a degree, how memories are stored and recalled and how stimulation could bring about visual representations of past, personal traumas (Wolf, Schöndienst et al. 2000). The addition of a linguistic analysis was a new departure in this area of study and one which researchers hoped would be a more 'natural' way of gaining more insight, 'into some of the strategies and detours of a mind working at recollection' (ibid)(p343).

Notwithstanding the complexities inherent in physiological correlates of different epilepsies and the small numbers of patients used NES, as a discrete condition, at this stage began to emerge as being described differently in linguistic terms. That is, a person with NES talking about their experiences tended to leave a listener with an incomplete impression of what their experience actually consisted of (Surmann 2002). The implications of pauses and the German, 'leere' (translated as emptiness) in the accounts of people with NES, were considered significant and related to what might have initiated the seizures, but which people did not verbally articulate. [45]

That people with NES tended to dissociate themselves from their seizures became apparent (Gülich and Schöndienst 1999) and this finding was mirrored in later studies. Surmann found that descriptions of seizures by people with NES were confusing, repetitive, appeared incomplete and did not formulate, what could be considered, a phenomenological experience (Surmann 2002). There was a reluctance to focus on their seizures, which was considered a physical expression of unresolved psychological conflicts (Schondienst 2002) cited in (Surmann 2002)(p13) and as in Gülich and Schöndienst (1999), there was a sense in which they appeared to be concealing what had happened and this was beginning to be considered as evidence for a diagnosis of NES (ibid). NES patients tended 'not to know' about their seizures (Gülich and Schöndienst

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[45] These authors considered this 'emptiness' relevant enough to be further explored with patients in therapeutic consultations because states of consciousness leave certain 'linguistic traces' and are important to note in therapeutic contexts with seizure patients.

1999) and, when triggered by others into giving a description, they often listed their *physical* symptoms (Gülich and Schöndienst 1999).

Notes on individual epilepsies

Gülich and Schöndienst (1999) attempted a linguistic differentiation between NES and focal and generalised epilepsies [46] seizures and auras. It had been hypothesised that there may be different language patterns relating to different hemispheres and analysing these could actually help in locating the seizure foci. Also, if surgery is being considered, this location is crucial and these subjective symptoms need to be assessed (Gülich and Schöndienst 1999). It is now well established that initial seizure symptoms help to locate where a seizure begins (Noachtar and Peters 2009). It was also suggested that there could be differences in language in people with epilepsy and NES (Wolf, Schöndienst et al. 2000).

In addition, subjective symptoms of epileptic auras were also important to assess as objective findings, because of their role in helping patients develop ways in which to interrupt their seizures (Wolf, Schöndienst et al. 2000). Although this study was, at that time, ongoing and the methodology undeveloped, it addressed several questions relating to different epilepsies and, specifically, whether NES patients describe their seizures differently from people with partial epileptic seizures.

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[46] In generalised epilepsy, EEG suggests that both brain hemispheres are involved in the beginning of the seizures and consciousness is usually impaired. Baxendale, S. (2006). Epilepsy: An approach to case formulation. Formulation and treatment in Clincical Health Psychology. V. Nikcevic Ana, A. Kuczmierczyk, R and M. Bruch. Hove, Routledge.

One patient with cryptogenic [47] right temporal lobe epilepsy with complex automatisms and rare generalised tonic-clonic seizures had many of the attributes of people with focal and generalised epilepsy (Wolf, Schöndienst et al. 2000). She used adversative structures, elaborate self initiated reformulations, meta discursive comments and uses the present tense about events which were not talked about in chronological order. True to the promise of CA methods, that *something* will be found in an analysis, the emotion of fear emerged unexpectedly as a major theme for this patient. Past personal traumatic experiences were evoked by her seizures, appearing to her in a visual form (Wolf, Schöndienst et al. 2000) illustrating the point mooted above that talking to people at length will result in their providing different information about their lives in this case, highlighting the processing, recollecting and recreation of traumatic memories (ibid).

One person having tonic clonic seizures and another with Idiopathic Generalised epilepsy (IGE) [48] had common attributes in that they narrated events. Given that people with these types of epilepsy do not have warnings about their attacks and, therefore, cannot offer subjective descriptions, this is understandable (Gülich and Schöndienst 1999). There were also similarities with IGE and NES notably, that other people were needed to trigger their talk about seizures, they exhibited little formulation effort, people with NES used pre existent phrases and people with IGE talked about details other than the seizure itself. None of the other epilepsies exhibited these attributes. Other than the IGE example above, the epilepsy and NES patients exhibited linguistic differences.

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[47] Cryptogenic means hidden cause.
[48] Idiopathic epilepsy has, 'no clear underlying cause other than hereditary disposition to seizures.' (p174). Baxendale, S. (2006). Epilepsy: An approach to case formulation. Formulation and treatment in Clincical Health Psychology. V. Nikcevic Ana, A. Kuczmierczyk, R and M. Bruch. Hove, Routledge.

Although patients with focal epilepsy (as did NES and IGE patients) responded to triggers by others to talk about their seizures, they also showed elaborate, self initiated formulations. People with epilepsy made meta-discursive comments, some were vague and hesitant. Others described images, hallucinations, auditory or visual illusions. Some had 'mental diplopia' and used 'adversative structures' to explain their experiences (see box 4, p63), for explanations of these terms).

Surmann (2002) attempting a finer grained differentiation of seizures than previous studies and found several pointers to the diagnosis of focal epilepsy. Having unexpected seizures which are never the same, people with focal epilepsy intensely formulated their experiences, saw their seizures as threatening at varying levels (some even being afraid of dying) frequently personalised them and gave them the ability to move. Surmann also found differences between IGE with absences and focal epilepsy (Surmann 2002).

Bethel authors later began to reconsider individual epilepsies and why people with different seizure types communicated differently about them (Schwabe, Howell et al. 2007). This begs the question however, whether a focus on different, individual epilepsies could muddy the water in terms of differentiating between epilepsy and NES.

These four early studies examined over 67 transcripts in the same corpus at this time [49] and the *main* attributes identified, relating to the different seizure types are aggregated in table 2 below. Shading and emboldening of text, denotes attributes already seen to be occurring in NES only.

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[49] Perhaps more as it was not clear exactly how many Furchner had examined, although she did comment that she was working on 'our' corpus, implying this was the original, Bethel interview corpus recorded in clinics.

Chapter 3.2. Conversation analysis and differential diagnosis of seizures.

A narrative synthesis: An overview

Table 2.

Different linguistic formulations and efforts of people with NES and different epilepsies

Attributes	NES	Epilepsy	Focal epilepsy left temporal	Epilepsy with focal and generalised signs	Cryptogenic right temporal lobe epilepsy with complex automatisms and rare generalised TCS.	Idiopathic generalised with absences -ve status
Responses triggered by another person	√		√	√		√
Adversative structures used		√	√		√	
A tendency not to know and a sense of emptiness in descriptions	√					
Talks of detail other than the seizure itself						√
Lists physical symptoms	√					
Metadiscursive comments		√	√		√	
Uses existing common phrases	√					
Use of the present tense				√	√	
Little formulation effort	√					√
Elaborate self initiated reformulations			√	√	√	
Descriptions of visual or auditory illusions or hallucinations		√	√	√	√	
Mental diplopia			√		√	
Resistance to focussing on seizure experience	√					

Early work on metaphor

Rhetoric is continually at work in clinical consultations as doctors and patients try to persuade each other, and 'much argument and effort to influence others rests on the poetic and evocative use of language' Perelman (1982), in (Kirmayer 2000)(p156). Metaphor is such an influence used in discussion and the use of metaphor is common in 'codifying, representing and remembering experience' (Kirmayer 2000)(p155). Surmann' s (2002) work was important in these early studies, his principle focuses being on metaphor and the use of 'vivid language' and, as Perelman implied, that this could tell us something about a patient's condition.

Surmann worked with the cognitive theory of metaphor. That is, according to Lakoff and Johnson (2003) human conceptual systems being metaphorically structured we automatically think in metaphorical terms. Thus metaphor is an intuitive, unconscious method of attempting to express complex experiences. The essence of metaphor being to understand and experience one thing in terms of another. Significant concepts underlying the metaphors people use can be uncovered by examining this linguistic strategy and this analysis can build up a picture of someone's experiences (Lakoff and Johnson 2003).

In terms of recognising and analysing metaphor, Surmann questioned the extent to which metaphors express our sensory experiences and whether the use of certain metaphors actually shapes and gives meaning to our experiences. He argued that concepts related to the metaphor are selective and used specifically as they can point to particular characteristics of a person's experience. These concepts are important to identify because they will highlight the shape of a person's personal metaphoric system, the concepts they use being products of their cognitive and emotional processing. Their subjective experiences verbalised metaphorically were an expression of this (Surmann 2002).

Sometimes things are too difficult to describe to others and people can fail to express their experiences in a coherent fashion (Surmann 2002). However, even failed and contradictory metaphors can be useful to examine, because, if the concepts *behind* them are concentrated on, this will offer some insight into people's subjective experiences. For example, people may talk about their seizures coming, developing or, happening, (i.e., metaphorically they are being seen as an event) and this could tell us something about the condition itself. Unimportant concepts will be absent and by examining the picture offered by patients one can find a coherent pattern of meaning behind what can appear to be conflicting metaphors. 'Faded' or conventional metaphors can also be explained differently by people and reworded, although the original meaning can remain intact (Surmann, 2002).

Metaphoric constructs depicting the seizure as a threat were beginning to be noted as present in people with epilepsy whereas NES patients had none or incoherent metaphoric conceptualisation (ibid). It was noted that metaphorical predications, though not termed as such in these early papers, were present in some transcript examples, people saying for example, things were, 'pressing down', 'pulling down' (Menz, Lalouschek et al. 2005). [50]

Early work on conscious and unconscious states

Also being noted in conversations was that unconscious/conscious states were being described by patients in terms of the degree to which these are experienced. This would be considered a definite departure from a pure CA

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[50] In this description of a study examining pain experiences with a view to classifying pain representations for the purposes of differential diagnoses, it offered an international review of the status of linguistic research in pain representation and thus reinforced the relevance of using this for other conditions. The authors cite a lack of studies in this area using a conversational analytic approach. The Bethel seizure studies are cited as being extremely promising, being multi disciplinary bridging CA and epileptology. Menz, F., J. Lalouschek, et al. (2005). The representation of Pain and Illness Narratives: Questions of Orality, Gender and Transformation. A discourse analytic and medical semiotic study Institut fur Sprachwissenschaft der Universitat Wien

because, as an approach, CA does not consider the cognitions of participants. However, if participants are introducing such concepts which require cognitive appraisal, then these were important to note and needed to be researched in this context given that descriptions of consciousness are important in diagnosing seizures.

Gülich and Schöndienst (1999), focussed particularly on the psychodynamic concepts of consciousness and the state of dissociation. NES was seen as a particular state of consciousness, dissociation protecting an individual from 'extra ordinary levels of arousal', verbal expressions of the trauma being expressed as seizures, Brenneis, (1998) in (Gülich and Schöndienst 1999)(p202). The empty accounts of people experiencing NES were seen as depicting isolation and an unconscious transferring of the 'symbolic space' as a form of defence, to another person - who had very little to go on in terms of information about their seizure experiences (Gülich and Schöndienst 1999)(p222).

People with focal seizures balanced 'making conscious' by keeping a distance from their seizures (Gülich and Schöndienst 1999)(p222). People with petit mal and generalised seizures required the presence of another person to be 'an externally initiated substitute ego' so that they could work on repetitive, dramatic and stereotypical narrations (Gülich and Schöndienst 1999)(p222). An effort to complete gaps in their consciousness pointed to a diagnosis of focal seizures (Wolf, Schöndienst et al. 2000; Surmann 2002).

Clear verbal markers of consciousness were found in that the 'gap' in consciousness was clearly marked in epilepsy patients (Furchner 2002)(123). Memories of before and immediately after the gap pointed to a movement in state from, 'dynamic to static' the end of which was often characterised by something unusual having occurred, such as being found in an odd situation or pose (Furchner 2002)(129). The temporality of consciousness was recognised,

people remarking that, 'a few metres were missing', they reconstructed their time spent being unconscious and this was set within their aura experiences (Furchner 2002)(p124).

People with NES however, often equated the seizure with complete unconsciousness and offered no reconstruction of this period. They represented the lack of consciousness, with phrases such as, 'I just went'. They knew this had happened and could offer much trivial information about the setting and context in which the seizure took place. The seizure, itself however, was only briefly described (Furchner 2002). Unconsciousness was seen by NES patients as equalling the seizure, and as 'proof' that a seizure had occurred. The unconscious experience is the dominant aspect of the seizure, it was so complete that it could not be challenged, (Surmann 2002). 'Holistic' descriptions such as 'I know nothing', is one example of a comment made by a patient with NES (Furchner 2002)(p123).

Later work on conversational attributes pertaining to differentiating between epilepsy and NES. Studies 5 to 14

In later studies, different epilepsies were not differentiated and a clearer juxtaposition of characteristics attributable to epilepsy and NES began to appear. The emphasis moved towards a more detailed and sophisticated analysis and outlined four main areas. If, and how, people:

- Reformulations of seizure experiences and symptoms (Table 3, below)
- Described seizure suppression attempts (Table 4, below)
- Depicted metaphoric constructs or metaphoric predications (Table 5, below)
- How people make sense of their consciousness/unconscious states (Table 6, below)

Study findings are annotated across the following tables and serve to illustrate the development of emerging and sustained patterns of communication as the research progressed, and as over 100 conversations had been analysed.

Reformulation of seizure experiences and symptoms

People with NES and epilepsy could both exhibit the same characteristics and
people with both conditions offered descriptions of visual, auditory illusions and
hallucinations. However, these anomalies were subsumed in the context of the
whole interview being analysed and one or another diagnosis being determined
(Plug, Sharrack et al. 2008i).

Table 3.

Reformulations of seizure experiences and symptoms

Attribute	NES	Epilepsy
Person exhibits resistance to focussing on seizure experiences	(Schoendienst, Surmann et al. 2005) (Reuber and Plug 2007 ii) (Reuber and Plug 2007iii) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i) (Plug, Sharrack et al. 2010)	
Person has a tendency 'not to know' and a sense of emptiness is evident in descriptions	(Schoendienst, Surmann et al. 2005) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)	(Plug, Sharrack et al. 2008i)
Responses are triggered by another person	(Schoendienst, Surmann et al. 2005) (Plug, Sharrack et al. 2008i)	
Narrative descriptions of events are given	(Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)	
Person exhibits little formulation effort	(Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)	(Plug, Sharrack et al. 2008i)
Person exhibits elaborate, self initiated reformulations	(Plug, Sharrack et al. 2008i)	(Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)
Events are not talked about in chronological order		(Reuber and Plug 2007 ii) (Reuber and Plug 2007iii) (Plug, Sharrack et al. 2008i)
Adversative structures [51] are used		(Schwabe, Howell et al. 2007)
Person lists physical symptoms	(Plug, Sharrack et al. 2008i)	
Negation	(Reuber and Plug 2007 ii) (Schwabe, Howell et al. 2007)	
Patient talks of detail other than the seizure itself	(Reuber and Plug 2007iii) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)	
Descriptions of visual/auditory illusions/hallucinations	(Plug, Sharrack et al. 2008i)	

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[51] See box 4 for explanations of these terms

Descriptions of seizure suppression attempts

People with epilepsy were employing explicit practical strategies to interrupt or prevent seizures occurring (Schwabe, Howell et al. 2007; Reuber and Plug 2007 ii). Although these differed from person to person, they could help patients, their professional and lay carers in formulating and putting into practice, personal seizure inhibition strategies (Plug, Sharrack et al. 2008i). People with NES did not verbalise such strategies (Schwabe, Howell et al. 2007; Reuber and Plug 2007 ii).

Table 4

Descriptions of seizure suppression attempts

Attribute	NES	Epilepsy
No attempt to interrupt/stop auras /seizures	(Reuber and Plug 2007 ii) (Plug, Sharrack et al. 2008i)	(Plug, Sharrack et al. 2008i)
Person gives descriptions of attempts to interrupt/stop seizures/auras		(Reuber and Plug 2007 ii) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)

Depictions of metaphoric constructs or predications

Following the work of Surmann (2002) further work on metaphoric conceptualisations continued to show a difference between NES and epilepsy. Because the work done in this project was based on the concepts behind metaphors rather then the metaphors themselves, exploring underlying concepts uncovered elements relating to seizure conditions.

In-depth formulations of fighting metaphors gave this attribute the possibility of being of diagnostic value for epilepsy and the characteristic of 'nebulous'

metaphoric concepts and not seeing seizures as external to self or as a threat had pointed to a diagnosis of NES in earlier studies (Surmann, 2002).

The metaphor of the seizure being an enemy, threat, external to self which had to be fought continues to be present in the talk of people with epilepsy (Plug, Sharrack et al. 2009i, whereas, for NES patients the seizure was not perceived as such (Schöndienst, et al, 2005). For people with epilepsy the concept of the seizure being an independent entity which acted upon a patient (Schwabe, 2007) from outside of themselves (Schwabe, Howell and Reuber, 2007) and of its own volition, the individual being a victim of the seizure was identified (Plug, Sharrack et al., 2009i). The electric socket metaphor, depicting a seizure as suddenly occurring, suggested that seizures were not perceived of as controllable by a person with epilepsy (Plug and Reuber 2007; Schwabe, Howell et al. 2007).

For people with NES, although the seizure was still the subject, it was not perceived as being independent but as a backdrop to a patient's actions. However, the patient with NES was not completely independent of the seizure, they still had to experience it but appeared to have more 'semantic agency' over it than people with epilepsy do (Plug, Sharrack et al. 2009i)(p10). People with NES *experienced* the seizure rather than being its victim, one way of expressing this was that the seizure is a place or space the patient has to go to, travel through, or come out of people with NES using this metaphor more than people with epilepsy (Plug, Sharrack et al. 2009i). The concept of seizures being an event or situation is used more by people with epilepsy (Schoendienst, Surmann et al. 2005. NES patients in one study did not describe metaphoric constructs (Reuber, 2007ii, Reuber and Plug 2007ii: Plug, Sharrack et al, 2009i) and metaphor was not coherent in another (Schwabe, Howell et al. 2007).

Table 5

Depictions of metaphoric constructs or predications

Metaphor	NES	Epilepsy
No metaphorical constructs	(Reuber and Plug 2007 ii)	
Metaphor incoherent	(Schwabe, Howell et al. 2007)	
Specific metaphor of enemy, external threat and of fighting the seizure		(Reuber and Plug 2007 ii) (Reuber and Plug 2007iii) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i) (Plug, Sharrack et al. 2009i)
Seizures not seen as a threat or originating externally	(Schoendienst, Surmann et al. 2005)	
Metaphor as place or space	(Plug, Sharrack et al. 2009i)	
Metaphor as event or situation		(Plug, Sharrack et al. 2009i)
Electric socket metaphor		(Schwabe, Howell et al. 2007)
Metaphorical predications		(Plug, Sharrack et al. 2008i)
Seizures act on a person		(Plug, Sharrack et al. 2009i)
Seizures are in the background	(Plug, Sharrack et al. 2009i)	

Making sense of consciousness/unconscious states

The Bethel project found clear differences in how people with NES and epilepsy
depicted and made sense of levels of awareness or, what is termed in the
literature as unconscious or conscious states. Furchner s early work in 2002,
was seminal here and followed up in many later studies. In the early studies
people with NES equated their seizure with complete unconsciousness not
attempting to fill this 'gap' in their experience and this continued to be the

finding in later studies. On the other hand, people with epilepsy did several things they; attempted a reconstruction of this period of unconsciousness, placed the unconscious experience in the temporality of the seizure as a whole, defined between levels of consciousness (see table 6) and clearly marked the beginning and ending of an 'unconscious period'.

Table 6

Making sense of consciousness/unconscious states

Consciousness	NES	Epilepsy
Reconstruction of consciousness		(Furchner 2002) (Reuber and Plug 2007 ii) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)
Places unconscious experience in the context of the whole seizure		(Furchner 2002) (Plug, Sharrack et al. 2008i)
Grading of unconsciousness		(Furchner 2002) (Plug, Sharrack et al. 2009i) (Schwabe, Howell et al. 2007) (Plug, Sharrack et al. 2008i)
Little details of gaps in consciousness	(Furchner 2002) (Reuber and Plug 2007 ii) (Reuber and Plug 2007iii) (Plug, Sharrack et al. 2008i)	

That people with epilepsy address their states of consciousness has been found in two other studies which focussed on subjective experiences of participants and may be worthy of further exploration with epilepsy and NES patients.

Chapter 3.2. Conversation analysis and differential diagnosis of seizures.
A narrative synthesis: An overview

One, using content analysis has analysed these in relation to seizure dynamics and evolution in relation to contents and levels of consciousness (Johanson, Revonsuo et al. 2003). Descriptions assessed; whether the patient was aware of having a seizure at all, if they had any kind of subjective experience or completely lost consciousness, and, if contents of consciousness were present, whether these were normal or alien to patients. At some point in the seizure, all patients reported not knowing what is happening around them. During the recovery period, an awareness of self returns, followed by the ability to think, then the ability to speak (Johanson, Revonsuo et al. 2003).

The second using a form of dream analysis is the first to undertake a content analysis of subjective experiences in people with partial epilepsy and their temporal progression i.e., divided into phases beginning with premonitory symptoms, preictal periods, an aura, an actual ictal period and post ictally. The main issue in this particular study was how to define consciousness, that is how to distinguish between the contents of consciousness, and if this could be done. Given that consciousness has never been satisfactorily defined in the area of seizure experiences across many studies, this study attempts a clarification of the terms, 'conscious', 'unconscious', 'awareness', 'unawareness' and 'impaired awareness' (Johanson, Valli et al. 2008). These studies are discussed later in the thesis.

This section has offered an overview of the Bethel work, the following section is a conceptual expression and interpretation of the work thus far and attempts an answer to the original synthesis question, 'How far do Conversation Analytic derived approaches identify that, the nature of the language used by people to describe their seizures as implications for differential diagnosis of epileptic and non epileptic seizures?'

3.3 Conversation analysis and differential diagnosis of seizures.
A narrative synthesis: A conceptual expression of the literature.

'How far do Conversation Analytic derived approaches identify that, the nature of the language used by people to describe their seizures as implications for differential diagnosis of epileptic and non epileptic seizures?'

Expression of the synthesis (Pope, Mays et al. 2007)(p82)

Traditionally, doctors have taken the initiative for 'actively structuring' patient/doctor conversations (Beach 2001)(p13). Maintaining such notions of 'asymmetries', deciding which agenda is the important one and working towards this, can limit how patients can contribute to this conversation (ibid). This method of history taking can inhibit patients in that they often do not get the opportunity to talk about their 'lifeworld concerns' (Stivers and Heritage 2001; Schwabe, Howell et al. 2007)(p178).

Beach uses the phrase 'lay diagnosis' to explain the way in which patients use communicative practices and behaviours in their attempt to explain their situation to health professionals and others (Beach 2001)(p13). That is, they can still take the initiative sometimes in the form of 'narrative expansions' (where the patient orients to topics which especially concern them). Paying attention to, and addressing these could elucidate explanations that would not have shown themselves otherwise (Beach 2001).

Other researchers in the field of CA have 'noticed' phenomena which can help doctors determine a patient's concerns. Verbal strategies that patients use, such as a 'pre-announcement' (that they want to talk about several things) and 'in situ announcement' (they initiate an unexpected change of topic mid consultation) are used by them in order to introduce, change or add to the topics of conversation in a consultation. Again these should not be dismissed as being unimportant, but managed by doctors as important elements of everyday

consultations (Campion and Langdon 2004).

The conversations conducted by the authors in this synthesis have explicitly taken this view and have developed history taking into a formal, phased conversation which offers patients ample opportunity to introduce their own concerns regarding their seizure experiences. In a history taking about seizures particularly, this sort of departure is best addressed as it could offer clues to a diagnosis. For example, the strange and sometimes difficult conversations doctors had with NES patients were seen as harbouring important diagnostic clues and such attributes were later formally and positively accounted for (Schoendienst, Surmann et al. 2005).

CA as deployed in the Bethel project

Later studies began to introduce a 'phased' conversation, which was derived from original Bethel analysed conversations (Schwabe, Reuber et al. 2008) and at the same time furthered the work by formulating the specific hypotheses that using CA would highlight conversation attributes and categories that could distinguish between epilepsy and NES (Reuber and Plug 2007iii; Schwabe, Reuber et al. 2008).

However, these categories can only develop as analyses are undertaken and this has to be on two levels. The first being on a case by case analysis of the minutiae of subjective content of individual people's formulations and other linguistic tools they use (Schwabe, Reuber et al. 2008). The second is to move beyond this to reach a consensus of relevant attributes which link directly to specific seizure types (Schwabe 2000; Schwabe, Reuber et al. 2008).

The way in which CA was used in this project and that the pure 'instrument' of CA itself could alter in pursuing an 'external goal' (that is, of attempting to find a difference between seizure types) was a point mooted by Gülich and

Schöndienst (1999), and later by (Schwabe, Howell et al. 2007) and (Schwabe, Reuber et al. 2008). This began to happen early in the project, however and the current approach and methodology now focuses on patients' words rather than those of both conversation partners (Schwabe, Reuber et al. 2008). Certainly, the fundamental concept of CA, that of only analysing naturally occurring conversations is not applicable to most of these studies, and structuring a conversation is not what a conventional CA does.

However this development was justifiable in this project because, although pure CA was the first choice of early researchers, it was necessary to move away from this. Interviews as developed by these researchers were eliciting particular communication profiles, and linguistic attributes were appearing which differentiated between epilepsy and NES (Reuber and Plug 2007 ii). Important research questions were emerging relating to these differences, which needed answering, and the concepts these questions encompassed were not within the 'remit' of pure CA. For example, the concepts of consciousness and cognitions of this are, traditionally, outside the scope of CA. Although not to IPA, and this particular point will be discussed later when it is considered how IPA can contribute to this specific element of the research.

Adjusting CA to a history taking approach to further explore differential diagnosis of epileptic and NES.

The conversations in this synthesis were, in the main carried out by doctors experienced in epilepsy, i.e., experienced in the 'culture' studied. The linguists who undertook the analyses below were not, initially, part of this culture, and offered a detached, objective analysis of what was happening on a technical level. However, the linguists' (sometimes the same people throughout the project) knowledge of seizure language, it could be argued, increased as they became more familiar with seizure discourse and this may have had implications for their 'diagnoses'.

The initial interviews were authentic CA conversations, i.e., naturally occurring and thus not 'phased' or manipulated in any way, between epilepsy doctors and patients in various clinic, outpatient and in-patient settings, although some conversations were recorded specifically for research purposes (Gülich and Schöndienst 1999). Phasing of conversations was instigated because it was realised early that conversation styles for each condition were emerging (Gülich and Schöndienst 1999). As patients were describing things beyond what a traditional CA analysis considers, the approach was formally modified – that is, the doctor did not lead the conversation, refrained from asking questions of the patients until directed (Schoendienst, Surmann et al. 2005) and concentrated on patients' narratives (Reuber and Plug 2007 ii; Schwabe, Reuber et al. 2008).

As the project as a whole began to evolve and additional linguistic clues began to emerge differentiating between NES and epilepsy, the original CA approach shifted to accommodate this new knowledge to what could now be termed 'Seizure Discourse Conversations'. The psychoanalytic stance of early work had been maintained (Gülich and Schöndienst 1999) and took into account how and when in a conversation things important to patients themselves were spoken about (Schwabe, Reuber et al. 2008).

Authors noted other differences in linguistic behaviours of people with NES and epilepsy. For example, people with epilepsy considered seizure signs and symptoms (semiology) important whereas people with NES did not. Previous findings that the seizure descriptions of people with NES lacked effort and detail, that they evaded attempts to expand on these and tended 'not to know' about their seizures, with longer and longer pauses appearing in their narratives (Schoendienst, Surmann et al. 2005) were reproduced in later studies.

Chapter 3.3. Conversation analysis and differential diagnosis of seizures.
A narrative synthesis: A conceptual expression of the literature.

Seizure Discourse Conversations

Taking into account clues and cues found in previous study conversations, subsequent studies began to conduct conversations with the specific goal of differentiating NES and epilepsy. This approach to conversations elicited particular conversation attributes which differentiated between NES and epilepsy (Reuber and Plug 2007iii). A major finding was that people listening to the accounts of people with NES found it very hard to imagine what their seizures were like (Schwabe, Howell et al. 2007).

As said above, the formal history-taking interview offered patients ample opportunity to introduce their own concerns and doctors ample opportunity to pick up on these. Interviews incorporated a schedule of three clear, time limited stages (see box 5) which allowed patient the opportunity to set the conversation agenda, to describe (or not) their seizure experiences and doctors could probe and question them about these at an appropriate point (Reuber and Plug 2007 ii). These methods elicited certain behaviours in people and were not anymore the natural laboratory of CA, but a specific intervention or tool. The work had thus shifted from 'unmotivated looking' to 'hypothesis driven' studies (Schwabe, Howell et al. 2007)(p713).

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Box 5.

A CA staged history taking seizure conversation

Phase 1
This has the potential to be of the greatest diagnostic significance and the question
usually asked of the patient is, 'what do you expect to get out of this conversation
today?' People with epilepsy usually talk about their seizures straightaway, however
people with NES often avoid this.

Phase 2
The doctor attempts to elicit more explicit information about three seizures: first, last
and worst, requesting the person to expand on or explain further some aspect of seizure
experiences, also gathering information about levels of consciousness. People with
NES often talk more about what was happening around them during their seizures or
where they were physically, whereas people with epilepsy can attempt a reconstruction
of feelings leading up to a seizure, loss of consciousness, how long they thought it had
lasted, feelings following a seizures, and can give a listener a good idea of what their
seizure was like.

Phase 3
Challenges aspects of what people have said about their seizures and succeeds in
analysing the conversation as a whole. Patients with NES do not generally focus on the
seizure experience in this phase, do not elaborate on subjective symptoms and can tend
to stray onto other topics. If patients do offer descriptions of subjective symptoms,
however, they are more likely to have epilepsy
(Plug, Sharrack et al. 2008i).

Continuing the iterative approach of the project, working hypotheses were now
being formed, 'to establish the predictive and discriminatory power of a
linguistic analysis based on what has been found thus far' (Schwabe, Howell et
al. 2007)(p723). This allowed experimental hypotheses to be tested with

patients pre-diagnosed with VEEG, and linguists (blind to these diagnoses) analysing and correctly predicting which condition people had. Allowing the patient to talk about their own concerns was considered of paramount importance in patients with unclear seizure diagnoses. Details such as; who introduces the topic of seizures, whether a patient works to describe their seizures to another person and how much detail they include in this were all important pointers. Authors were, at this point, beginning to consider clinical guidelines for seizure professionals (Reuber and Plug 2007iii) as findings were now being replicated across studies.

Given that a typical seizure may not occur when the patient is undergoing VEEG, the importance of taking a relevant history is reinforced. Clusters of linguistic and other features present in interactions were identified as 'concordant' with either NES or epilepsy. The three stage conversation model was important to adhere to, and to analyse as a whole because individual differences in seizure accounts can act as 'red herrings' to clinicians. For example, someone with epilepsy may not amplify their seizure description when given the opportunity in phase three of the conversation, where this would be expected, whereas someone with NES could exhibit this attribute thus muddying the analysis if this is not undertaken for the whole of the conversation (Plug, Sharrack et al. 2008i). Using descriptions of attempts to suppress seizures is an area in which people with epilepsy and NES polarise, although there are instances of people with epilepsy not exhibiting these phenomena. However, again, in analyses over the whole interview one or another diagnoses predominates

Implications for practice

The interview formula developed by the Bethel authors could now, potentially, be incorporated into 'routine clinical practice' (Plug and Reuber 2008ii)(p13), as a specific research intervention in the form of a seizure discourse conversation

(although researchers warned that it is not an easy process to learn) (Schwabe, Reuber et al. 2008). Major points to look out for would be, at what point in a conversation does a patient introduce something (Plug, Sharrack et al. 2008i), what do people say the seizure *is* (Plug, Sharrack et al. 2008i), how willing are they to discuss their experiences, how do they describe their experiences, do they stop and start sentences (Reuber and Plug 2007i), relate their seizure trajectory, show hesitation or simply repeat their accounts (Plug, Sharrack et al. 2008).

The first ten minutes of a consultation with a seizure patient were seen as particularly crucial for diagnosis. Seizure specialists could, for instance, listen out for whether people resist talking about their seizures in this phase, which could 'reflect the dissociation from traumatic experiences' or, 'an interactional reflection of an escape/avoidant coping style - which is a key psychopathological feature in NES' (Plug, Sharrack et al. 2008i)(p16).

It had been noted previously that doctors, when taking the history of a patient for diagnostic purposes, needed to listen out for elements of conversation they would not traditionally have considered relevant (Wolf, 2000). For example, what had been considered irritating elements of conversations with NES patients could actually be specific, positive diagnostic pointers (Reuber and Plug 2007 ii; Plug and Reuber 2008ii).

Studies had, at this point, analysed over 100 interviews in many settings and analyses were becoming increasingly sophisticated. Bethel began to explore several further hypotheses such as whether findings applied only to German speaking people, or whether the interactive features would be similar in English speaking patients, and in different clinical settings. People speaking either German or English however, exhibited similar features to each other, 'the interactive nature of the challenge' overriding that of any different linguistic features present in either language (Schwabe, Howell et al. 2007)(722).

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Illness representations

More recent work by Bethel authors (Plug, Sharrack et al. 2010) has focussed on the role of illness representations in the differential diagnosis of seizures and in particular, the role of diagnostic labels. (This work also links to two papers discussed in the IPA chapter). [52] [53] This work was undertaken in clinical settings with the semi standardised interview procedure described in previous studies. At the beginning of the interview, there was no mention of seizure labels and a diagnosis was not presented so, importantly patients were blind to their own diagnosis. All nouns patients' used were analysed statistically and qualitatively. Clear significant differences emerged in terms of preferences for labels across both NES and epilepsy patients. People with epilepsy preferred the term 'seizure', over 'fit' and 'blackout', whereas NES patients preferred, 'fit' and only NES patients used the term 'blackout', and 'dispreferred' the term seizure (ibid)(p24). This was notwithstanding that people with NES had previously been diagnosed with epilepsy so had already been exposed to epilepsy terminology. People with epilepsy also tended to use other 'epilepsy-specific' terminology such as, 'absence', 'partial seizure', 'tonic clonic' etc., The term 'attack' was resisted by many patients whereas doctors commonly used this (ibid).

Reasons for these differences could be that epilepsy patients engage with their seizures and their effects, diagnosis and treatment thus the use of medical terminology such as seizures equates with this interest. NES patients, on the other hand, mirroring their tendency to resist talking about their seizures, use more lay terminology (Plug, Sharrack et al. 2010).

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[52] Green, A., Payne, S. and Barnitt, R. (2004). "Illness representations among people with non-epileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model." Seizure 13: 331 - 339.
[53] Thompson, R., Isaac, C., L, Rowse, G., Tooth, C., L and Reuber, M. (2009). "What is it like to receive a diagnosis of nonepileptic seizures?" Epilepsy & Behavior 14: 508 - 515.

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Comments on the Bethel project

As an intervention, this form of history taking has great potential. Ideas for
practicing clinicians were formulated from this project, some easier than others
to incorporate into everyday clinical practice, others requiring more formal
procedures to be in place. For example, following a consultation with a patient a
clinician should consider how difficult would it be for them to convey the
experiences of this patient to another person. Another is to audio record the
conversation in order to examine it later for communication styles. [54] If possible
observing the patient talking in other contexts, to other health professionals and
with people out of the clinic can be useful in this regard.

A main pointer to differential diagnosis however, appears to be the *volunteering*
of information about subjective seizure symptoms and experiences by epilepsy
patients and this usually happens at the beginning of a consultation. Additional
questions would need to be asked of a patient in terms of factual information as
people can have clinical conditions alongside their seizures such as depression.
The Bethel authors, (in the main, clinicians themselves) consider that doctors
could be alerted to picking up at least some conversational attributes using this
method (Plug and Reuber 2008ii).

Mentioned in many of the studies in this synthesis, was that the interactions
were video taped and, although one study did mention a patient with epilepsy as
pointing behind him when talking about his seizures, (Reuber and Plug 2007iii),
little was said about the analysis of non verbal interactions in this work.
Interest in 'bodily actions' has long been a feature of CA in terms of 'co-present
interaction' (Kitzinger 2009) given that silences and gestures are considered
integral to the analysis (Maynard and Heritage 2005) and which may offer up
further clues in differential diagnosis. A later study discussed below undertaken
after this synthesis was completed did however, utilise video analysis in a study

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[54] This may involve instigating ethical procedures however.

where both linguists and neurologists were blinded to patients' VEEG diagnosis
(Reuber, Monzoni et al. 2009).

This ongoing work using a form of analysis derived from a CA approach to
neurological history taking, is possibly the first to use this in the area of
differentiating seizures (Reuber and Plug 2007iii). It is an area of study
researched by few people and, given the high rates of misdiagnosis, is extremely
useful, the work above clearly identifying a non random clustering of particular
attributes which point towards a diagnoses of epilepsy or NES (Schwabe, Howell
et al. 2007)(p713).

Identifying particular 'communication profiles' across many cases (Schwabe,
Howell et al. 2007) offers additional differentiating factors to those from the
vast amount of quantitative work already done, and may have the potential to be
more useful in this regard some original factors having since been disregarded
as being diagnostically irrelevant (Schwabe, Reuber et al. 2008).

Although the Bethel research is not at the stage where a diagnostic tick list could
be collated for practicing clinicians, [55] findings were considered relevant enough
to potentially be part of a 'multidimensional clinical decision process' (Schwabe,
Howell et al. 2007)(p723). The structured, three stage interviews offer
explorative techniques for talking to people with seizures, particularly those
with NES, who can be difficult to converse with (Schoendienst, Surmann et al.
2005). Authors thoughts later returned to whether any features correlated with
certain individual dispositions or organic abnormalities and whether this,
therefore, could identify different linguistic features in different epilepsies, and
whether a specific non verbal analysis could yield further clues (Schwabe,
Howell et al. 2007).

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[55] As is the case for syncope for example.

Conclusion

The consultations within the above project were undertaken, in the main, by neurologists expert in the field of epilepsy, patients were from various clinical settings, analysts were linguists but not expert in seizures and the boundaries of CA were being stretched beyond its original intentions. This 'new' method has succeeded in adding another dimension to differential diagnosis (Schwabe, Reuber et al. 2008).

It was not always clear whether all or some *patients* knew of their diagnosis at the time of interview and whether this could have affected the way in which they communicated their experiences. However, one study found that even if NES patients previously had recourse to epilepsy oriented language, they did not choose to use this in terms of labels and titles for their condition (Plug, Sharrack et al. 2010).

The topic to be discussed in the project could have been perceived by patients as being already pre defined, i.e., about seizures (notwithstanding the initial communication by the doctor which did not mention seizures specifically). After all, interviews took place in epilepsy clinics and in hospitals with in and out patients. This could have influenced findings in that patients were expecting to talk about their seizures and may have been reticent to introduce other topics of conversation which may have been pertinent to their diagnosis. In addition, interviews in later studies were time limited which could have further limited patient input and perhaps have given the impression that limited specialist time was available to listen to them. This is research in the real world however, there *is* a time limit on clinical consultations thus this work reflected everyday neurological clinical situations.

The work in the Bethel Project firmly places the role of language in the differentiation of seizures and opens up the arena to other methods of analysing

seizure discourse conversations. The project is ongoing and in the United Kingdom, studies continue to explore both linguistic and interactional cues to diagnosis using the same interview format.

Update. Current work

Recent work has developed the CA approach to differential diagnosis still further to include qualitative assessments of many of the attributes identified above and translating these into numerical scores. Audio and video recorded conversations using the standard Bethel interview approach with new patients and a neurologist who was blind to their VEEG diagnosis were analysed by linguists (equally blinded). Linguists gave written assessments on 17 aspects of linguists and interaction, these then being translated into numerical scores. The purely qualitative assessments gave greater accuracy with the overall result that linguists correctly diagnosed 17/20 patients. The interrater agreement being comparable to that achieved using methods such as EEG. It is suggested that, if those attributes having more diagnostic relevance were given more statistical weight, this would further improve the performance of the numerical measure in this (Reuber, Monzoni et al. 2009).

There is also a shift in thought about the context of the interview following the Bethel project and that 'third party contributions' of carers, family members and/or friends may yield more clues to diagnosis. The efficacy of the open history taking interview method should be considered in terms of using this in outpatient clinics rather than conventional question-answer encounters (Reuber, Monzoni et al. 2009).

This research sets the scene for other methods of exploring patients' experiences held in alternative locations of the patients' choice away from a clinical environment, perhaps with other people present and which does not focus on an intervention. An interview with an experienced, female qualitative researcher

who is not an expert in the field of seizures, had the potential to generate a very different interview and additional findings (Chambers-Evans, Stelling et al. 1999).

The nature of NES as a mind-body problem, i.e., that NES, as a physical manifestation arising from emotional problems a patient has would benefit from a shift to the viewpoint of another professional other than a neurologist (Langfitt 2007). A shift from the long term focus on seizures themselves with a move towards subjectivity, a topic of investigation in its own right and one which facilitates an exploration of lived experiences, could add to what has already been found in the traditional biopsychosocial model of health and illness and further our understanding of NES.

This present study attempts to move the understanding of NES towards an approach based in phenomenological psychology. The next chapter introduces such an approach, that of Interpretative Phenomenological Analysis (IPA) and the method of choice for this study. The theoretical and historical antecedents of this approach are articulated along with examples of how it works in practice illustrating this with a selection of empirical studies which explore unusual experiences similar to, and including, NES.

4 Let it shine on me: Interpretative Phenomenological Analysis- its philosophical, theoretical and epistemological underpinnings

This chapter gives a background to the science, theory and methodology of Interpretative Phenomenological Analysis (IPA). Chapter 4.1 illustrates, with examples from empirical studies, how IPA works in practice. This is followed by a 'case' for an IPA of seizure experiences in chapter 4.2 and in chapter 4.3, the methods used in this study will be described.

IPA's main concern is the meaning of experiences for individuals, (Smith and Eatough 2008) this being its 'main currency' (Smith, Flowers et al. 2009). It is one of many qualitative methodologies and one which adopts a hermeneutic model in psychology, 'applied in a proper ontological context' (Van Langenhove 1995)(p11). Its roots are in phenomenology; which offers ideas about how to examine and understand lived experiences, hermeneutics - the theory of interpretation, and idiography - a concern with the particular rather than the general (Smith, Flowers et al. 2009). This idiographic approach, that is, understanding a 'case' in its own terms, entails interpreting how a phenomenon has been experienced by particular people in a particular context (Smith, Flowers et al. 2009). This involves engaging deeply, empathically and critically with the particulars of an individual's experiences, privileging these rather than any theoretical stance or preconceptions, and is rare in qualitative psychology (Smith and Eatough 2008). The power of an IPA study is to facilitate the 'the shining forth of a thing' that was previously hidden (Tadasha 2000)(p146).

IPA is not about following a set of procedures but is rather, a dynamic, iterative process involving a complete immersion in someone's talk in real time, and in the subsequent transcript generated. This is at several levels incorporating an ongoing process of, reducing, revising and writing an interpretation of this. Phenomenological researchers intentionally attach themselves to the worlds of

their participants in order to know the essentials of that world (van Manen 1998). This approach 'requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience' (van Manen 1998)(pxi), the most important thing being, 'that the interpretation is inspired by, and arises from, participants' own words (Smith, Flowers et al. 2009)(p90).

This chapter section will first give a brief overview of the traditional biopsychosocial model of researching health and illness, and how phenomenological approaches can offer additional understandings to those discovered in the natural sciences. Some the theories and ideas belonging to the 'phenomenological project' (Smith, Flowers et al. 2009)(p18) which underpin the IPA approach placing it within this framework to show 'how IPA enacts these ideas' will be explained below (Smith, Flowers et al. 2009)(p203).

The bio psychosocial model of researching health and illness

Returning to a ' sense of life' (Sadala and Adorno 2002)(p283)

The biopsychosocial model of health and illness, predominant in mainstream psychology is based on systems theory, itself rooted in the 1940's revolution of Cybernetics (Crossley 2000). This is an understanding of systems by observers without a need to gain insight into why systems behave as they do, the limitations of this being that the observer is outside looking in and this is only a partial view of how systems work (Featherstone 1996). Most research within this model has used traditional experimental methods with objective knowledge emerging from these, independent of such concepts as the goals of researchers or the social and cultural research context, relying instead on pre-defined models of health and illness related behaviours. That is, it adheres to the rational scientific approach in psychology, examining beliefs, the aetiology of conditions, being concerned with targeting and preventing certain behaviours,

so that data and findings can then be compared to biomedical findings (Crossley 2000). It contains the 'in principle' limits of the ideas and criteria accepted as being mainstays of traditional science, i.e., as being systematic, methodical, critical and generalisable (Giorgi 1995)(p24). This has been described as a multiple explanatory framework rather than an integrated one [56] (Crossley 2000), but one which does not easily accommodate, for example, the concept of somatisation and unexplained conditions (Green, Payne et al. 2004).

'The importance of mind' (Smith, Harre et al. 1995)(p11), once sidelined, is now recognised as important in the discipline of psychology and 'a new paradigm' has emerged in psychology overtly concerned with understanding personal meanings (ibid)(p3). This involves, describing, interpreting and self reflection with critical analysis in order to understand what experiences mean to people (van Manen 1998).

Critical (hermeneutic) psychology - in particular health psychology, uses the study of the phenomenology of illness in order to examine meanings and experiences of health and illness (Crossley 2000). Qualitative research methods have very different methods and tools through which they can explore what things mean to people and the manner in which these meanings are transmitted (Harré 2004). In particular, phenomenological research methods have been advocated in health psychology when exploring the meanings of people's lives in a particular context (Marks 2002). This can transcend the 'outsider looking in' view of the biomedical model, and offers another (although, still partial) view which moves one step closer towards understanding people's lived experiences (Willig 2001). Using other research methods does not negate or render invalid the medical model's views and findings about health and illness. Rather, it contributes additional evidence to medical perceptions which cannot encapsulate the whole story (Holloway, Beatrice et al. 2000).

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[56] See Crossley (2000) for a more detailed critique of the biopsychosocial model.

Chapter 4. Let it shine on me: Interpretative Phenomenological Analysis- its philosophical, theoretical and epistemological underpinnings

Positivism has long been unable to answer certain questions in the human sciences (Sadala and Adorno 2002). Whether quantitative research was the only possible scientific paradigm is questionable because it does not account for, or address, human vicissitudes. Science can give us an 'approximation' of things but we also need to gain an understanding of phenomena that 'escape' science, for example, experiences that are manifested in our perceived worlds which are important for our primary understanding of events and which need to be understood in order for natural science and human science to work together (Davis 2004)(p16). The phenomenological model is fundamentally different from natural science, which can be considered only one 'branch of empirical science as such' (Giorgi 1995)(p32).

Merleau-Ponty has eloquently illustrated the differences between 'scientific' and phenomenological approaches giving the example of what light 'is'. Scientific explanations would be contain descriptions about the properties of light; electromagnetic radiation, wavelengths, particles, intensity etc, whereas a phenomenological approach would consider the appearance of colours, hues, reflections and shadows. These are both accurate descriptions of the same thing but seen in two entirely different ways (Davis 2004).

Human science

The term, 'human science' is synonymous with the terms ' phenomenology' and 'hermeneutics', (van Manen 1998)(p2). In human science, the 'thing' of natural science is not analysed as a thing by itself, but by how people perceive it, understand it and attribute meaning to it (Giorgi 1995). In contrast to natural science which studies the behaviour of natural events, human science studies people - who have consciousness (van Manen 1998).

Perception, cognition, memory, imagination, attention and awareness - all modalities of intuition, are in mainstream psychological science what

consciousness is in human science. This distinction between these two types of intuition allows a conception of human science which is different to, but no less rigorous than, traditional scientific methods. 'Concepts, ideas, essences, images etc., 'are just one type of object presented to consciousness, and can be studied systematically, and methodically towards a 'critical pursuit of knowledge' (Giorgi 1995)(p32).

The science of the individual

However, in order to contribute to knowledge which pertains to many individuals, there is a paucity of knowledge about *individual* psychological functioning and Smith has long argued that the science of the individual cannot progress until more projects detail the lives and experiences of individual human beings (Smith 1995). These are complex, messy and sometimes turbulent, necessitating a sensitive approach which allows access into people's life worlds, and which can develop their descriptions into multi layered interpretations (Eatough 2007).

IPA is an approach ideally suited to examining the kernel of a phenomenon, it takes into account how a person 'is' in their own personal world and culture not unlike ethnographic methods employed in anthropology (Andermann 2000). It offers insights into individual perspectives and behaviour which can compliment other, 'medical' findings (ibid). [57] There is no direct, 'clear and unmediated window' into the life of a person (Eatough, 2007). Through person-centred interviews and systematic, analytic interpretations, IPA attempts to make sense of how individuals are making sense of a phenomenon - a double

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[57] However, ethnomethodological writing represents a whole culture, studying interaction and tending to search for the order in social settings as it is interpreted by its members, rather than individual accounts which IPA reifies. Denzin, N. K. (1998). The Art and Politics of Interpretation, Evaluation, and Presentation. Collecting and Interpreting Qualitative Materials. N. K. Denzin and Y. S. Lincoln. Thousand Oaks, Sage.

hermeneutic (Smith, Flowers et al. 2009). In practice, this entails gaining a 'third-person view of a 'first person' account' (Larkin and Clifton 2006)(p110).

Phenomenology as science

'The founding principle of phenomenological inquiry is that experience should be examined in the way that it occurs, and in its own terms.' (Smith, Flowers et al. 2009)(p12)

Natural science can be seen to be excluding, 'the very source of all knowledge and value', that is, the subjective accounts of experiences. Giorgi argued that phenomenological philosophy needs to 'establish psychology as a human science' (Giorgi 1995)(p42) within a framework of 'psychological phenomena as spontaneously lived' (ibid)(p25), if it is going to be considered a science at all. Phenomenology is the mode of access to 'first person experience of conscious states'. It can support and make clearer scientific knowledge by defending the need for, and adding in, the roles of consciousness and subjectivity, as being integral to what we know about the natural world (Moran 2000)(p15).

Phenomenology devotes itself to defending these accounts because they are a component part in understanding everything in the world (Moran 2000)(p21). It analyses 'things' using a different philosophy and methods - those needed when studying consciousness and subjectivity and the ways in which people engage with their world (Giorgi 1995). Phenomenology can then became a science of discovery in addition to traditional science (Todres and Wheeler 2001).

Phenomenology tries to reach the 'truth' of the manner in which 'things' appear to consciousness and before anything imposes on this, such as everyday commonsense or scientific knowledge of the thing (Moran 2000)(p14). It can clarify and support science or even completely reject traditional accounts of knowledge, i.e., that our internal representations are duplicates of what is

externally 'out there' (ibid). What we take for granted as *known* however, is a different knowledge to *how* we know it and this is captured using language as the main methodological tool (Todres and Wheeler 2001). Connections between experiences are structured and organised through verbal expressions, which are 'open to being appropriated and understood by others' and can, therefore, be considered scientific (Giorgi 1995)(p38).

It was Brentano (a 19th century philosopher and psychologist) who envisioned 'phenomenology as an exact science' (Moran 2000)(p23), and who coined the phrase, 'descriptive Psychology' conceptualising it as 'an a priori science of the laws of the mental, identifying universal laws on the basis of insight into individual instances' (Moran 2000)(p8). This root is very important to IPA, the importance of the individual 'case' being fundamental to IPA, individual cases 'unfold'[ing] how 'something *is*', even traditional science studying 'unique occurrences' (Smith, Flowers et al. 2009)(p30). Husserl developed Brentano's descriptive psychology into a general 'descriptive science of consciousness' and agreed that, by studying many people in depth, there was the potential to reach 'scientific' implications of a phenomena and phenomenology being a 'conceptual clarification' [which would] 'form part of a wider 'critique of reason' (Moran 2000)(p9).

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Intuitions

'In Phenomenology, 'intuition "possesses its object"', and embodies 'perception (presentation), and imagination and memory (representation)'. Levinas, 1963/1995, in (Nortvedt 2001)(p33).

As a method of inquiry, phenomenology aims to go beyond what is assumed empirically about human life, to place oneself into the object of enquiry in order to reach the fullness of the lived human experience (Moran 2000). This involved intuitions, in the Husserlian sense of being the 'highest stage of knowledge' and 'hard won insights' which were in many types of conscious experiences (i.e., not only reached in scientific disciplines such as mathematics) and which promised then, as it does now, a vast area of the exploration and classification of the essential nature of all conscious experiences (Moran 2000)(p10). Schleiermacher suggested that we can only understand our place in the universe if we accept that we all have a link to a world that 'transcends both our cognitive and practical activity' (Bowie 1998)(pxvi).

Consciousness: Going back to the things themselves

A phenomenological analysis begins 'with the act of consciousness' and 'the basic presence of consciousness to something' (Giorgi 1995)(p31). Husserl was searching for a means of enquiry whereby people could come to know the 'essential qualities' of their experiences. To return to the 'the experiential content of consciousness' was, for Husserl, to go 'back to the things themselves (Smith, Flowers et al. 2009)(p12). Husserl (himself a mathematician) became adverse to the objective of 'doing science based on the laws that regulate physics and mathematics' (Sadala and Adorno 2002)(p282). It concerned him that phenomena as experienced were somewhat hidden by pre-existing theories and constructs, which served only to illustrate the *general* characteristics of a phenomena. This is not seeing 'things' in their own right (Smith, Flowers et al. 2009).

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We already *know* about things on the level of engaging in everyday, mundane tasks, phenomenology however, 'lets things be as they are' (Guignon 1993)(p7). Our everyday perceptions are merely 'abstract representations of the world' (Davis 2004)(p15), not reaching the 'fundamental structure' of a thing (Davis 2004)(p14). Disengaging from these everyday activities, and 'attending to the taken for granted experience of it', will allow us to reflect on this experience (Smith, Flowers et al. 2009)(p12), which can then be 'honoured in non-reductionist ways' (Todres and Wheeler 2001).

The implications of Husserl's existential, transcendental phenomenology was a major challenge to third person accounts in traditional science, in that it explained consciousness by examining its structures within a person [58] (Moran 2000). By doing this, as contemporary work in neurophenomenology illustrates (Le Van Quyen and Petitmengin 2002; Petitmengin, Navarro et al. 2007), it constitutes a challenge and additional perspective to 'third person attempts' in natural science, in elucidating the nature of this consciousness (Moran 2000)(pxiv). Any explanations of a 'thing' should not be decreed upon it until we know about it as we engage directly with it, that is, how it appears to consciousness (Moran 2000).

Merleau-Ponty claimed that the scientific edifice was based on the world as directly perceived, and was, therefore, a second order expression of a world (Moran 2000)(p14), which ignored the nature of consciousness in phenomenology (MacDonald 2001)(p112). 'Consciousness is the only access human beings have to the world' and it is this human virtue which relates us to things that present to our consciousness (van Manen 1998)(p9).

Relating to experiences of consciousness and its importance, is IPA's emphasis on the cognitive, 'any science of cognition and mind must, sooner or later, come

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[58] This root is Brentano's and his attempt to establish psychology as a descriptive science which would elucidate universal laws based on insights from individual instances.

to grips with the basic conditions that we have no idea what the mental or the cognitive could possibly be, apart from our own experience of it.' (Varela 1996)(p331).

Intentionality

Intentionality describes 'the relationship between the process occurring in consciousness and the object of attention for that process' (Smith, Flowers et al. 2009)(p13). The principle of 'intentionality' is a person's 'inseparable connection to the world' (van Manen 1998)(p5) and the cornerstone of phenomenology is that intentionality is the property of consciousness which allows this 'human engagement with the world' (Nortvedt 2001)(p30).

Consciousness is about the 'phenomenal presence' of an object, not the object itself. As well as consciousness being directed to something that is not itself, it can also be aware of itself, or the products of consciousness such as thoughts, ideas, feelings and memories. Internal (or immanent) objects, (Giorgi 1995)(p33), are objects of awareness which are part of the same consciousness as the act. This distinction has implications for this study in that epileptic seizures being organic, could be considered immanent and, therefore, an integral *part* of consciousness. NES on the other hand, not being organic and external to a person's consciousness, could be a something that consciousness would be directed *towards*.

Merleau-Ponty viewed intentionality as being basic to 'a symbiotic relationship between the act of perception and the environment of the perceiver', (Moran 2000)(p20). Acting as a virtual agent, intentionality gives meanings to the things we do and how we express these meanings. The task of an interpreter is to reduce these experiences of consciousness in order to reach the essence of a phenomena (Sadala and Adorno 2002).

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'There can be no presuppositionless knowledge' (Guignon 1993)(p14)

Although we experience the world as a Gestalt whole, this is amidst 'complex shadings of perceptual awareness' (Moran 2000)(p396). Husserl advocated the phenomenological epoché before exploring a phenomena (Moran 2000), and bracketing or putting aside assumptions and presuppositions about the world (Haggman-Laitila 1999) as we already 'know' it. Bracketing can be explained in mathematical terms, i.e., pre suppositions of a phenomenologist are put aside and treated separately, as in a mathematical equation (Smith, Flowers et al. 2009). However, when what we previously took for granted becomes a phenomenon to be studied, and involves balancing what we already know about it in general terms, and allowing ourselves to discover the particular and unknown.

Suspending this 'natural attitude' would edit out our previous assumptions, concerns and engagement with ordinary life, as we would only attend 'to what is given to us in intuition' with no prior scientific or philosophical hypothesis being allowed into our 'new' vista, so that essential features of the phenomena are truly isolated (Moran 2000)(p10). This bracketing or suspension of 'all ontological judgements about the nature and essence of things and events' would then allow us to reach the interpretations of people of what they think is real to them (Holstein and Gubrium 1998)(p139).

To Husserl, our 'thinking and reasoning about the phenomenon at hand' should go through a process of 'eidetic reduction' which involves moving away from, and not being distracted by, what we already know about 'something', towards 'every salient particularity of a given phenomenon', which would be a pre-cursor to a scientific account of that same something (Smith, Flowers et al. 2009)(p14). Husserl's ideas of shifting the focus of investigation from what our *senses* give our consciousness of our experiences, to *how* we experience the objects,

involved transcendental reductions which means a return to, and being completely engrossed in, the pre-given 'life world' (Moran 2000)(p12). His work guides contemporary IPA researchers in their need to focus, systematically examine, reflect on, and be attentive to, the contents of consciousness (Smith, Flowers et al. 2009).

Existential phenomenology

Rather than the complete and radical procedure involved in Husserl's reductionism which brackets out all scientific knowledge and theories (Finlay 2008), Heidegger's hermeneutic, existential phenomenology argued that we *cannot* suspend our own ideas (MacDonald 2001), indeed we need this prior perspective to begin to 'know' otherwise (Guignon 1993). Heidegger moved on from Husserl's ideas of pure description, to argue that all description involves an interpretation (Moran 2000)(p20). The range of possibilities within an interpretation (Guignon 1993) being based on, 'fore-having, fore-sight and fore-conception' and, eventually, a consideration of the personal context of the phenomenologist themselves (Finlay 2008)(p8).

More recently, interpretation and the notion of bracketing, is explained and expanded in terms of '*managing* pre-understandings' (Finlay 2008)(p5). That is, by conceptualising phenomena in terms of our own biographies, knowledge, and exploring our 'fore-understandings' because, as human beings 'our horizons of experience', both past and present, are inextricably embroiled in our perceptions of the world (Finlay 2008)(p8). This expands the mathematical allegory above, by the taking into account of what was in the 'brackets' in the first place but in terms of what we have discovered anew. That is, they are put aside, but still present in that they are a part of our 'calculations' or eventual interpretations.

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Merleau-Ponty, consciousness and the body

Merleau-Ponty drew upon both Husserl's and Heidegger's contribution to the phenomenological project. He argued for 'an account of embodied human being in the world' (Moran 2000)(p13), discussing this in terms of the relations between consciousness and embodiment (Moran 2000). This also further expanded Heidegger's ideas of the contextualisation of our experiences, and our 'worldliness' in terms of the body rather than simply our 'embodied' relationship to the world (Smith, Flowers et al. 2009)(p18). Merleau-Ponty understood and confirmed the importance of epoché and, whilst agreeing that complete reduction was impossible, it does allow us to step back and to be open to seeing and being surprised by new and contradictory things as we understand our involvement in the world (Finlay 2008)(p10). For Merleau-Ponty, a person exists in a world and their body is the means by which they are anchored in that world, it being the central conduit in which we gain a sense of the world we inhabit (Sadala and Adorno 2002).

Merleau-Ponty further developed Husserl's thinking into an existentialist phenomenology, which is not abstractly based but which places the individual, as 'a historical person' as they actively live in the world (Sadala and Adorno 2002)(p286). A return to the very thing itself involves experiencing a world which has not previously been reflected upon, and in which people learn about themselves in particular situations (Sadala and Adorno 2002). In practical research terms this means that people will give a description of things from the standpoint of where they are at the moment we talk to them. Another moment may give us a different perspective of the same phenomena. As interpreters we can attempt some understanding of phenomena and its general structure but not its totality (ibid).

Sartre extends this existential notion that some understandings are split from conscious understanding and that human beings go through a process of

'becoming' (Smith, Flowers et al. 2009)(p19). That is, whilst we have a self consciousness which engages physically and meaningfully with the world in which we live, we need to know ourselves from the perspective of many other experiences (Smith, Flowers et al. 2009).

For IPA, that our body shapes our knowledge about the world is important and, 'physical and perceptual affordances of the body-in-the- world' are significantly more important than abstract or logical ones' (Smith, Flowers et al. 2009)(p19). The existential phenomenology of Merleau-Ponty is particularly relevant to the phenomena of seizures which are bodily based and because a person's lived experience is not always what they think it is. One way of reaching these experiences is through phenomenology, as this can 'reclaim' them and 'language and perception hold the key to unlocking them' (Wilde 1999)(p29). The idea of the 'data source' of bodily experience being the central point of scientific reference however, is a concept which could be considered problematic for some (Stelter 2000)(p63).

Experimenting with phenomenology

More recently, the phenomenological method has been integrated into studies on consciousness, perception and epilepsy and can involve training participants to develop their phenomenological descriptions (Gallagher and Brøsted Sørensen 2006)(p120). This is not an attempt to 'naturalise' phenomenology, but to reassess the terrain in which it can work. The findings of phenomenological studies, being considered scientific and thus a form of methodological control, can inform work in the neurosciences and move towards an 'objective interpretational framework' in empirical work (ibid)(p131). These ideas will be discussed further in chapter 6.

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Hermeneutics - the theory of interpretation

Hermeneutics originally represented a theory which supported the interpretation of biblical texts. It questions the ways in which we do this and the reasons for the interpretation, and whether it is possible to uncover the original meanings in a text (Smith, Flowers et al. 2009). Interpretivist roots stem from hermeneutics - the Verstehen sociological tradition of understanding phenomena and phenomenology (Denzin 1998).

Rather than a methodological device, interpretation is about adopting a certain ontological position, being on the same plane as those one is researching so that the object of investigation is about language in a shared world. An interpretivist methodology has also been described as a sensitising concept, providing a researcher with directions along which to look with the goal of engaging with and understanding the lived experiences of people from their point of view. It has a concern for the life world and for understanding a social actor's definition of an experience, Blumer, (1954) in (Schwandt 1998).

The art of interpretation is making sense of what has been learnt and telling this story, in a coherent fashion, to others. This story can be perceived differently by different communities of researchers, and how the researcher tells the story can take the reader into the centre of a particular experience (Clandinin and Connolly 1998).

Schleiermacher, a 19th century theologian, focussed on both grammatical and psychological meanings in texts (Bowie 1998). A text as written by someone else is unique in its intentions and linguistic techniques. An interpreter should then engage with this text and be a part of the interpretation in that they need to understand the writer, the text, the original context in which it was written, and thus reach an interpretation which goes beyond what the original author intended and understood (Smith, Flowers et al. 2009). Although an

interpretation is *grounded* in a participant's words, it can 'transcend or exceed the participant's own' terminology and conceptions' Smith (2004)(p114) in (Larkin and Clifton 2006). That is, an IPA can add something to this; theories can be used to explain something, a larger data set may offer connections to it, the analysis is systematic and detailed, and it may reach some 'thing' in a person that was not apparent before.

Heidegger and 'Living in time' (Moran 2000)(p20)

Heidegger's major contribution to the development of phenomenology was to define 'phenomenology as hermeneutic' (Smith, Flowers et al. 2009)(p24), and that the method is needed in order to elucidate the meaning and nature of 'Being' (Krell 1978), with 'a hermeneutic lens' (Smith, Flowers et al. 2009)(p18), with which to view it and bring it to light. Rather than Husserl's concern with the psychological processes of perception and consciousness, Heidegger wanted to tease out ontology and existence itself, utilising the term dasein ('there being') as being something he wanted to establish the nature of (Smith, Flowers et al. 2009).

There is a already a pre existing, intersubjective world in which we all 'know' about and act within and understand (Smith, Flowers et al. 2009). That is, 'being' is something we are all doing every day and it is predicated in relation to the world, people and things (Krell 1978) in terms of its visibility. However, for Heidegger, related to surface appearance are hidden meanings (Smith, Flowers et al. 2009). The 'phenomenon' (translated as to appear) of these is something that presents itself to us whereas it was not apparent before. Things will show themselves and be 'brought to light', which requires hermeneutic thinking, in order for this to show (Smith, Flowers et al. 2009)(p24). This brings us back to the concepts of fore-conceptions, upon which the new interpretation is founded and which are made sense of in terms of the 'new' thing. The notion of

bracketing discussed above, because of the circularity of an interpretation, then becomes something that is only achievable in part (Smith, Flowers et al. 2009).

The hermeneutic circle

An IPA interpretation is a dynamic, iterative process. The concept of the 'hermeneutic circle' illustrates this (Smith, Flowers et al., 2009)(p28).
This allows a researcher to go back and forth within this circle, examining parts and wholes of texts, relating these to the participant's life, the phenomena under study, and personal ideas relating to this (Smith 2007). A researcher can, at one point, be immersed in the world of their participant and, at another point return to their own world (Smith and Eatough 2008), all the time being inductive and open to new aspects of a phenomena participants may elucidate, perhaps going back to the literature to explore these further (Smith 2004).

Researcher's fore-structures can be used reflexively and insightfully in what could be described as a dance of interpretation, whereby the researchers can shift their focus continually to and fro, considering their pre understandings, reflection, naivety and also be open to the new knowledge their participants offer them (Finlay 2008). In terms of any fore-structures they may have, engaging fully with a participant will naturally sideline these at that point in time, and they may not even become apparent until an interview is over. The main point is to not let the *thing* make sense in view of these fore-structures, but that the fore-structures must be made sense of, 'in terms of the things themselves' Heidegger. (1962/1927)(p195) in (Smith, Flowers et al. 2009)(p25), i.e., the *thing* itself must be reified.

One of Smith's own studies (Smith, 1999) in the next section illustrates this point, fore-structures (some based in his prior reading around the topic) about his participants were not enough to 'account' for what they told him and this,

irrevocably altered his fore-understandings which were replaced by ones grounded in their words (Smith 2007).

An IPA interpretation

An IPA interpretation is grounded in the text, 'tentative and emergent', and at one particular time, but moving beyond this at several levels going beyond simply describing phenomenon and engaging more with social psychological perspectives (Landridge 2007). It can empathise with participants, and try and feel like what it would be like to be them, but it also has to question what they have said in order to understand and represent them (Smith, Flowers et al. 2009). It can pick out metaphor, examine contradictions, and 'temporal referents', theory can inform an interpretation, perhaps initially being couched in speculative terms although they may later be linked more formally after the interpretation is complete (Smith 2004)(p45). Whether an interpretation is ever complete depends to a point on the level of researcher expertise and can be simply adequate or stretch the imagination (Smith 2004).

Thus an IPA interpretation is a realist one in that the writer puts a personal interpretation into the lives of their participants, this is implicit in the interpretative process and resulting text, after all, as fellow humans we are part of some of the same world (Holstein and Gubrium 1998). Also the texts we interpret were generated for a specific purpose, i.e., our research and thus we are an integral part of them. Thus the IPA interpretation is affected by the analyst and their background (Smith, Flowers et al. 2009), and may involve a more critical interpretation, which a participant may not have perceived of, or acknowledged about themselves (Smith 2004) .

Chapter 4. Let it shine on me: Interpretative Phenomenological Analysis- its philosophical, theoretical and epistemological underpinnings

Deeper analysis

IPA, first and foremost is concerned with particulars of phenomena, producing a detailed in-depth analysis. Furthermore, it pays attention to how a phenomenon is experienced from the perspective of particular people in a particular context. Because of this 'cases' can then contribute to establishing generalisations of a particular phenomenon across cases (Smith, Flowers et al. 2009).

Thus a longitudinal IPA for example, can also result in a deeper interpretation of original data, different things will present themselves to the analyst as they increasingly become to know the person, what they are saying about a phenomenon, the temporality of a phenomenon and a participant's psychological processes (Smith, Flowers et al. 2009). This level of interpretation relates well to the ideas of Schleiermacher, who argued for reaching an understanding of development of the person and to understand them as well as their text constituting 'a detailed holistic analysis' comprising of inter-subjectivity (Smith 2007). The idea of gaining more contextual data about a person is gaining ground in the field of seizure differentiation (Reuber 2008; Thompson, Isaac et al. 2009).

This section has described the theoretical and epistemological roots of IPA and where it stands in relation to scientific thought. It has introduced how IPA fits into these and makes use of them whilst forging its own distinctive approach. The following sections will first, give an account of how IPA works as an approach in practice, bearing in mind the antecedents above. Woven through this section are aspects of debates and dialogues from the on-line IPA discussion group. [59] The IPA community dialogue is key to contributing to the evolution of IPA, as researchers explore and discuss different ways of using IPA in their

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[59] ipanalysis@yahoogroups.com All on-line communications appearing here are cited with the permission of each author.

research endeavours. IPA is relatively new and issues arising are continually discussed by active researchers. The e mail discussion group is a busy, dynamic and enquiring community. It is open to questions at all levels and provides an ongoing picture of how IPA is shaping as a methodology and method. Second, this will be illustrated with a number of individual studies selected for their relevance to this thesis.

4.1 How an IPA works in practice with a review of selected papers

Literature search methodology

A search for papers for this section was undertaken using the term
Interpretative Phenomenological Analysis in: Academic Search elite, Cinahl,
PsycINFO, MEDLINE, PsycARTICLES, and the International Bibliography of
the Social Sciences, from January 1999 – March 2009, and which identified 142
hits. All hits were all scrutinised by reading abstracts, if available, or looking at
the whole article before selecting relevant literature according to the criteria in
table 7 below.

Generally, it is agreed that that no one search strategy is enough to identify all
potentially relevant records. Again, elements of 'Berrypicking', [60] Bates, (1989),
in (Barroso, Gollop et al. 2003) were used. The researcher added to this
personally contacting investigators in the field, because studies can pop up
serendipitously, offering further routes to follow and maintaining a continual
dialogue with other researchers can uncover other papers, references and
unpublished work or work in press. [61] However, although this is all considered
'good practice' in a literature search, it can make it difficult to give precise and
chronological information on the history of a search.

From 142 hits, 6 individual empirical studies were selected, related to the
concepts in table 7. Given the potential misunderstandings mentioned by Evans
above relating to meanings in abstracts and titles, the search did not pick up one
relevant study known to the researcher (Dickson, Allan et al. 2008). Two more
relevant papers were found in the references sections of papers already
identified in the search (Holt and Slade 2003; Bramley and Eatough 2005). It
also identified one paper where IPA was only applied to the beginning of

[60] This directed search also allows for an iterative and creative searching process to take place
including subject searches in bibliographies, footnote chasing and tracking and searching
citations.
[61] For example, two other IPA researchers using artwork in their interpretations were discovered
by this route.

interviews, the remainder of them given to asking specific questions of participants relating to an existing model which was being explored (Green, Payne et al. 2004). One paper and one book were published after the search was undertaken (Smith, Flowers et al. 2009; Thompson, Isaac et al. 2009). The final list of the twelve selected studies organised by the criteria described are below in table 7. Books and papers relating to the theoretical, methodological and evaluative aspects of IPA are included in the thesis bibliography.

Table 7

IPA empirical studies selected

Individual studies. Titles and concepts	Number of participants
Theory building	
1 (Smith 1999) "Towards a relational self: Social engagement during pregnancy and psychological preparation for motherhood." British Journal of Social Psychology 38(4): 409 – 426	4
Non epileptic seizures – linking IPA with existing models	
2 (Green, Payne et al. 2004) "Illness representations among people with non-epileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model. Seizure. 13: 331 – 339	8
3 (Thompson, Isaac et al. 2009) What is it like to receive a diagnosis of nonepileptic seizures? Epilepsy & Behavior. 14: 508 - 515	8
Anomalous experiences	
4 (Knudson and Coyle 2002) "The Experience of Hearing Voices: An Interpretative Phenomenological Analysis." Existential Analysis 13(1): 117 – 134	2
5 (Whitehead, Brown et al. 2007). (2007). "Waking on the operating table: An interpretative phenomenological analysis of anaesthetic awareness." Health Psychology Update 16(3): 34 – 39	2
Embodiment	
6 (Murray 2004) "An interpretative phenomenological analysis of the embodiment of artificial limbs." Disability & Rehabilitation 26(16): 963 – 973	14 face to face interviews 21 e mail interviews excerpts from over 200 communications from an on-line discussion group
7 (Holt and Slade 2003) "Living with an incomplete vagina and womb: an interpretative phenomenological analysis of the experience of vaginal agenesis." Psychology, Health and Medicine 8(1): 19 – 33	7
8 (Osborn and Smith 2006) Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis." Scandinavian Journal of Caring Sciences 20(2): 216 – 222	Interpretation drawn from an earlier study which used 9 women participants
Neurological conditions	
9 (Bramley and Eatough 2005) "The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study." Psychology & Health 20(2): 223 – 235	1
10 (Dickson, Allan et al. 2008) "Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis." Psychology and Health 23(4): 407 - 425.	8
Medically Unexplained Symptoms	
11 (Edwards, Thompson et al. 2007) "An 'Overwhelming Illness'. Women's Experiences of Learning to Live with Chronic Fatigue Syndrome/Myalgic Encephalamyelitis " Journal of Health Psychology 12(2): 203 – 214	8
Case studies	
12 (Eatough 2006) " I feel like a scrambled egg in my head: An idiographic case study of meaning making and anger using interpretative phenomenological analysis." Psychology and Psychotherapy: Theory, Research and Practice 79: 115 – 135	1

Evaluative, conceptual and practical issues in IPA

IPA represents an epistemology, an approach to researching topics and is beginning to build up a corpus of empirical studies, in some cases informing clinical practice (Jarman, Smith et al. 1997; Howes, Benton et al. 2005; Smith and Liles 2007; Kally and Cumella 2008), exploring stigma in relation to health conditions (Knight and Moloney 2005; Dickson, Knussen et al. 2007) and suggested directions for future research (Chapman and Smith 2002). The theoretical background outlined above underlies the methodology of IPA. Any or all of these can be drawn upon however, in the light of what methods individual researchers are using, i.e., 'one can be coherent without being purist' (Todres and Wheeler 2001)(p2).

The 'detective work' necessary for an IPA ensures that an interpretation is not simply a description of people's idiosyncratic experiences (Larkin and Clifton 2006) - although these are important in that they account for variety in phenomena - that is staying with, and giving voice to, a participant's experience and not moving beyond these in terms of analytical work done – and which is methodologically and philosophically sound (Landridge 2007). The IPA analyst however, moves beyond the data (ibid) seeking meanings in these descriptions (Moran 2000)(p229). There are inter-subjective dynamics between participants and researchers; the researcher identifies with the participant as another person who thinks and feels. This involves the researcher putting themselves in the shoes of their participants', and being empathic in that they are thinking what it is like to be the other person. They can also step back out of their participants' shoes, as they critically and questioningly engage with what they have been told by them, and as they attempt to see things participants cannot see of themselves (Smith 2007) [62].

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[62] Smith, Jonathan A. (2007) Keynote speech. The theoretical framework of IPA. Annual IPA Conference. University of Sussex.

The main consideration for a researcher is to consider whether their topic of enquiry is best explored using an IPA, with its philosophical underpinnings and cognitive focus (Smith 2004), some level of immersion in the philosophical arguments and ideas obviously being necessary (Berndtsson, Claesson et al. 2007). However, having decided upon an IPA, the approach demands much of a researcher, good interviewing skills, and an abundance of time because analyses are painstaking (Smith, Flowers et al. 1997), detailed and often evolve in ways not envisaged.

Operationalising the phenomenological attitude

IPA researchers then have to put into operation the phenomenological attitude which is not an easy task (Finlay 2008). The ability to embed 'thinking phenomenologically while doing phenomenology', could be considered a specific skill (Berndtsson, Claesson et al. 2007)(p256). There are arguments for training phenomenological researchers, in order to prepare their minds for phenomenological research, in spiritual methods which share Husserl's epistemology emphasising, 'knowledge by presence', (Louchakova 2005)(p87), in order to gain the skills necessary to 'do' phenomenology (Varela 1996).

Some of this training and preparation is adapted from spiritual systems, 'which enhance the capacity for knowledge' of a researcher (Louchakova 2005)(p87). As it is within the researcher that the analysis or interpretation lies, their mind and imagination being the tool for the analysis, ideally they should have been trained in how to 'enhance direct intuition' (Louchakova 2005)(p108). Asian philosophies for example, are 'living manifestations of an active, disciplined phenomenology', these can be learned like any other skill and work to extend and complement science (Varela 1996)(p346). The potential for participants to be trained in such methods has long been suggested (Varela 1996; Finlay 2008) and has been recently mooted in the IPA project in that this could then offer findings that are even more 'experience-close' (Smith, Flowers et al. 2009)(p204).

Practicalities

Methods of data collection

Methods other than one to one interviews, can be used to collect data for an IPA study and are indeed advocated where appropriate and circumstances allow (Smith, Flowers et al. 2009). One of the studies described below (Murray 2004), is an excellent example of additional data collection methods.

The IPA interview conversation

'we need to throw ourselves into the unknown' (Smith, Flowers et al. 2009)(p65).

An IPA interview could be considered an, 'interview conversation', in that the researcher should be part of this conversation and not simply a spectator, being *with* the participant rather than *doing* something to them (Smith and Eatough 2008). It is nevertheless undertaken for a specific purpose and extensive guidelines for undertaking IPA interviews are described in Smith, Flowers et al, (2009). However, major points to bear in mind are that; phenomenological interviewing is an inductive process, the participant is the expert on the topic in terms of their experience of this, and they may shift the focus of the interview considerably into a very different direction to that envisaged by the researcher (Smith, Flowers et al. 2009). An interview can involve incredible frankness, confessions and emotional disclosures from a participant and these in turn can elicit empathic responses from an interviewer (Miczo 2003). The researcher needs to be an 'active listener' and allow the interview to evolve naturally, silences are particularly important to 'let happen' and wait out, because participants are often searching for words at these times (Landridge 2007) and can often expand upon previous ideas after what seems to be a very long pause, and to interrupt could lose important 'data' (Smith, Flowers et al. 2009). An unstructured interview begins with a core initial question and often results in a participant summarising their main concerns and the importance they

attach to these, and which are not always what we expect (Smith, Flowers et al. 2009).

Participant numbers in IPA

'PS...I'm usually full after 6 – but I love n=1 – I think it's difficult but when people do it – I salute them.' (M.O.,) [63]

IPA gives voice to the individual voices of participants above all others, (Larkin and Clifton 2006) and does not make general claims about larger populations than those studied (Landridge 2007) using small numbers of participants. That is, it is an idiographic approach which emphasises details and particulars of someone's individual experiences, distinguishing it from many other qualitative methods.

Although sample size may be an important factor for those writing research proposals or defending research to varied audiences, it is advocated that between three and six participants is an ideal number for an IPA study as this has the potential to meet the methodological 'commitments' of IPA. [64]
IPA is, increasingly, using small numbers of participants because of the nature of the task in IPA being:

> 'to illustrate the particular qualities of the approach - detailed phenomenology, insightful hermeneutics, nuanced analysis'...
> 'Students are much more likely to produce authentic and high quality pieces of IPA if they can concentrate on conducting and analyzing a small number of well conducted interviews'. (J.S.,) [65]

One great advantage of having small numbers of participants is that one can memorise (probably up to ten) interviews without too much difficulty and this is

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[63] ipanalysis@yahoogroups.com On behalf Of Osborn, Mike. 12 December 2008. Accessed, 12 December 2008.
[64] ipanalysis@yahoogroups.com on behalf of Flowers, Paul. 29 May 2008. Accessed, 30 May 2008.
[65] ipanalysis@yahoogroups.com on behalf of J.Smith. 12 December, 2008. Accessed, 12 December 2008

useful if one wants to consider themes across cases later on (Smith, Jarman et al. 1999). However, the analysis are extremely time consuming and detailed (Landridge 2007). N=1 therefore, is being increasingly adopted by IPA researchers (Eatough 2006; Eatough and Smith 2006i) and this is becoming increasingly acceptable (Landridge 2007).

Interpreting across cases

Following individual interpretations, an interpretation across cases can be undertaken. This involves examining all cases for any connections or divergences between them, and illustrated by individual instances of these which can involve 'counting' of occurrences of themes (Smith, Flowers et al. 2009).

Member validation and reflective practice

Whether participants can be realistically be expected to contribute to an interpretation and at what level this could be at has always been debated within the arena of qualitative research. For example, attempting this with a group of professionals/researchers can work well (Barbour, Featherstone et al. 2000). However, it is less of a viable exercise with people with little in the way of research skills and knowledge and experience of academic writing (Landridge 2007). Ethical issues can arise from giving participants their words back to them in black and white (Barbour and Huby 1998)(p190). Handing back a verbatim transcript to a non academic participant, complete with their (and the interviewer's) ungrammatical speech, false starts, 'ers' and 'ums', can be overwhelming, disconcerting, embarrassing and even distressing for them (especially if the topic is an emotive one) (Forbat and Henderson 2005).

Theoretically driven concerns in phenomenology regarding asking participants for feedback are around the concept of questioning hermeneutics and that an interpretation goes beyond a participant's description and understandings and

that this interpretation may not be understood by them. However, offering them something that they can understand and feel confident in commenting on is acceptable (Landridge 2007). 'Member checking' as a concept in IPA has been the subject of more recent discussion in the IPA on line group with around 20% of IPA researchers undertaking this (P.F.,). [66]

Links between IPA and cognition

Cognition is 'dynamic, emotional and embodied' (Smith, Flowers et al. 2009)(p194).

IPA has a major interest in cognition, albeit with a different focus to that what is traditionally thought of as cognition in the social cognitive paradigm which reifies 'attitudes, beliefs and intentions' (Smith 1996)(p262) which have their place in a 'functional analysis' (ibid)(p263). However, 'putting human life back into these functional analyses', will extinguish their 'alienation from human life' (Varela 1996)(p345), who favours terms such as, 'embodied, situated or enactive cognitive science' (ibid)(p346). Cognition in IPA is not seen as information processing with all its attendant quantitative experimental methods, rather as a 'science of meaning making' (Smith and Eatough 2006)(p325).

Whilst IPA agrees that there is a 'chain of connection between account, cognition and physical state' (ibid)(p265), it seeks to fill the gap between an object and a person's perception of that object (Smith, Flowers et al. 1997). For example, in chronic illness (the object) where quantitative methods will use locus of control or coping measures, IPA will seek to explore how people make *sense* (the gap) of their conditions. Knowledge about physiological events related to seizures is all very well, but it is only one view of what is happening to people during what are very personal experiences.

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[66] Ipanalysis@yahoogroups.com on behalf of Flowers, Paul [P.Flowers@gcal.ac.uk]
11 June 2007: accessed 12 June 2007.

Interpreting a person's cognitions is at the heart of IPA and it strives to unravel 'the relationship between what people think (cognition) say (verbal account) and do (behaviour/physical state)' (Smith and Eatough 2006)(p15). IPA considers that how people talk about their bodies relates to their thoughts and beliefs (Smith, Jarman et al. 1999). Cognition (thinking or perceiving) as a mode of relating to our environment is part of an enactiveness in the world and, therefore, part of the process of interpretation (Stelter 2000). Some, for example, (Willig. 2001; Landridge 2007) argue that this focus on cognition is not 'at ease' with the 'phenomenological' element of IPA. That is, phenomenology should focus on pre-reflective experiences, the 'natural attitude' (which involves only being conscious of being conscious) and which does not involve an individual in reflection (Smith, Flowers et al. 2009). However, as people talk about their experiences, they begin a process of reflection, some of it unconscious and some 'self-conscious' (ibid). Heidegger and Sartre emphasised the importance of other concerns in people's lives which affect these experiences, that these have 'existential significance' and need reflecting upon in the context of their experiences (Smith, Flowers et al. 2009). A person will, therefore, think about and make decisions based on these concerns consciously whilst still remaining within the natural attitude. Thus cognition for IPA becomes a meaning making process, and an interpretation will unravel this individual process (ibid).

IPA and language

IPA is of course, inextricably bound up with language and making meaning from people's talk in their interviews, interpretations being both limited and enabled by language. However, rather than constructing meaning, IPA places the use of language into the cultural context a person is living in and creates an understanding around this (Smith, Flowers et al. 2009). Interviews are often about conversations with other people that have occurred at other times, some of the meanings associated with them can be communicated non verbally and be co-constructed (Miczo 2003). If people are not able to articulate fully what

things mean to them, the IPA researcher can uncover these by listening to how a person tells them about their life. This telling of their story is necessary in order for them to work through their situations (Frank 1998)(p206).

Building theory with IPA

IPA does not import external theories in order to fit the data although these can inform the interpretation, initially being couched in speculative terms, they may later, be linked more formally after the interpretation is near completion (Smith 2004). IPA studies can, potentially, help develop theories rather than searching for excerpts that fit an existing model or theory - through a process of 'analytic induction' (Smith 1999)(p413), and which are true for all cases in a model. Models can emerge from an interpretation based on theory underpinning IPA but most importantly, any subsequent model which does emerge should be rooted firmly in the data (Smith 1999). Although a number of studies have analysed 'within a pre-existing theoretical framework', in IPA this is normally done *after* the interpretation is nearly complete (Brocki and Wearden 2006). In any case, individual cases are interpreted separately before any attempt is made to look 'cautiously' across cases (Smith 1999)(p412), this acting as 'proof' that cases have similar attributes and can, therefore, contribute to a model based on multiple cases. Any theory postulated can be further built upon by adding in additional cases (Smith 1999)(p413). For example, the final study in this section, Eatough, V. and Smith, J., A (2006) challenges established theories of emotion.

Critique of empirical papers

The studies described below were chosen because their topic areas resonated either with concepts in this thesis, such as embodiment or unusual experiences, or they illustrate the potential of IPA in illuminating lived experience and in building theory.

1 Smith, J. A. (1999). "Towards a relational self: Social engagement during pregnancy and psychological preparation for motherhood." British Journal of Social Psychology 38(4): 409 – 426

Smith's multi method study of four women about to become mothers took a temporal look at their transition into motherhood and followed their progression. Using multiple interviews with four women, diaries and repertory grid analysis undertaken longitudinally, constituting 'real time and retrospective date' and respondent validation, the four cases being individually interpreted. A negative case analysis tested a theoretical hypothesis of the relational self until one was produced which was true of all cases. For more details of this process see, (Smith 1994; Smith and Hayes 1997). However, until all new mothers have been included it remains a hypothesis.

Smith's model of the relational self – 'that pregnancy can accentuate the symbiotic relationship of one's perception of self and others, and that this aids psychological preparation for mothering' (Smith 1999)(p409) was based on the longitudinal study (Smith 1994; Smith 1999; Smith 1999a) and personal long term reflection. Based on the theory of self reconstruction, the new theory of the 'reconstructive self' emerged (Smith and Hayes 1997) in relation to these four women. This was later related to existing theory, in particular to Mead's concept of the self and that 'self' comes into being by interacting with others. A concept the women brought out in the interviews, i.e., relations with others, was one the author did not bring into his interview schedule, having no pre-understandings of this concept in relation to the process these women were going through.[67]

NES and linking IPA with existing models

2 Green, A., Payne, S. and Barnitt, R. (2004). Illness representations among people with non-epileptic seizures attending

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[67] Smith does acknowledge that being male may have contributed to this also.

a neuropsychiatry clinic: a qualitative study based on the self-regulation model. <u>Seizure</u>. 13: 331 – 339

'Like dentists drills in my head'. (Person with seizures)(p334)

Whilst acknowledging that the use of an existing model has to potential to miss other processes that could be occurring, one study has evaluated Leventhal's self regulation illness representation model in the context of NES with a view to using measures based on this model for this patient group. The 'common sense' model of Leventhal's emphasises that a patient's personal representation of their illness in terms of perceived threat, will affect their coping behaviour and illness outcome. Individual elements of the model are, identity, (symptoms and label of condition) cause, time line (time to develop and duration), consequences (effect on life style) and controllability or cure. Only the beginnings of the interviews were given over solely to participants (for an IPA analysis) with very specific questions being asked of participants for the remaining of the interviews and relating specifically to Leventhal's model. The analysis was primarily a coding of transcripts relating directly to elements of the model which the authors suggest could have constrained the analysis somewhat. Text remaining was extracted, and then examined for codes pertaining to additional themes found in the data.

In relation to the model, identity, symptoms and labels, numerous accounts, experiences and labels for their condition emerged. Most participants had incoherent ideas as to the cause of their condition, and were ready to accept psychological factors including stress, abuse and trauma. No-one referred to positive consequences of the condition, or could articulate a disease trajectory.

Uncertainty was a predominant theme which related to most elements of Leventhal's model. People's accounts of seizures were complex and confusing, and because they were uncertain about their diagnosis in terms of its causes, its process or mechanisms, they could not elucidate clear ideas about its trajectory.

However, those who believed it was internally and psychologically rooted, also believed they had more control over their condition. Also, that being given an acceptable label for their condition will help patients in terms of control, coping and outcome is a finding that relates to more recent studies in this specific area (Plug, Sharrack et al. 2009).

The IPA element of this study brought out two themes which did not fit with Leventhal's model. These were about acceptance and coping; participants' own acceptance of their condition, and the understanding of others. Individual acceptance was related to the feelings of people and ranged from hopelessness, resignation (a major one) to positive coping. Coping was also related to acceptance from others, with comments from participants about attitudes of hospital doctors and inferences that they were seeking attention. Although stigma was not mentioned specifically, there appeared to be felt stigma, for example from friends who had withdrawn their support.

The main finding was that people need a label or identity in order to relate to elements of the self regulation model. The model appears to require a person to have an illness identity in order to identify a cause, and beliefs about illness trajectories and control rely on the former being present. People with NES however, do not always receive an explanation they can understand (a recent paper has addressed this (Hall-Patch, Brown et al. 2010). Without a 'common sense' explanation of their condition, they cannot begin to formulate ideas about control.

3   Thompson, R, Isaac, C, L, Rowse, G, Tooth, C, L, Reuber, M (2009). What is it like to receive a diagnosis of nonepileptic seizures? Epilepsy & Behavior. 14: 508 - 515

Linked to the above study, insights into receiving a diagnosis of NES are lacking and do not explicate why some patients react differently to others. The fact that some patients have lived with an epilepsy diagnosis for some time before a true

diagnosis of NES is given, that there are various labels given to the condition and that people can have serious psychopathology makes the communication of the diagnosis a challenge for clinicians. Patients' and doctor's beliefs about the causes of NES are often radically different, for example, patients can believe their seizures are physically based whilst still acknowledging psychological stress. Some patients will carry on taking AEDs. This difference in lay and professional beliefs is a major stumbling factor in delivering a diagnosis of NES and how this is done can influence clinical outcome.

From a total of eight patients, four of these disclosed sexual, emotional and physical abuse. Seven disclosed stressful events at the time the seizures began including mental health problems and domestic abuse. They talked about altered consciousness, with seizures feeling 'unreal and strange'. Passivity, helplessness and loss were feelings described by patients, relating to loss of control during a seizure and in other areas of their lives such as role, independence and isolation.

People tried to make sense of the cause of their seizures, NES meant different things to different people and the sense they made of it affected their acceptance of the underlying rationale of psychological causes and subsequent treatment. However, until this understanding was reached, people could not resolve the diagnosis. Some welcomed the diagnosis, whilst it some rejected is as not being relevant to their lives. Patients' life experiences were important in that this can shape a response to a diagnosis. Knowing about their own personal narratives is inextricably linked to how people with NES accept their diagnosis as integral to their life.

Anomalous experiences

4   Knudson, B. and Coyle, A. (2002). "The Experience of Hearing Voices: An Interpretative Phenomenological Analysis." Existential Analysis 13(1): 117 – 134

'I'm reflecting off my soul'. (Participant hearing voices)(p128)

This study used two cases to explore how people diagnosed with schizophrenia and hearing voices, perceived and coped with their hallucinations and offers insights into how the phenomena can be managed clinically. The rationale for this study mirrors some of what has been argued above, that we need to know about the content of experiences at a phenomenological level and not just from the view of 'objective science' (p118). In this particular field of study seeing 'hallucinations as an experience' rather than seeing them, in medical terms, 'as a symptom of psychopathology' (p131), can expand our knowledge of them. These two case studies highlight how 'voices' are not easily divided into a) hallucinations or, b) simply, 'a thought popping into your head' (p127). This is in terms of who owns them and therefore, whether they can be controlled, and that voices can be perceived as personalities in their own right. How people react to them emotionally and how they deal with them on a practical level is illuminated. For example, increasing levels of sensory stimulation are commonly used, one participant going for long walks to shout at her voices in order to relieve their troublesome effects. This 'hydraulic theme' of needing to release built up aggressive and sexual energy and 'a need for catharses was a main finding in both participants (p125).

Idiographic insights in these two case studies are interleaved with examples of theory, such as those linked with cognitive adaptation and the construction of meanings which in turn link with IPA's interest in cognition. People having these kinds of experiences need to go through these processes at an early stage. Also, Giorgi's notion of immanent objects Giorgi (1995) in (Smith, Harre et al.

1995) matched the quality of the phenomena in that they were not external entities (although the hallucination/thought distinction muddied this somewhat).

Interviews elicited confidences about drug use and ideas about causation, including 'divine retribution' (p123), which reflect doubts in medical knowledge about the origins of such things. That IPA can accommodate subjective and sometimes unreal experiences such as images and hallucinations Giorgi (1995) in (Smith, Harre et al. 1995) supports the use of the approach for these kinds of experiences.

5 Whitehead, E., Brown, K. and Giles, D. (2007). "Waking on the operating table: An interpretative phenomenological analysis of anaesthetic awareness." Health Psychology Update 16(3): 34 - 39

Regaining awareness during surgery can happen in between 1% and 7% of cases. Unless it is understood what this experience entails from the patients' point of view, it cannot be discussed in these terms with patients with a view to alleviate long term psychological distress. For example, patients are paralysed during surgery, some are intubated (so that a person could not talk if they regained awareness during surgery) and their eyes are taped up, procedures which not many people are aware of, (Grunshaw 1990) and (Wang 1998) cited in this paper and which they should perhaps be informed of before they undergo operations 'just in case'.

This study explored the cases of two women as they gained awareness during, 1) a caesarean birth and, 2) a gynaecological exploration. Obviously the themes identified could be specific to women and the authors suggest that if regaining awareness during sex-specific procedures occurs, this requires specific support. They relate their findings to theories of control particularly in the area of feelings of sexual assault in women, the powerlessness they feel and the need to resolve these experiences. Themes elucidated from the women included:

- **Powerlessness -** in terms of the intubation, one participant was a trained singer who needed to have full control over her breathing. Panic attacks as a response to stress followed her experience.

- **Being the victim of an attack -** one woman had previously been raped and she described the feeling of the surgeon penetrating her body with his hands and instruments as feeling like a rape.

- **Development of new fears -** both women experienced behaviour change and nightmares relating to the experience and procedures described above. One at visits to the dentist felt 'trapped' in the chair, the other developed a fear of the dark, relating to waking up finding her eyes taped up.

- **Resistance from hospital authorities as to the reality of their experiences** – the women were, either not believed, their mental health was questioned, and/or, the hospital was perceived as wanting to hide their experiences.

This study had implications for clinical practice. Although the women shared some themes and had other individual ones, they experienced similar after effects. Therefore, strategies could be applied in general before surgery and to alleviate symptoms if a person should regain awareness during surgical procedures. These could include advance explanations and video examples of procedures. Intubation does not, in fact, stop a patient breathing, rather it ensures that there is a safe airway so a person would be able to breathe. However, what they could not do is speak, because, the vocal cords are held open by the tube, (personal communication P.C., 24/04/2009). When the singer talks about the intubation experience having after effects of affecting her breathing in her singing, this was not actually the physical effect of the intubation. Suggested for further research are explorations of the experiences of staff involved in these cases.

Embodiment

6   Murray, C. D. (2004). "An interpretative phenomenological analysis of the embodiment of artificial limbs." Disability & Rehabilitation 26(16): 963 – 973

'The phantom becomes the prosthesis: extending the body' (p969)

This study progressed the work in the area of prosthesis, in that it focussed on the use, rather than non-use of artificial limbs and why people reject these, and also linked it to the embodied experience of 'body image' and the relationship and perception of the body to technology (p963). In order to use an artificial limb successfully, a whole body image with the missing phantom limb as an integral, working part of the image is essential (Sacks 1995). That is, this involves a phenomenological view of prosthetic devices as being incorporated 'into the form and praxis of the body', i.e., a 'phenomenological osmosis' Leder (1990) in this paper (p964). The authors give Merleau-Ponty's example of a blind person with a cane and that this 'withdraws into the sensorium of the body', so that it becomes 'an extension of the realm of the senses' (p964). Whether it is reasonable to think that a process of adaptation to a prosthesis does take place, such that it becomes a part of the body, has been found to be the case in quantitative studies which 'measure' performance. What remains to be explored is the phenomenal experience of users and this study added much to knowledge of the body and its relation to the world.

This study viewed participants as experts in the use of prosthesis and was unusual in that not only did it conduct and analyse using IPA, 14 face to face interviews and 21 e mail interviews, but also consisted of an analysis of e mail communications from over 200 people over a wide geographical area, and a computer based discussion group over a period of two years. This all ensured a temporal picture of the phenomena. All findings were notated as to their origins and the interpretation consisted of a mix of these. This way of gathering

alternative 'rich verbal accounts' is accepted in IPA (Smith, Flowers et al. 2009).

The study gave an overview of the temporal [68] experiences of losing a limb identifying both individual and general properties of these phenomena. This began with an adjustment to new sensory information filtering from the brain. That is, that a limb was missing in terms of a difference in weight distribution for example, and the practical issues relating to prosthesis. This orientation very quickly evolves into a 'subconscious compensation' of body and brain orientation to accommodate a lost limb (p967), allowing the prosthesis, when attached to the body, to balance it out again. A missing leg was more problematic in that in learning to walk again, people needed to learn anew to do something which was intuitive before. However, this again evolved into time into what it was before, a 'pre reflective use' (p968). One participant related an incident when he forgotten he had taken his leg off and tried to get out of bed without it causing him to fall on the stump which was extremely painful. Others were always aware of the prosthesis although again, over time this awareness faded until a specific task needed to be carried out such as carrying a heavy weight necessitates an assessment of the logistics of carrying out the task. However, as the authors point out, one would have to consider this with anatomical limbs.

This is an exemplary IPA study in terms of its relevance to Merleau-Ponty's conceptualising of the body as being central to our sense of the phenomenology of things and the proprioceptive image of our body we all have. One participant with congenital limp deficiency (it could be argued that this hand was not in her proprioceptive image of her own body never having had it at all) learned to hold a book with her prosthesis and then had a new form of knowing, i.e., what it was like to hold a book with this new left hand. This artificial hand thus 'redesigned'

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[68] 'Temporality is inseparable from all experience' (p342). Varela, F. (1996). "Neuropheomenology. A Methodological Remedy for the Hard Problem." Journal of Consciousness Studies 3(4): 330 - 349.

what would have been, 'the 'natural' topography of her body', thus imbuing to them 'implicit knowledge', i.e., that it could hold a book, knowledge which is normally 'embodied' (p969).[69] The study also illustrates the concept that the body is 'experienced ' in, and constructed partly by, the brain, representing events but which are 'not identical to the things themselves' (Velmans 1996)(p191).

The addition of unusual data gathering methods such as e-mail for example resulted in interviews which resulted in increased frankness, more focus, and denser accounts on the part of the participants, (which because they were typed, also did not require time consuming transcription work either!). In addition, the same study used a computer discussion group which offered many additional data and analytic opportunities. This is an example of an innovative use of resources which had the positive offshoot of facilitating an on-line discussion group for prosthesis users.

7   Holt, R., E and Slade, P. (2003). "Living with an incomplete vagina and womb: an interpretative phenomenological analysis of the experience of vaginal agenesis." Psychology, Health and Medicine 8(1): 19 – 33

Vaginal agenesis which has an incidence of between 1 in 5000 and 1 in 10,000 female births. The young women with this condition relating this to a feeling of not being 'whole' and similar to being born without a limb but, unlike people with limb deficiency, their lack was invisible to most others. Their bodies were seen as normal but not normal, disabled but not disabled, having huge implications for their reproductive and sexual life. Denial of the condition (a strategy used by some) prevented women from incorporating this (new, when diagnosed) element of themselves into their sense of self (Holt and Slade 2003)

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[69] My own, newest grandson was born with 'tongue tie' and had trouble suckling because he had never known what it was like to be able to use his tongue, it had never moved prenatally and his brain, therefore, did not include this in his proprioceptive sense. He had to learn this postnatally when his tongue was released surgically and it took him some time to accommodate his new body topography!

and I would argue, body topography. IPA in this case failed to reach elements of the condition the authors were concerned with, i.e., the choice of how to have sex. Because IPA is participant-led none of the women brought this topic up. The authors suggested that a longer term relationship with the women may have resulted in them being able to discuss this topic. Participants did want to talk to other women with the condition however and it may be the case that this could have facilitated a group discussion at some later point and - some topics may need to remain unresearched.

8   Osborn, M. and Smith, J. A. (2006)."Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis." Scandinavian Journal of Caring Sciences 20(2): 216 – 222

'You don't think about your body unless it goes wrong.' (Participant with back pain)(p219)

Studies on MUS are particularly relevant to this study given NES falls into this category of conditions. Like NES, chronic lower back pain is a recognised condition and has been cited as being problematic in public health. This study relates to the theoretical construct of the self which is not static and has a temporal dimension to it, the complicated role of the self in relation to the 'embodied experience', of chronic pain which can result in 'a fractured experience of bodies at varying levels - one participant's pain becoming their whole body. As seen in the study above, body dysfunction or pain in this case, can result in the parts of the body affected suddenly 'appearing' into consciousness and being seen as 'not me' whereas before the pain, or for the parts of the body that did not exhibit pain, these remained taken for granted and not attended to. Participants, like those with Parkinson's Disease below, were forced to think about 'the inner workings' of their bodies and that they lost control of these and were 'carried out by them but not a part of them' (Osborn and Smith 2006)(p219). In terms of pain management, this study offers some ideas for therapeutic work in acknowledging the recognition and importance of,

developing 'a more secure and positive sense of self' (p220), and accepting the limits of the body.

Neurological conditions

9   Bramley, N. and Eatough, V. (2005)."The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study." Psychology & Health 20(2): 223 – 235

Parkinson's disease (PD) a condition for which there is no cure, involves symptoms such as, 'tremor, rigidity, postural instability and slowness of movement' (p223). The authors of this study identified a 'lack of fit' between patients' perceptions of their symptoms and those of their specialists. That is, health outcomes, coping factors and symptoms have all been identified, whilst what it is like to live with PD is a more recent qualitative research endeavour. Idiographic approaches in particular, appearing to be absent completely but also extremely relevant as each patient has a very different experience.

One participant's experiences of physical symptoms in her body reflect that her medication (L-dopa which gives physical movement and the ability to think) actually reflect 'neurological events' in that she experiences of feeling a loss of "connection" until this drug has taken effect whereupon her body suddenly springs into action. However, she does not have control over the side effects of L-dopa which involve 'facial and torso twisting and limb jerking' (p227). Her body and its functioning, in short, is a slave to the medication she takes and, although she regulates this herself, she considers herself psychologically 'addicted' to it. The extreme body movements she experiences are she feels, not of her or belonging to her and not part of her 'normal embodied experiences' (p227) and her body, having no agency over itself, 'no longer represents who she is' (p229). In a normal functioning body, a person is not consciously aware of how physiological experiences of vision, sound, audition and touch are as combined into a 'whole' bodily processes, they simply perceive the experience as

one unified conscious experience - phenomenological consciousness (Tye 2003). This patient however 'feels' each element of her body as being separate, she has lost the ability to walk without conscious thought and, unless she talks herself through the motions required she cannot do this. Other, additional and isolated symptoms, like sweating bouts are to her significant, distressing and embarrassing.

10   Dickson, A, Allan, D, O'Carroll, R. (2008). "Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis." Psychology and Health 23(4): 407 – 425

Acute spinal cord injury is ... one of the most devastating traumatic types of neurological impairment (p407).

Over 700 people suffer a spinal cord injury each year and the total of affected people is around 25,000. These are often young people and they will live long lives of a significantly reduced quality, suicide being a major cause of death. The interview process and they way in which it was conducted was described in detail, particularly in relation to ethical issues such as participants breaking down during interviews, researchers immediately terminating these interviews. Themes which occurred in most of the interviews were presented and couched in the context of a loss of control and of an independent life. Implicated in spinal cord injury is the effect on emotions, and the theory of biographic disruption and the concept of self was applied to the findings in this study.

However, the overarching theme for me in terms of what an IPA can discover was the notion of the absence of a functioning body for these people particularly in the area of experiencing double incontinence and the practice of daily manual bowel evacuation being seen by one male participant as akin to a rape. The authors suggest that this aspect of the condition only arose in the context of using an IPA, because participants were able to choose the topic of conversation and talk about what were to them, key issues in their lived experience. Other

research only touches upon this topic in the veiled context of management and treatment of incontinence rather than this impact upon the individual.

The discussion concluded that this devastating aspect of spinal injuries had the most detrimental effect on people's quality of life. As in the study above about chronic pain (Osborn and Smith 2006) these authors also considered the 'the mind-body connection' and how this affects how people feel about their 'self' suggesting this as a focus for further study.

Medically Unexplained Symptoms

11   Edwards, Thompson, et al (2007). An 'Overwhelming Illness'.
Women's Experiences of Learning to Live with Chronic Fatigue
Syndrome/Myalgic Encephalomylitis. Journal of Health Psychology
2 (2): 203 – 214.

This study aimed to fill the gap in knowledge about how people learn to adapt to, and to live with, CFS/ME using a specific methodology which did not prescribe a particular focus. CFS/ME, much like NES is a condition which is now recognised by the medical profession and, as explained in the medical background section is diagnosable, (having several diagnostic criteria attached to it) thus a genuine 'entity' for patients and clinicians (p204). Unlike this study, however, participants had a definite diagnosis and had had time to consider, reflect upon and adapt to their condition. Like people with NES the diagnostic process of CFS is a prolonged one, and people attempt to reach causal explanations and represent their illness in certain ways in order for them to adjust psychologically and cope with their condition. In this study these were in terms of 'positive reinterpretation' (p211) which prevented them from being overwhelmed by CFS, towards an acceptance of the condition which the authors linked to theories of cognitive adjustment, (Calabro 1990) cited in this paper. Loss as a theme in this study was multidimensional and related to loss of self, of a physically fit body, cognitive losses, loss of friends and the previous, joint

activities done with them, career and financial loss and roles in the family, all of which were often experienced as bereavements which does have implications for clinical practice. Like NES, treatment for CFS/ME is not drug based, (although people may need medication for depression and pain) and sufferers sought out treatments such as yoga, meditation and relaxation and other alternative therapies. Relating to the debate above about respondent validation, the authors stated that they had employed this in the form of sending individual themes with quotations to participants, however, this was not expanded upon in the discussion.

Eight female participants were interviewed for this study and their findings were collated to illustrate two phases in experiencing the condition, 'being overwhelmed', and, 'learning to live with it'. Women moved between these phases with the help or hindrance of mediating factors, drawn from the interpretation, such as support and understanding, knowledge and acceptance. Loss of a career was important and the effect of this loss had on themselves and on significant others. The 'invisibility' of the condition, trying to fight this physically, due to personal and external pressures were also salient issues.

Case studies

12   Eatough, V. and Smith, J., A (2006). "I feel like a scrambled egg in my head: An idiographic case study of meaning making and anger using interpretative phenomenological analysis." Psychology and Psychotherapy: Theory, Research and Practice 79: 115 – 135

This paper is one of a larger date set [70] from interviews from a single participant. It reports on one of theme which emerged from these interviews, that of

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[70] The other being, Eatough, V. and J. Smith (2006i). "'I was like a wild wild person': Understanding feelings of anger using interpretative phenomenological analysis." British Journal of Psychology 97(4): 483-498.

meaning making in personal anger and conflict (the title of this paper best conveying how this particular participant felt).

This participant used various cultural frameworks of meaning to explain her angry and aggressive behaviour. The influences she attributes as causing behaviour, those of biology, hormones, her mental state and use of alcohol are undermined by counselling sessions which challenge them with competing explanations for her behaviour which include her socio-economic position, childhood experiences and feelings of self worth. However, the strength of the frameworks she was used were too powerful to be replaced by more realistic ones relating to her past life.

The analysis was examined theoretically and challenged the mainstay psychological theories of emotion and cognition in terms of their exclusion of how emotional processes work in real life i.e., that *how* people actually behave does not always fit these models and this limits the explanation of emotional processes over time and the effects of other people on our emotions. That is, they explain to a point, how people 'do' emotion and miss out on what it is to '*be* emotional' (p118). Cause and effect models neglect to take into account turbulence of a person's life and bear little resemblance to real life situations. Cognitive emotional approaches too, neglect the meanings of things and the interpersonal element of this. Existing explanatory models require some elaboration in order to take into account the complex concepts and beliefs which people use in appraising and attribute their situations.

Conclusion

The empirical studies selected illustrate that IPA is well suited to being used in 'unexplored territory' (Reid, Flowers et al. 2005)(p23), can accommodate subjective and sometimes unreal experiences such as images and hallucinations Giorgi, in (Smith, Harre et al. 1995) and has the capacity to reach insights which would not otherwise have been reached. Some of the studies have drawn upon existing models and theories, challenging or adapting them. Others explored embodiment both in terms of 'felt' and 'not felt' bodily sensations in relation to organic and non organic conditions.

The two studies relating directly to this thesis are important not least because they are qualitative and because they both add to the work in the field using an IPA these being the first applied to this area and not captured elsewhere. Merleau-Ponty's approach to embodiment is particularly salient to the study of seizure experiences because a person's lived experience is not always what they think it is. Some understandings are split from conscious understanding and one way of reclaiming these is through phenomenology (Wilde 1999).

The case for an IPA of seizure experiences is in chapter 4.2, comparing it to CA followed by the description of the study method and design for this study in chapter 4.3.

4.2 The case for extending the findings of the Bethel project with an IPA of seizure experiences

There are both similarities and differences between CA and IPA and these are important to consider when making the case for extending the work already undertaken with a very different approach.

Similarities in CA and IPA both:

- Have an interest in the phenomenological perspective
- Research about what is of significance to participants
- Allow people to follow their own agenda
- Focus on naturally occurring data. In reality, however, conversations for research are conducted within this context (although ideas for the Bethel phased conversation format were rooted in original naturally occurring, prior 'real time' conversations with patients).
- Record conversation in real time
- Analyses are driven by the data.
- Undertake systematic analyses
- Analyse case by case. CA's main aim is to identify attributes of phenomena across a corpus. On the other hand, IPA's raison d'être is to offer, in depth, individual, multi layered analyses (Smith 1994i). However, as IPA develops as an approach, it is envisioned that as more studies are undertaken in particular areas, the potential for an accumulation of cases, over time, contributing to a larger data corpus could 'develop stronger theoretical statements' (Smith, Flowers et al. 2009)(p205).
- Establish observable patterns inductively
- Are not bound by theory
- Need a context to the analysis
- Pay special attention to deviant cases
- Analyse an interactive collaborative language
- View the patients as 'experts'

The similarities illustrate a similar, shared theoretical base in phenomenology, and a shared focus on patients' concerns as being paramount in that these 'drive' the analysis. Both CA and IPA argue for naturally occurring conversations in 'real time'.

Both CA and IPA analyses are rigorous and systematic, and they are both analysing interactive collaborative language (Friedland and Penn 2003), however, at this point CA and IPA begin to diverge. CA is firmly grounded in how participants orient to each other (Maynard and Heritage 2005), with a focus on *how* people talk rather than *what* they say. IPA, on the other hand is a co-construction between people, its basic premise being that the interpreter is trying to make sense of the participant making sense.

CA is a prescribed way of analysing talk between people and follows certain conventions, identifying inhibitors and facilitators to the exchange of information between them. It takes no account of any other interactions between interviewers and interviewees, it does not infer any thoughts or intentions onto what people say, staying with conversation patterns and sequences (te Molder and Potter 2005). The analyst is working objectively, looking at 'activities' of people in the transcripts, whether spoken or non spoken. These include, turn taking, topic management, repairs, how topics are change, all of this being seen as independent of the cognitions of the participants. The analysis is undertaken using a prescribed, rigorous approach (Drew 1995) which could, in theory, can be replicated by somebody else leading to the same conclusion.

In IPA there is a focus on common meanings, the way in which these are expressed in language and descriptions. IPA is, primarily, interested in people's subjective verbal descriptions of phenomena. IPA goes beyond CA in that it is intersubjective, and the reflexive interpretative process begins during (or even before) an interview conversation. IPA does not reify the text only as CA does, and can reach beyond this (Miczo 2003). It involves thinking about what another person is feeling, or even how the researcher is feeling, thus making the researcher's background and standpoint explicit and an integral part of the interpretation.

CA has its own conventions and rules for transcribing conversations (Drew, 1995)

CA conversations are transcribed and analysed in specific and predefined ways following explicit rules and conventions resulting in an analysis grounded in 'fine detail of speech exchanges'. This analysis is open for examination by others (Holstein and Gubrium 1998)(p145). For the Bethel project, they were then closely examined for issues specifically related to the aims of this project; how people conducted their conversations in terms of how easily and at what point they articulated their concerns, what influenced their ability to convey these, in terms of their conversation style. That is, whether it could be identified that Epilepsy and NES patients differ in terms of communication methods.

The way in which an IPA conversation is transcribed is flexible

IPA acknowledges that a research interview involves real time interpretations by conversation partners. An IPA conversation is inextricably linked to the evolving analysis/interpretation and this makes describing the process of transcription and notation employed complex. However, researchers should attempt to make clear choices they made (and at what point) when engaging with the interview conversation at this level of interpretation (Lapadat and Lindsay 1999). This is because there are methodological, epistemological and theoretical issues associated with the transcription process, which may affect our interpretations and which need addressing. For example, whether this has a prescribed format [71] whether it is verbatim (Kitzinger 2009), whether all false starts, passing comments and other details such as voice levels, lengths of pauses etc are transcribed should be considered (Forbat and Henderson 2005).

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[71] Conversation analysis (CA) have always produced very detailed transcripts Kitzinger, C. (2009). "Conversation Analysis for Psychologists." Qualitative Methods in Psychology Section Newsletter 7(May 2009): 23 - 27.

Although there are no specific guidelines to follow, in IPA a verbatim transcript at least is necessary (Smith and Eatough 2006). Non verbal gestures, tones of voice and pauses can all be noted for later reflection in analysis. Added to transcriptions as the analysis progressed were new thoughts as they occurred that it became a working document for me in terms of inputting evolving thoughts and impressions.

In relation to this comment, the issue of the transparency and 'validity' of an analysis is worth addressing at this point. Although IPA is a creative approach, it can and does aim to make this process clear to others in terms of an 'audit' (Smith, Flowers et al. 2009)(p183). Yardley's ideas about validity consist of four broad principles are favoured in IPA. The analysis should be sensitive to context, there is commitment and rigour, transparency and coherence and the research is important and makes an impact (Yardley 2008). A paper chain of 'evidence' can be made available for others to follow and track the process of the interpretation. Beginning usually with the first raw data of the transcript adding in other relevant tables and documents can help illustrate the process that an interpreter has taken (Smith, Flowers et al. 2009). [72]

Phased conversations are adhered to whereas IPA conversations can be structure free

The CA staged conversation structures were strictly adhered to in the Bethel project, (see box 5, p86) and this contributed to the rigour and validity of the subsequent analysis. An IPA conversation, however, need not be structured, especially in the case of an experienced researcher (Smith, Flowers et al. 2009), because IPA researchers think on their feet and aim to be responsive to participants' concerns. In addition, interviews out of the 'clinic', with someone with a different training background, could elicit details which may not be forthcoming in a time limited clinical encounter (Langfitt 2007).

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[72] An illustration of the processes of interpretation I went through with each individual, across cases and in the CA synthesis are all in the thesis appendices.

The importance of the social context was recognised by the neurologists consulted for this study, and the implications of different locations on the information given from patients;

> 'And does it make a difference and then it's like. I can see differences in people that come to the hospital, when I see them in the hospital and when I see them in the GPs' rooms.' A.M.,(201–203) [73]

Undertaking an interview in a person's own personal space therefore, may result in biographical details being disclosed which, if taken into account, may add to an interpretation of their experiences.

At the heart of IPA is a commitment to cognition

The cognitions of conversation partners is peripheral to CA (te Molder and Potter 2005) [74] whereas IPA sees cognition as one 'aspect of being in the world', and these cognitions are accessed through stories people tell us, the language they use and by our interpretation of these (Smith, Flowers et al. 2009)(p191). It is this major difference between CA and IPA which could make the difference in terms of uncovering new aspects of the phenomena of seizure experiences.

Rather than thinking of cognition in terms of experimental work, IPA 'reworks' the notion of cognition, relating this to language, and exploring it in-depth through conversations with people (Smith 2004). What makes an experience significant for someone involves people engaging in, and taking stock of, issues in their lives which affect them. An IPA interview will tap into these and potentially, trigger further reflections by a participant, followed by the double hermeneutic of the researcher making sense of them making sense of all of this. An IPA, for example, will consider people's cognitions in terms of how they interpret causes and consequences of symptoms of illnesses (Deary and Chalder

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[73] Please see document C in the thesis appendices
[74] Although there is the question of how an analysis of a conversation can be undertaken without 'recourse to cognitive notions?' (p4). te Molder, H. and Potter, J. (2005). Conversation and Cognition. Cambridge, CUP.

2006), factors which have implications for diagnosing and treating people with NES (Reuber 2008i).

Subjective experiences are beginning to be recognised as being as important to consider along with their related, cognitive processes. People with epilepsy, for example, can be triggered to remember what precedes their seizures by informing them of their non verbal metaphoric gestures. Often data from neuro imaging are not enough in themselves, requiring verbal descriptions of *how* they were experienced in order for them to be interpreted fully (Petitmengin 2006).

Summing up the case

First person descriptions of seizure experiences are not common, those of epilepsy are present in various publications, (Schachter 1993; Schachter 1995; Schachter, Montouris et al. 1996) (Schacter and Andermann) forthcoming. Others, including those of NES, are on the internet for people to study [75] (Herxheimer, McPherson et al. 2000). However, these are not collated for the purpose of facilitating differential diagnosis and have not been addressed by research.

Levels of awareness during seizures is something already identified in the CA work as worthy of further study, and onto which IPA could also shed additional light. Two existing studies have already used qualitative methodologies to 'discover' previously unavailable information about seizure experiences and consciousness (Johanson, Revonsuo et al. 2003; Johanson, Valli et al. 2008).

It is recognised that qualitative in-depth interviews generate rich data which can help doctors reach a deeper understanding of the complex social and

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[75] The Health Experiences Research Group (formerly the DIPEx project) is an electronic data base of first hand patient narratives about various conditions including epilepsy. Interviewees cover a range of ages, social class, stage of illness and specific conditions including rare ones. These are divided into areas such as living with the condition, reactions of others etc. Each condition has audio and visual links to interviews offering support and information to both patients and clinicians. www.healthtalkonline.org and www.youthhealthtalk.org

behavioural issues which affect people's health (Reeves, Lewin et al. 2006). Rich descriptions from patients about their seizure experiences could be useful for newly diagnosed patients to be aware of, as well as giving more information about the biological mechanisms of the epilepsy and the effectiveness of medication (Johanson, Revonsuo et al. 2003). In addition to the knowledge we already have about NES for example, an IPA could begin to explore the familial, social and environmental backgrounds of people with this condition (Phibbs 2006).

The additional perspective of an in-depth IPA of seizure experiences will extend both the Bethel work and the medical work in terms of how they are conceptualised. It will also help realise the aims of this study, which are to explore subjective seizure experiences and to inform practice being of use through, potentially, adding to an emerging seizure discourse. Thus IPA will not only offer a new vista to explore (Öhlen 2003), that of phenomenological accounts of people's seizure experiences, but has the potential to move forward 'scientific' knowledge about seizures.

Interesting outcomes for this study, as it was for the CA work, could be methodological ones in that first, it is extending the boundaries of IPA, an evolving qualitative analytic approach by adding in to the interpretation, art work and poetry [76] as an integral part of this interpretation. Second, a shift in approach to the 'pure' method of IPA similar to that which occurred with the CA work may be also appropriate for IPA.

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[76] Although these methods are beginning to be discussed between other IPA researchers.

4.3 Study methods and design

Rationale for method

The scientific and philosphical underpinnings of IPA described in chapter 4 support the method used in this thesis. The theoretical elements of this and their place in the hermeneutic process (Watson and Girard 2004) are also explained in the previous chapter. This study used IPA, poetic interpretations and some interpretations of drawings by participants. Although these could be considered jointly authored between the researcher and participants, the researcher took responsibility for the final accounts. Pseudonyms were used in the analyses.

Aims of study

- To explore subjective seizure experiences
- To inform practice, by adding to an emerging seizure discourse, and informing explanatory material for people experiencing seizures.

Figure 1.

Representation of the study design
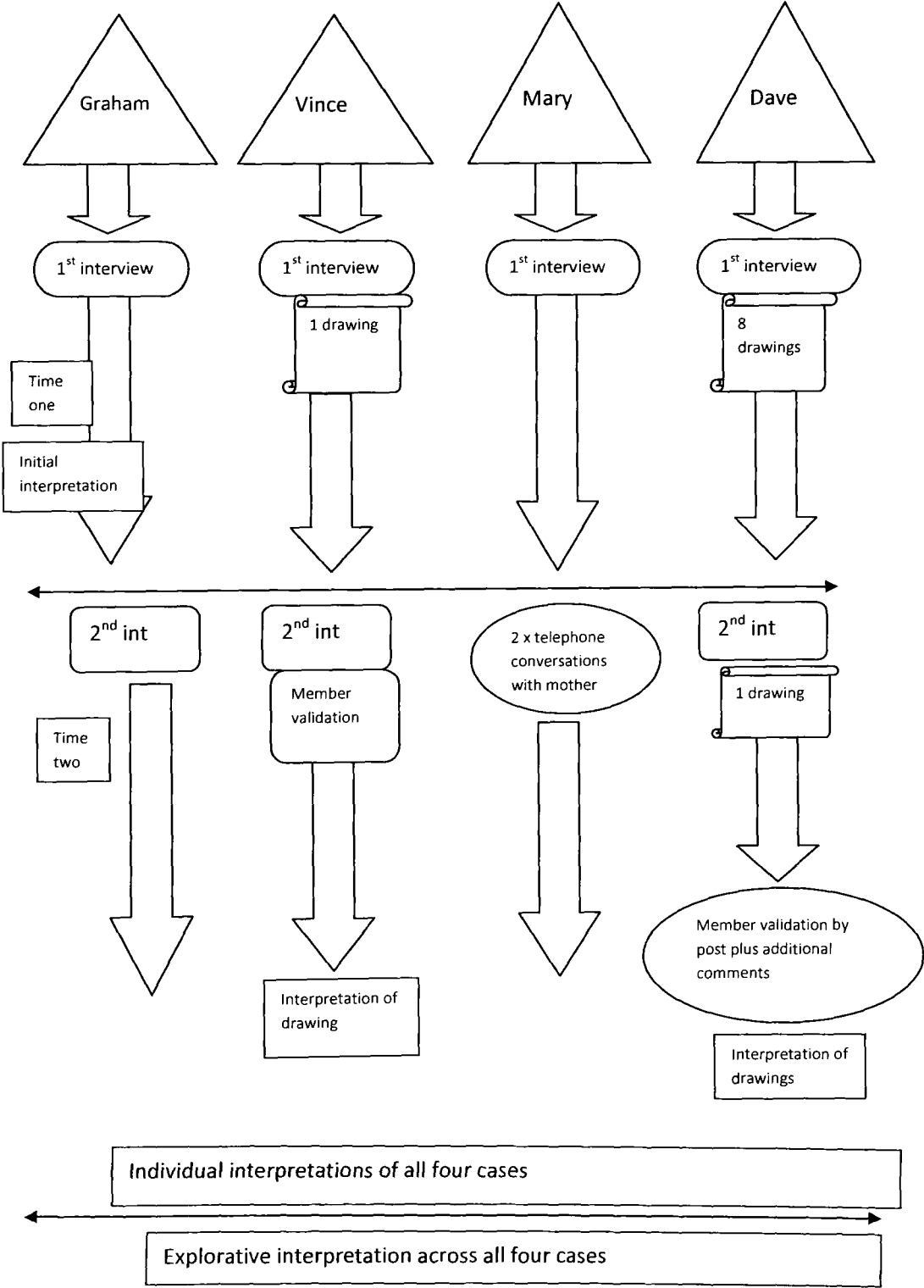
The study had Ethics & Governance approval from Hull & East Yorkshire Hospitals NHS Trust and was supported by A.M., [77]. The study and method was presented to practitioners in the neurology department in Hull making clear to them that the study was not about searching for a diagnostic 'test' for epilepsy, but was essentially about gathering detailed experiences of seizures, potentially highlighting distinctive features or useful pointers which could add to an awareness of, and acknowledge any patterns present in patients' seizure experiences.

This chapter will outline how the study was undertaken again weaving some aspects of debates and dialogues from the real time, on-line IPA discussion group. [78]

<u>Issues of participant numbers in IPA</u>

'PS...I'm usually full after 6 – but I love n=1 – I think it's difficult but when people do it – I salute them'. (M.O.,) [79]

It is proposed that four participants being interviewed once, three of them being interviewed a second time, telephone conversations with the mother of one participant, e-mail communications with A.M., with additional written and pictorial data from participants added to the 'the richness of local experience' (Andermann 2000)(p172), and constituted a sufficient corpus of data.

Recruiting more participants was considered. However n = 4 was arrived at for the following reasons;

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[77] Consultant lead neurologist at Hull Royal Infirmary Hull Hospitals NHS Trust.
[78] ipanalysis@yahoogroups.com All on-line communications appearing here are cited with the permission of each author.
[79] ipanalysis@yahoogroups.com [ipanalysis@yahoogroups.com] On Behalf Of Osborn, Mike [mike.osborn@ruh-bath.swest.nhs.uk]
12 December 2008

a) Small numbers are usual in IPA studies (Smith, Flowers et al. 2009) given that the purpose of IPA is to offer in-depth, individual, multi layered analyses (Smith 1994i).

b) N = 4 was therefore, considered sufficient given the newness of this approach to seizure experiences. This study aimed to explore in depth individuals' seizure experiences. The number of participants needed to be small enough to achieve a saturation of themes within each individual case.

c) Previous CA research (on which this study builds) began with observations of single patients. Subsequent studies also had small numbers, which accumulated over a decade to a total of around 100, theory being developed incrementally.

This study does not claim that any superordinate or subordinate themes identified pertain to this patient group *as a whole*. What distinguishes IPA from many other qualitative methods, especially grounded theory, is that it does not claim to reach a point at which all potential themes are identified i.e., to reach 'saturation' through a process of constant comparison in order to reach a theory grounded in the data (Bowen, 2008). Rather, of paramount importance in IPA are the uniqueness of individuals and their concerns, interests, etc at the moment the researcher talks to them. This results in 'base line' high quality in-depth, skilled analyses and interpretations of small samples.

However, as an IPA develops and as, potentially, more studies are undertaken in an area (as in the CA research), the potential for an *accumulation* of cases, over time, contributing to a larger data corpus could 'develop stronger theoretical statements' (Smith, Flowers et al. 2009)(p205).

Critique of participant selection

Jusification of selection of study participants

In IPA the chief criterion for sampling is that participants are experiencing the same sort of phenomena, in this case, seizures. If participants for example, had been depressed or anxious about these experiences this would have been reflected in their interviews given that depression and anxiety are common in people with seizures (Kanner, 2003).

Impact of n = 4 on findings

IPA study findings are drawn from small numbers of participants, some longitudinal studies reaching theoretical conclusions. Findings in IPA are individual, personal and idiosyncratic. They cannot be generalised yet have a positive impact in that they can be translated into concrete, practical ideas as heuristics, concepts or principles can be offered for practice or for further research (see conclusion below). They can also be seen as the beginnings of a larger corpus of data

Design of study

Thus study was an 'extensive idiographic design' whereby all participants were experiencing one or more common property of a condition, that is, they were all experiencing seizures, all newly referred patients at an epilepsy clinic, and their seizure diagnosis was in question. This was chosen over an intensive design and one which focuses on one particular individual and constructs extensions which are integral to the phenomenon (Smith, Harré et al. 1995).

Recruitment process

Around 1500 people are newly referred to the Hull neurology clinic each year - an average of 28 per week. Neurologists were asked to recruit at two points, six months apart. The neurologist wanted to recruit participants in the clinic himself. This is considered an acceptable way for participants to be referred into a project (Smith, 2009)(p48).

A.M., and his medical colleagues invited newly referred patients attending the
neurology clinic in Hull, who had a definite query on their diagnosis, to take
part in the study. Patients in the acute admissions setting were also approached
as were private patients. Registrars working with both of these specialists also
discussed potential new patients with A.M., for approval to request participation
from them. A.M., confirmed that the four participants in this study were
representative of the spectrum of patients seen on a daily basis.

Participants

Patients chosen for inclusion were:

Newly referred patients without a definite diagnosis - but not 'new' patients who
had been referred on from other hospitals for other reasons, for example, for a
second opinion.

These criteria were discussed with, and confirmed by the neurologist supporting
this study. The status of being a new patient was important because they would
be unfamiliar with technical terms and language used for seizures (although one
participant had a son who was a patient in the clinic already), and it ensured
that there was no firm diagnosis at the first interview. This is also especially
important because people with a definite diagnosis of NES can be in confused or
aggressive states (personal communication A.M.,), which could affect the
interview process.

Patients were not screened/assessed for current anxiety and/or depression
because the stance in IPA is that the researcher should go into an interview with
as few influences and preconceptions as possible about participants. Exclusion
or inclusion on these grounds was therefore unnecessary. [80]

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[80] A further discussion of how depression as distress would arguably affect the descriptions of
the lived experience of seizures is on page 357.

Patients excluded were:

Those who were not considered appropriate, for example, Medico-legal cases and patients with heart disease. These patients were excluded on the grounds that they are not confined to neurology clinic attendance, their seizures being a secondary concern and explainable by their heart condition.

Ethics Patient Information Leaflets [81] with a personal letter from the researcher were left at the clinic along with an 'expression of interest' form for patients to return to her. Around 15 initial PIL's were given out overall by the supporting neurologist: four people returned the expression of interest form to the researcher. The researcher then contacted these patients to arrange to discuss the study in more detail, gain formal consent and an interview. They all agreed to take part including the possibility of a second interview and to contribute further if it was deemed appropriate.

Homogeneity

Given the aim of this study and that IPA aims to interpret how people make sense of a common experience, this was a homogenous sample in terms of people having the same experiences – those of seizures and linked to the study design above – albeit very individual ones. That is, participants' diagnoses were unclear, they could have had epilepsy or NES or a combination of both. Neither patients nor the researcher knew of their diagnosis [82] – their subjective realities being the most important things to focus on (Osborn and Smith 1998).

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[81] Please see document A (Patient Information Sheet) in the thesis appendices.
[82] However, at one first interview the participant said he had been told that he had epilepsy.

Demographics of participants

Participant 2. Vince	Participant 1. Graham	Participant 3. Mary	Participant 4. Dave
Number of interviews: 2	Number of interviews: 2	Number of interviews: 1	Number of interviews: 2
Age: Early 60's	Age: 51	Age: 31	Age: Approximately mid 40's
Married and living with his wife	Caring for terminally ill wife, and son with autism	Unmarried, living with two children. Her parents residing with herat the time of interview	Single and lived alone

Procedure

The interviews were unstructured and not time limited. An interview schedule is helpful in IPA for novice researchers as this can help them remember issues they are interested in. However, if an interviewer has more experience, unstructured interviews can allow unexpected and unanticipated findings to emerge (Smith, Flowers et al. 2009). Not having an interview schedule to consult ensures that a researcher is fully immersed in the talk of a participant and they can respond to a participant's concerns probing relevant areas in real time (Smith, Flowers et al. 2009).

Each interview began with the researcher saying, 'I just really want you to tell me your story'. How the interview evolved after this depended on how a participant replied to this opening and ensured that;

a) participants defined the issues important to them without being influenced by the researcher's prior assumptions

b) it maintained the potential of IPA to identifyand explore unexpected topics

c) this 'implements IPA's inductive epistemology to its fullest extent' (Smith, Flowers et al. 2009)(p70).

Four people newly experiencing seizures were interviewed once, and three of these a second time approximately 18 months later,in order to gain a temporal view of their experiences, using an unstructured conversational type interviewing style. They had originally formally consented to being contacted a second time, and the subsequent interpretation was a dovetailing of further meetings and communications, and of any other information they offered, notating from which interview/communication an interpretation arose (Flowers 2008).

It is justified in hermeneutic interpretative phenomenological research to see participants more than once (Flowers 2008). The rationale for this included; that the nature of their experience could change, for example by medication, cessation of the seizures, or because participants would no longer be completely naive to the language and terminology used in neurology. A second meeting also allowed participants to complete their stories if necessary and to provide a degree of closure for them (Orbach 1997) being the end of their formal contribution to the research.

Incorporated into the second interview was an additional, tentative element given the initial analysis and subsequent reading on the topic (see below, section on The Ictal Consciousness Inventory (Cavanna, Mula et al. 2008).

The very nature of qualitative research and that participants can incorporate life stories as they recount their experiences (Good and Good 1994; Flowers 2008) means that interview conversations were lengthy, digressed and included other family members (Good and Good 1994). For one participant in this study, his wife was present at both interviews [83] and the mother of another was invited into the interview by the participant[84]. Participants not only talked about seizures but, to a greater or lesser extent, their general life stories too. However,

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[83] Which added to the length of the interview somewhat but also allowed my participant to consider and complete a drawing for me (see 'Vince').
[84] Which added in much value to this interpretation (see 'Mary')

these were 'data', and the value of this more than justified interview length and digressions.

Recording of interviews

Two small audio recorders were set up, both recorders being kept running until the researcher was leaving the house or the participant was leaving the premises. This is important as people can often say important things when the tape is turned off which could be missed otherwise, and using two recorders served to mitigate against technical disasters. [85]

Interview conversations: the personal position of the researcher and practicalities

People talked in the context of a research interview with a chartered health psychologist grounded in that discipline. Whilst not a medical clinician this context was kept in sight and the interview location was the choice of the participants'. The researcher was working from a realist perspective in that a personal interpretation into the lives of their participants was acknowledged as being present as was some theoretical knowledge of the field. The researcher viewed the participants as being experts in their seizure experiences and was interested in the cognitive processes they went through over a period of time. She aimed to be empathic and to respond to the issues and concerns of participants as they arose in real time. She was trained in counselling skills and had immersed herself in the phenomenological literature in order to be able to practice this approach whilst with participants. Entering the life worlds' of participants' and attempting to adopt a phenomenological attitude (Finlay 2008) was a prerequisite to capturing the meanings of their subjective

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[85] Video taping interviews has long been advocated for qualitative research but I am not sure how appropriate this is for IPA, possibly this could encroach upon the intimacy necessary for such an approach. Holstein, J. A. and J. Gubrium, F (1998). Phenomenology, Ethnomethodology and Interpretative Practice. Strategies of Qualitative Inquiry. N. K. Denzin and Y. S. Lincoln. London, Sage.

experiences, and in order to interpret these in the context of their lives from this 'third-person data' (Smith, Flowers et al. 2009)(p33). Interpretation began as she talked to participants.

Participants were were given the opportunity to tell their story and, to a great extent, controlled how and what was told, and therefore its subsequent interpretation (Kirmayer 2000). They told their stories on their own 'terms' and in their own idiosyncratic ways (Haggman-Laitila 1999)(p15). They decided the focus of the interview at all points even though, as mentioned above, this sometimes meant long digressions in order for their phenomenological world to emerge, via the language they themselves used to attribute meanings to this (Smith, Harre et al. 1995). Interview techniques appropriate for IPA were deployed (Smith, Flowers et al. 2009). Three participants offered their story as 'lived' at two points in time (Kirmayer 2000)(p156).

Each interview was begun afresh (Smith, Jarman et al. 1999) participants were so different this was the only way to proceed. Two participants also drew their experiences, one completing a whole series of nine drawings. These were incorporated into the interpretation even though they were unexpected (Willig. 2001) as was a pre-written description of the experiences of one participant.

Process of transcription

The interviews were transcribed verbatim being listened to many times over and corrected or added to as previous words not discerned were added in. The transcription process developed as the interpretation progressed. For example, phrases, words, ideas that appeared interesting, important, contradictory or unusual were emboldened. Parts of texts which were relevant to an aspect of the interpretation, such as the poetic interpretations, or where participants were generally chatting or it was otherwise not relevant were shaded.

Process of interpretation

Transcripts were repeatedly read and listened to (Smith and Eatough 2006), to ensure a thorough knowledge of them, and a 'richer' interpretation (Smith, Jarman et al. 1999)(p227). Each interpretation of the data began after the first interview, and was completed after the second interview.

To ensure plenty of space for notation, transcripts were copied onto A3 sheets leaving room at either side of the transcript for written notes about first thoughts, interesting or significant comments people made. Later, when looking through them, words and phrases with future themes in mind were highlighted.

Initial theme ideas were listed from the work above, using comments, participants' phrases and my own ideas. These were examined again in the context of the interview and grouped into main and sub themes with extracts pertaining to these beside each one. Tables were constructed in order to connect them together further and to check that the concepts in superordinate and subordinate themes were upheld by what participants had said. Particular extracts pertaining to all theme ideas were identified and noted.

Further into the individual interpretations, for the poetic component, clusters of descriptions, unusual words and phrases were highlighted and the original words making up the poem saved separately for working on, so that an eventual comparison with the final poetic interpretation was available for the purposes of illuminating how this form of interpretation was developed. Original notations follow on from chapter 5.6 as an 'audit' of this process.

The 'doing' of IPA is a personal, creative and iterative process (Crist and Tanner 2003), and as such is difficult to describe. However, for the purposes of audit and validity, (Smith, Flowers et al. 2009), 'raw data' including notated

transcripts and other 'workings' pertaining to this process are in the thesis appendices for each individual participant.

Material for interpretation

This study had four participants all interviewed in depth once. Three of these participants were interviewed again for a temporal insight into their experiences. The total conversation time available for interpretation was nearly 7 hours of transcribed material. The second interviews incorporated items from a 20 item inventory relating to levels of consciousness in epilepsy (an explanation and description of this is below).

Where clarification of issues raised in the second interview were required two participants were contacted on the telephone and another was written to. One participant ('Mary') was not available for a second interview, and there was no response to two letters, which included pre paid reply envelopes back to the researcher. However, her mother spoke to the researcher on the telephone twice about events since her first interview and these conversations were useful in helping me make more sense of the first interview. The researcher also spoke with the neurologist about her.

Member validation

An element of 'formal member validation' was undertaken by asking two participants, if they agreed with a *fragment* of their interpretation. That is, they were given 'poetic interpretations' (that is, their own words but 'shaped' by the researcher, to give more evocation of meaning) of what they had said to consider. They confirmed to the researcher that they were accurate depictions of their experiences.

The Ictal consciousness inventory (Cavanna, Mula et al. 2008)

Following the first interview and from further reading of the literature, the issue of levels of awareness and consciousness during seizures had become salient and it was considered that descriptions of these were important to notate in case it offered any hints towards a differential diagnosis. Thus although the second interview conversation was still unstructured, items from a recently validated, self report scale for people with epilepsy were included where appropriate, that is, specific questions were asked about consciousness.

This particular inventory was originally designed to attempt a distinction between simple and complex partial seizures, examining both levels and contents of consciousness over every seizure a person had experienced, based in turn on the assumption that levels and contents of consciousness mirror different neural functions. It has not been used with NES however (Cavanna, Mula et al. 2008). Asking these questions in the context of IPA was not intended to try and attempt a diagnosis, it was used simply to gather a general picture about possible differences in my participants' experiences of consciousness which *may* relate to aspects of epilepsy and NES in view of the evidence thus far.

Contents of the inventory

Briefly, the inventory assesses *levels* of consciousness and reflective consciousness by asking patients about their; 'general awareness of time, place and other people's presence; understanding of other people's words; verbal and non verbal responsiveness; gaze control; forced attention; and voluntary initiative' (Cavanna, Mula et al. 2008)(p185). Respondents have a choice of three levels of reply to a total of 20 questions which are scored: 0= no, 1 = yes, a bit (yes, vaguely), 2 = yes, much.

Questions about the *contents* of people's consciousness and subjective experiences included whether they experienced; dreamy states, derealisation symtoms (including time and space), feeling of the presence of an absent person, illusions, hallucinations jéjà vu/vêcu, unpleasant and pleasant ictal emotions (Cavanna, Mula et al. 2008)(p185).

Interpretation of art work

One thing of interest identified in the literature search for the exploratory study (Featherstone 2004) was work on drawings done by people with epilepsy and the diagnostic potential of these. Drawing materials (coloured felt tip pens and pencils) were taken to the interviews should participants find verbalising their experiences difficult or if the conversation should falter, and with a view to designing an information leaflet for seizure patients. When participants were asked if they wanted to draw their experiences, two participants did so, the other two declined. One did a single figure, a second a series of eight drawings in the first interview and a single drawing in his second interview, all of which are reproduced in their individual interpretations.

It is considered that all of the above resulted in a saturation of themes within each individual case. Supervisors also examined each case in order to ascertain triangulation.

Interpreting across cases

IPA reifies the individual, therefore each participant was initially intepreted completely independently. In addition to the usual IPA notation of transcripts, a tentative look across cases was taken for the purposes of indentifying anything that may contribute towards a seizure discourse for either condition. Language and terms used to describe seizure experiences were noted for each participant, with the number of times they were used, general and seizure specific themes, as were modes of telling, such as reiterating comments, descriptions of feelings,

contradictions, the use of metaphor and metaphoric predication, illness beliefs and trajectories of interview conversations

These details were transferred into separate documents for a comparison of themes across the four participants (see chapter 5.7). All 'workings' are in the thesis appendices in the folder entitled 'Across case interpretation'.

Use of research findings

Patient information leaflet

Plans were made to engage with participants throughout the project, and to communicate some level of the interpretation to them with the possibility of including elements of their contribution in the form of drawings, poems and salient phrases in the booklet.

The idea of a booklet was fledgling and to draft one which contains descriptions of experiences of different seizure types with a clinical commentry designed for all those involved in seizure care. Participants in the study may be asked to comment on the contents of this draft which will, potentially, help people to recognise the diversity of this condition, and help people with epilepsy and/or NES and their families and carers to share their experiences. A draft of this leaflet is in chapter 6.

Screening Tool

A further fledgling idea is that of a screening tool. That is, should particularly salient concepts arise which are specifically related to either epilepsy or non-epileptic attack disorder, these could be incorporated into the design of a brief interview screening tool to use with newly referred patients. This could then address initial core questions for health care professionals, before moving onto more detailed probing - as is in the recommendation for patients with

depression, who are asked two initial questions, the answers to which both give an indication of the level of their depression (Whooley. 1993). A draft screening tool is in chapter 6.

5 Interpretations: Foreword

'I just really want you to tell me your story, just sit back and if you look at this sort of sponge that I brought. I mean I know bits about seizures but I don't know about you, so you can fill this sponge with all your, things about you. Pretend that's me!' V.F., [86]

IPA as an approach and method is one which is mindful of a person's individuality, life history, and personal position. IPA is well-suited to the phenomenology of seizure experiences, this being under researched and an unusual experience (Brocki and Wearden 2006)(p89). Using IPA and not interview schedule allowed the researcher to 'stray from the beaten path' and follow up unexpected landmarks or interesting features on the way (Smith, Flowers et al. 2009)(p41). This includes the poetic interpretations and interpretations of drawings by participants.

As said above, unstructured interviews can allow unexpected and unanticipated findings to emerge (Smith, Flowers et al. 2009). Not having a strict interview schedule sat well with this project, because of the lack of knowledge about the subjective experiences of seizures, and because the researcher had some years experience as a qualitative researcher (Smith, Flowers et al. 2009). In the event participants turned out to be so diverse in their experiences that this approach was more than justified, allowing the researcher to 'attempt to implement IPA's inductive epistemology to its fullest extent' (Smith, Flowers et al. 2009)(p70). Given the researcher's prior knowledge of the area, the concept of bracketing encouraged her to distance herself from what has already been deemed

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[86] This was the opening for the interview participants. That is, I knew something of the theoretical issues surrounding the difficulties in diagnosing NES and epilepsy in neurology and had experienced some descriptions of *epileptic* seizures from participants in an earlier, exploratory study. However, this had been about *living* with epilepsy and was not specifically about seizures experiences and descriptions. I had no experience of NES however before undertaking this study. Featherstone, V. A. (2004). What is it like to live with epilepsy? An exploratory phenomenological study. Psychology. London, City University. **Master of Science (Health Psychology).**

significant thus far on the topic, 'forget' this for a time and to, 'go with the flow' of the interview (Smith, Flowers et al. 2009)(p77) not making any make assumptions about what may emerge from interviews in terms of what would be important to participants, or impose potential models or theories onto the data.

The very nature of qualitative research is that participants can incorporate life stories as they recount their experiences (Good and Good 1994; Flowers 2008). This means that interview conversations are lengthy, can digress and include other family members (Good and Good 1994). As mentioned above, for one participant in this study, his wife being present at both interviews added to the length of them somewhat but also allowed him to consider how to complete a drawing (Vince). Mary's mother being present in a significant proportion of the interview greatly added to her interpretation given that the researcher only had the chance to see her once.

Four interpretations of seizure experiences are presented below. These are detailed, nuanced analyses of particular 'cases of actual life' - the task of an IPA (Smith, Flowers et al. 2009). Participants were all patients newly referred and at the beginning of coming to terms with what was happening to them. It was considered that at the first interviews, my participants' were at an acute stage in their lives. At the second ones participants were at a more chronic phase and where more coherent narratives were emerging (Kirmayer 2000)(p171).

Seeing three participants twice, allowed a follow up of participants' experiences, an opportunity to fill in any perceived gaps in their stories, reinforced things participants had already said and offered some possible answers to some of the mysteries in their tales. Interpreting them individually, in depth and not in relation to each other, allowed an exploration of individual experiences whilst drawing on the researcher's existing knowledge of the topic, alternative theoretical perspectives and frameworks, and connecting them to psychological literature (Smith, Flowers et al. 2009). Both interviews were analysed and presented as single analytic chapters.

Contextual data and/or additional interpretations

Writing up phenomenological research does not lend itself to conventional forms of presentation (Landridge 2007) and the interpretations of the four participants are all different. Poetic interpretations which were constructed from two participants' interviews are in Chapter 5.6, and some art work was also explored, Dave's interpretation being focussed on his series of nine drawings, and Vince's one drawing being a section of his interpretation. The interpretation of these drawings does not purport to be an analysis of artwork or even an exploration into whether they can indicate epilepsy or NES but add immeasurably to interpretations. [87] Each interpretation is preceded by a 'mini biography' (Landridge 2007)(p90), in order to orient the reader to each participant's world.

Interviews took on their own dynamics and the researcher responded to issues as they arose in real time. The interpretations are each presented in a way which is appropriate for each participant; Graham's (G) being presented in terms of a metaphor analysis, Vince's (V) is based on a theoretical model which examines how people integrate a new self following illness, Mary's (M) is very much about the illness representations of her and her mother, and 'questioning' hermeneutics (Smith, Flowers et al. 2009), and Dave's (D), is based around a series of nine drawings he did.

Short data sections are notated at the end with the initials of the speaker, e.g. D:(with line numbers or ranges of line numbers) and which interview these are from (1) or, (2). Longer sections with more than one person speaking have this notation at the end of each section, e.g., (line number) (interview number). One PhD supervisor, P.C., was present at the second interview of Dave and any data sections including him are notated thus.

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[87] However, it has been argued that there is the potential for such an endeavour, and there are art scales available by which this can be done. Gantt, 1998, in Stafstrom, C. E. (2005). "Using artwork to better understand patients with neurologic disorders." Epilepsy & Behavior 6(2): 113 -114.

Patient information booklet

There is a significant lack of patient information for people with NES, given that plenty of information exists for other neurological conditions such as Multiple Sclerosis and Parkinsons disease, other rare conditions and other psychiatric conditions including OCD, phobias, PTSD and schizophrenia (Benbadis 1997). A recently formulated one has been well received by patients. [88] However, some ideas for a leaflet have been added and which could offer patients something different in the way of information about seizure experiences (see chapter 6).

Interpretation across cases

IPA is committed to detailing particular phenomena in a particular context (Smith, Flowers et al. 2009), being concerned with the diversity and texture in human experience Spinelli (1989) in (Willig. 2001). However, whilst undertaking individual interpretations, attributes of conversations thought to be of interest when looking across cases were notated in independent, working documents. This was by way of bracketing them out in order to reduce 'noise' from these, (Smith, Flowers et al. 2009), whilst still working on the individual interpretations. These documents formed the basis for chapter 5.7 (Smith, Flowers et al. 2009)(p38).

There are concerns about doing this because IPA is not about testing hypotheses and could fundamentally alter the IPA focus from the idiographic to the general. However, in view of the aims of the thesis this was justified as an exploratory exercise.

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[88] http://www.shef.ac.uk/content/1/c6/08/82/45/NEST%20Patient%20Booklet.pdf

Research Audit

Rather than being a set of rules to follow, 'method' in phenomenological research is a guide to practice and a creative process which does not hinder ways in which to understand phenomena, (Landridge 2007). However, in order to illustrate 'inner workings' as the analysis was being undertaken, both individual and across cases, relevant documents are included in the thesis appendices, and follow IPA guidelines on offering these to readers (Smith, Flowers et al. 2009).

What follows is an interpretation of the four cases. Chapter 5.1 will offer a justification for using artwork in an interpretation, chapters 5.2 to 5.5 will offer the individual interpretations of Dave, Vince, Graham and Mary respectively. Two participants received poetic interpretations of fragments of their interviews, allowing them to validate some of the interpretations. Chapter 5.6 is a poetic interpretation of Dave and Vince. Chapter 5.7 offers an interpretation of superordinate and subordinate themes occurring across and between cases (Smith, Flowers et al. 2009).

5.1 Sparks of creativity: the potential of using art work in IPA

'The way in which we live feelings and experiences are not always available to verbal description.' (Gillies, Harden et al. 2005)(p201)

Studies using artwork as a way of describing experiences include the experience of being diagnosed with, and being treated for, breast cancer (Bell 2006) and of aging (Gillies, Harden et al. 2005). One rationale for using art work for in this study was based on a comment by Willig that language constructs reality rather than describes a particular version of an experience, and therefore, art work, being non verbal, may transcend this and give additional insights into a topic (Willig. 2001). In their study this was not found to be the case however. Paintings done by them as academic researchers in a study on aging, when interpreted only served to confirm that meanings were still communicated through already existing language based categories (Gillies, Harden et al. 2005). In the case of seizures which can be 'bizarre' experiences (Johanson, Valli et al. 2008) the drawings of Vince and Dave were used as an aid to verbalising their experiences, and left permanent traces of what these experiences had meant to them at that 'moment'.

In terms of this study chapter and its antecedents, previous empirical neurologically related studies herald the beginnings of differential diagnoses of seizures though an assessment of art work, in children (Kozma 1978; Stafstrom and Havlena 2003), and more recently in adults (Anschel, Dolce et al. 2005). Drawing with children is one way of engaging with them (van Manen 1998) and children with epilepsy have been found to draw pictures relating to their own type of epilepsy, for example, tonic clonic (showing them shaking) or absence epilepsy (staring) as well as illustrating psychological attributes such as feelings of depression (Stafstrom 2005). Children's' depictions of their headaches can show differentiation between migraine and non migraine which can be observed by blinded assessors (Stafstrom 2005). Also related to migraine, drawings which illustrated features of migraine, such as pounding pain and visual

disturbances, have correctly predicted a diagnosis of migraine in 90% of cases when a clinical diagnosis, and those by an art therapist of 20 years experience were made separately (Strafstrom, Rostasy et al. 2002). [89]

Art work from people with seizures has been classified into themes which could further an understanding of 'underlying neurophysiological bases of ictal, postictal and interical experiences'(Schachter 2009)(p14). These are; seizure experiences, psychiatric morbidity, and the psychosocial aspects of the condition. People with simple partial seizures have depicted visually symptoms which reflect the 'primary manifestation' of their experiences. Such symptoms not apparent to others can mirror the 'anatomic localisation of the seizure focus and/or the network activated by the seizure and, as such offer a window into brain-behaviour relationships and neuroethology' (Schachter 2009)(p13). Others such as those with cognitive simple partial seizures can draw images depicting out-of-body experiences. Postical states, not well understood and which can involve feeling a loss of contact with reality and visual perceptual distortions have been drawn by people. The process of regaining consciousness has also been represented as has anxiety and depression. There is the potential to further interpret these visual representations of people experiencing seizures into 'testable hypotheses' (Schachter 2009)(p14). The section below will describe some empirical studies which have used art work of people with epilepsy, NES and migraine.

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[89] A study was identified which explored whether Rheumatoid Arthritis(RA) draw their pain differently to people with Rheumatoid Arthritis/Fibromyalgia Syndrome (RAFM)? However, this is as yet unpublished. Kirkham, M., A. (2007). Do people with Rheumatoid Arthritis(RA) draw their pain differently to people with Rheumatoid Arthritis/Fibromyalgia Syndrome (RAFM)? , School of Sport, Health and Exercise Sciences, George Building, Bangor, Gwynedd, LL57 2PZ

Insights from empirical, neurological studies using art work with adults and children.

1   Stafstrom, C. E. and Havlena, J. (2003). "Seizure drawings: Insight into the self-image of children with epilepsy." <u>Epilepsy & Behavior</u> 4(1): 43 - 56.

A study with 105 children, who were being assessed for their self image for psychological assessment were asked them to draw what it is like to have an epileptic seizure. These drawings highlighted some attributes which were not always identified in other clinical encounters. Pointers were also found for seizure types, which were assessed after dividing the children into epilepsy type or syndrome groups and after being discussed with art therapists and neurologists after they had added their own comments about the drawings post hoc. Although there were not enough drawings to use as diagnostic tools, some attributes correlated with seizure types; those with generalised tonic clonic, complex partial showed a helping figure in the picture depicting helplessness, those with Benign Roland Epilepsy reflected a 'poor body schema' (p54), fear of losing control, and drooling - an embarrassing aspect in this syndrome. Ninety percent of drawings illustrating absence seizures depicted staring and abnormal eye movements, whilst those with complex partial seizures showed auditory symptoms, speech problems, nausea, vomiting and urinary incontinence.

2   Anschel, D. J., Dolce, S., Schwartzman, A. and Fisher, R. S. (2005). "A blinded pilot study of artwork in a comprehensive epilepsy center population." <u>Epilepsy & Behavior</u> 6(2): 196 - 202.

A blinded pilot study which examined drawings by people with epileptic seizures and NES was the first of its kind and attempted to differentiate between the types of epileptic seizures and NES using three drawing tests. Art therapists assessing the work were not aware of people's diagnoses (which had been determined using VEEG monitoring) and used a formal scale to assess

drawings. The Formal Elements Art Therapy Scale (FEATS) being used to assess the tasks. [90]

The most significant difference in a structured task was line quality, which differed in people with epileptic seizures, theirs being sometimes erratic, out of control, not always continuous and including the drawing of wavy lines depicting seizure activity – all of which could mirror neurological damage, or could be due to other factors such as the effects of medication.

Free drawing showed only one association; in people with complex partial seizures with a temporal focus, their drawings, although detailed, lacked a cohesive wholeness. [91]

The main difference between epileptic seizures and NES however, was highlighted in a task in which they were given an outline of a male or female figure and asked to express how the seizures made them feel. If more than 10 colours were used this was a positive predictive value for having NES - as was the addition of dramatic designs around the outlines and increased use of colours.

3   Kozma, K. (1978). "Les phénomènes graphiques dans les dessins d'enfants épileptique." (Graphic phenomena in the drawings of children epileptic) Confinia Psychiatrica 21: 105 - 111. [92]

Drawings from more than 300 children were studied. It was found that that these drawings sometimes predicted seizure type and indicated the lateralisation of the seizure focus. Structuring, spatial activity and directional

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[90] Gantt, L & Tabone, C (1998). Formal Elements Art Therapy Scale: The rating manual. Morgantown, WV: Gargoyle Press.

[91] This paucity of integration is also the case in people with schizophrenia, whose drawings also lack detail. Gantt & Tabone, (1988) in Anschel, D., J, S. Dolce, et al. (2005). "A blinded pilot study of artwork in a comprehensive epilepsy center population." Epilepsy & Behavior 6(2): 196 - 202.

[92] This paper was translated by my daughter Heather, thank you.

control were better if the lesion was on the left hand side, those with a right hand side lesion had difficulty executing tasks, and in tasks which required sequential skills.

Those with focal seizures executed neat line drawings with a light pressure which became stronger just before a seizure. They also drew shapes without connections like islands. Children with multi focal seizures did not use much colour but do attempt to cover the entire paper surface available. When they wrote however, mistakes increased because of an acceleration of motor speed. The most frequent errors included omitting letters, careless formation, lines sloping semi laterally and errors in direction of letters, for example, 'b' as a 'd' or 'p' as a 'b'.

For children with generalised (absence) seizures, if they continued with a drawing they began before having a seizure, there was evidence that they lacked total control of their thoughts during the period of 'unconsciousness'. This was seen in both drawing and writing tests, drawings being interrupted remaining incomplete and, if lines were part of the drawing it was clear where control was lost. Drawing can be continued however, for example, the background of a picture is filled. The authors assumed in this case, that the children were sometimes aware of their momentary loss of consciousness and continued with this task in hand.

Children with more severe seizures, such as tonic ones drew square and rigid shapes applied with a strong pressure. Writing however, helped them relax as this required a variety of wider and freer movements. Those experiencing atonic seizures preferred painting as a medium, those with myoclonics showing differing degrees of pressure and a variety of slow and rapid movements when drawing a line. For children with a seizure focus on one side of their brain their pictures usually began on the same side as their seizure focus, shapes being repeated symmetrically on the opposite side of the paper. It was noted that this occurred in most of the patients with Jacksonian seizures.

Existing art work of people with epilepsy

'I felt a new me emerging like the monarch caterpillar under the puppet's foot, but at the same time I also felt manipulated by the doctors and the pills.' (V.D.,) [93]

Art work exhibited by people with epilepsy is described below as this is also beginning to enter the research arena in terms of the effects of epilepsy (and migraine) in art work done by patients suffering from these conditions.

The art work of people with epilepsy is regularly exhibited with the aim of demonstrating the feelings of people living with epilepsy through art, some of these images being very powerful. [94] Other projects host exhibitions, and workshops are held for therapeutic purposes [95] [96] As far as the researcher knows these particular images have not been analysed formally.

The influence of epilepsy and migraines in art

One on-going study [97] is gathering together thousands of images of the art of people with epilepsy and migraines, and combining this with evidence-based research, in an attempt to expand understanding of how neurological conditions impact on people's lives. The study also probes into the possibility that epilepsy and migraines given that these can co- exist could, in fact, stimulate and/or enhance creative expression.

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[93] Comment by **Vicki Deutsch** the artist. *Metamorphosis, acrylic painting converted to digital graphics. 2006.* http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by_18.html **Accessed 26/02/2009**

[94] http://www.expressionsofcourage.com/ **Accessed 26/02/2009**

[95] http://www.epilepsyconnections.org.uk/artwork.html **Accessed 26/02/2009**

[96] Art used in psychoanalytic therapy has been shown to help illuminate how people cope with the condition. Cregeen, S. (1996). "Making Sense: Brain Trauma, epileptic seizures and personal meaning." Psychoanalytic Psychotherapy 10(1): 33 - 44.

[97] **"Sparks of Creativity: the influence of epilepsy and migraines in art."** University of Melbourne. http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by_18.html. Accessed, 26/02/2009.
Associated web site - "Channel Z Artworks"

The artwork in this particular project represents central experiences people with these conditions would like to be more fully understood, for example; the need for individuals to fill gaps in consciousness when they emerge from generalised seizures with no memory of what happened, [98] one series of images depict the progress of a complex partial seizures beginning from the 'buzzing sensation' of an aura to the artist going into a 'a black hole of consciousness' to them emerging once again, eager to fill in the gaps in the this experience [99]. Another depicts the dreamy state described by Hughlings Jackson, incorporating, additional historical knowledge of Lewis Carroll and Vincent van Gogh who were both suspected of having seizures. [100]

A book, Visions: Artists Living with Epilepsy showcasing over 200 pieces of art work, each piece created by a person with epilepsy has been published (Schachter 2003), which captures insightful images which reveal what it is like to have epilepsy. Thus it could be the case that self-expression through various forms of art is an underused tool in neurology (Stafstrom 2005).

Conclusion

This section acts as a backdrop for an interpretation of the art work participants did which does not purport to be an analysis of art work; the drawings were not a specific task to perform but offered additional facets to two of my interpretations. The issues of interpreting art work requires some consideration (Bell 2006) although some assert that this does not require one to an artist oneself (Coad 2007). Interpreting art work is very new in IPA and other studies are being undertaken. Discussing this with the other IPA researchers suggest

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[98] **Seizure within the Mind by Andrew Schuler.**
http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by 18.html
Accessed 26/02/2009
[99] Howard Smith. Chambliss J. "Drawing from Epilepsy and Music: the artistic inspirations of Howard Smith," Epilepsy Report June 2007.
http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by 18.html.
Accessed, 26/02/2009
[100] **Multiple Realities by Denis Gagnon.**
http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by 18.html
Accessed 26/02/2009

that, at present, the descriptions of people as they undertake their art work are interpreted as a text would be, with the addition of a visual aid to this for both participants and researchers and for future reflection of interpretations. Artwork is useful in depicting physical experiences which are difficult to describe such as seizures, it can also serve to illustrate emotional processes people are working through and helpful for people who find it impossible or difficult to articulate their experiences (personal communication, M.C., 18/09/2009).

This study gave participants the opportunity to draw, and two participants completed drawings. The art work in this thesis is an expression of Vince and Dave's lived experiences 'transformed into transcended configurations' (van Manen 1998)(p74). As well as offering a focus for a whole interpretation in the case of Dave, the art work done by participants has added in non verbal subjective perceptions of seizure experiences. The drawings of Dave and Vince, being unique to them helped them describe and added to their verbal descriptions and left visual traces of their experiences. Dave's interpretation, which is based on a set of nine drawings, follows first.

5.2 Dave: The eight week cycle

Mini biography

I had two conversations with Dave, a man in his forties living alone, 17 months apart. Dave was referred to the neurology clinic by his GP following a seizure which happened about a year before I saw him for the first time. He had had EEGs which, he suggested were within normal limits, inconclusive CT scans and had started taking Epilim - an anti epileptic drug (AED) around 6 to 8 months previously and, because the seizures had improved since taking the medication, he was considering the experiences he described to me in retrospect.

Dave initially professed an ambivalence and lack of concern about his seizures because he argued, living alone they did not affect anyone else. However, in contradiction to this, he visited his GP the morning immediately following the occurrence of his first seizure and was taking steps to reduce personal injury and further damage to his flat after a bad chip pan fire. This attitude had shifted the second time we met, to a mood of him wanting to shut off from what happened to him - especially regarding those occasions when he did not remember his actions - and he admitted a fear of his experiences:

> D: It's like erm the other night, er I was nodding off right and I heard, I was well, nodding of and I erd, 'Mr G*******', umph I was awake, I was scared that I might have been, out and about, and I might have had an episode - in the street.
> VF: You've done that before.
> D: Yeah but that scared me.
> 199–203 (2)

The second conversation progressed into exploring whether his experiences had altered and how aware or unaware he was of them. He talked at length about the many medications he had tried and how the AEDs worked on eliminating specific symptoms whilst others remained. Given his exposure to epilepsy terminology, gained either in the clinic or, more likely on the internet, Dave had

become familiar with this and used it to describe some of what was happening to his body.

Structuring the interpretation

> D: What do you mean by draw?
> VF: Well, whatever you think it feels like, just draw it.
> 515-517 (1)

In Dave's case I struggled with the concept of 'themes' and trying to tease these out. van Manen offered a solution to this dilemma suggesting that, although 'themes' can offer some order and structure to writing, making sense of someone's lived experience is not 'rule bound' but rather, a 'free act of 'seeing'', and a process of 'insightful invention, discovery and disclosure' and this cannot always be captured in 'conceptual abstractions' (van Manen 1998)(p79).

Appropriating the notion of 'phenomenological qualia' the, "what it is like" character of mental states, that is 'the way it feels to have pain, smell a flower, see blue, the experiential properties of sensations, feelings, perceptions, thoughts and desires' (Monaco, Mula et al. 2005)(p155) aided me, along with his anecdotes and drawings, in representing Dave's experiences.

Dave's anecdotes about his experiences carried within them, the key constituents of his experiences (van Manen 1998). These 'in-vivo inventions' (my term) are used as subordinate themes to the first superordinate theme, 'the eight week cycle' and helped me 'get a better fix' (van Manen 1998)(p87) on Dave's experiences.

They captured and drew together a series of drawings Dave did for me in his first interview and which, he stoutly maintained throughout both interviews, constituted elements of what he perceived to be an eight week cycle of experiences:

'But one thing I have noticed, which I don't know whether it's true for
epileptics, whatever I've got seems to run in an eight week cycle.'
D:435-437 (1).

D: And, strangely I still can't break this cyclic form.
VF: Right
D: I still can't break this cyclic form.
50-52 (2)

The second superordinate theme, Dave's beliefs about the causes of his seizures

encompasses the subordinate themes of past events which Dave alluded to as

being the cause of his seizure onset. Superordinate and subordinate themes in

Dave's experiences are depicted in table 8.

Table 8

Superordinate and subordinate themes

Superordinate theme	1. The eight week cycle	2. Beliefs about the causes of seizures
Subordinate themes	1.1 Pseudo shaking 1.2 What it feels like in my brains 1.3 Daisy Dream worlds 1.4 I want more: The Epilim's definitely helped	2.1 Past events

Contextualising Dave's experiences

I first contextualise Dave's experiences and introduce them as he initially

described them to me, and set against the backdrop of living very close to a

cargo railway line which resulted in regular reverberations inside his flat:

'So I was basically by meself for year, I, coming up to when I noticed
there was something wrong. Now I was laid on me couch, late at night
watching TV. Now, I live close to a cargo railway line, so you can just feel

> the vibrations of the er cargo trains going by, like I said one night, I'm watching TV and I thought to meself, that's a really bloody big cargo train going by (laughing). D:16-25 (1)

> 'And the first thing I noticed was a hand flying by me face, I thought that's strange and next thing I know another hand was flying by me face. And I thought, well I can remember, I got as far as boll**** well, boll and I passed out. I came to, whenever, I must have turned the TV off by accident or something, I came to.' D:29-33 (1).

Dave's initial feeling was what he assumed to be a train passing by, but 'a' hand and 'another' hand flew by, which he dissociated from himself at this point. However, when later describing his drawings they become his own hands and his own actions. He remembers what happened immediately before he 'passed out' and immediately following when he 'came to'. This gap in his awareness between these two points he attempts to fill with what he assumes must have happened given the evidence available to him, i.e., he must have turned the TV off during this gap.

This experience appeared to be on a continuum involving 'jolts and bangs' which Dave replaced in the second interview with epilepsy terminology of 'myoclonic' and which culminated into what he thought of as himself losing consciousness and not knowing anything else until the following morning. He did not seem unduly alarmed at the idea of having a seizure at the time:

> 'I turned the TV back on again, and I thought to meself, I've had some sort of fit, cos I've worked for people that have had fits, me younger sister's got MS and she's had the odd seiz, seizure. So I thought well, I'm going to roll meself a cigarette, unfortunately, I couldn't roll one. Cos I get as far as pulling the cigarette paper out of the packet of cigarette papers, pull me bit of tobacco out the pouch and I'd have a jolt, bang, go all over the place, I thought I'll try again. Pull cigarette paper out, get some baccer, bumph again, now until it happened about four or five times when I passed out again.' D:37-44 (1)

It is unclear whether Dave was, in fact, unconscious for a period of time before going into normal sleep because no one witnessed this event. The only time

Dave talked about other people observing his seizures was in the second
interview when he reported back on a flat mate's comments on his 'absences':

> D: But he said er, especially if I'm on the computer I just, I go like
> that (mimes an absence - staring) he'd hear me mouth go (smack
> smack) or hear me moan or something. That's when he'd say, 'are
> you alright?' I'd go what, what?
>
> D: He's seen me do at least ten to fifteen ...
>
> VF: Seen you do....
>
> D: ... Absences
>
> VF: Where you don't know you've gone like that?
>
> PC: What does he say about them?
>
> D: Well he just says that I go blank- just blank.
>
> VF: What's blank then? Still?
>
> D: Yeah, apparently I just look away, our computers - his computer
> faces my computer. I'm that way, you're looking at me, I'm like
> that.
>
> PC: Mmm and how long does that last?
>
> D: Apparently he says anywhere from two minutes, three minutes.
>
> PC: Right.
>
> D: But sometimes, I'd argue with him that it happens.
>
> VF: Why would you argue then?
>
> D: Well, I don't know its happening, its just 'bumph' to me.
>
> 111–144 (2)

As mentioned earlier, Dave was concerned enough to make an appointment
with his general practitioner (GP) the following morning who referred him to
the neurology clinic.

Whilst awaiting this appointment, a series of experiences followed described
variously by Dave as, 'fits', 'seizures', 'convulsions', 'going stiff', experiences of
'being in an electric shock going through your whole body' 'flashing lights' and
'whole body shaking', the after effects of which could consign him to bed for
days at a time and which, he maintained, resulted in him once forgetting a chip
pan which subsequently set on fire and seriously damaged his flat. He also
described times where, 'I'm inside me flat, and I remember going 'aah' and the
next thing I can know is, I know, I'm on the floor, and I've pissed meself.' So I've
struggled to get to bed, and I've been in bed.' D:129 (1). He also introduced
early on, what he perceived as yet another phenomena, 'the black outs' D:184

(1), where he would go outside, be aware, undertake unusual behaviours of which he was unaware, being in 'auto pilot' then 'come to' again.

Superordinate theme 1. The eight week cycle

> Yeah, they still seem to be going in a, in a cyclic form, for some reason I can't seem to break the cyclic form.' D:45-46 (2)

In order to describe what amounted to accounts of an 'anomalous experience' for him (Vollmer Larsen, Handest et al. 2007)(p345), Dave had to verbalise these both as a novice in this task as well as there being, potentially, limits within his own vocabulary. As yet there are no agreed, 'proper words' with which people with seizures can draw upon for help in expressing what can be bizarre experiences (Petitmengin 2006; Johanson, Valli et al. 2008).

The drawings offer visual first hand depictions of Dave's seizure related experiences and, in offering additions to verbal expressions of such experiences could transcend barriers existing across art and science (Schachter 2009). In an amalgam of lay and medical terminology Dave described how experiences consisting of modality specific sensations, auditory and anomalous visual perceptions and different levels of awareness and unawareness felt to him. His drawings functioned as a way of communicating further his experiences to me Briggs (1986) in (Miczo 2003)(p42) along with his own idiosyncratic terminology.

1.1   Pseudo shaking
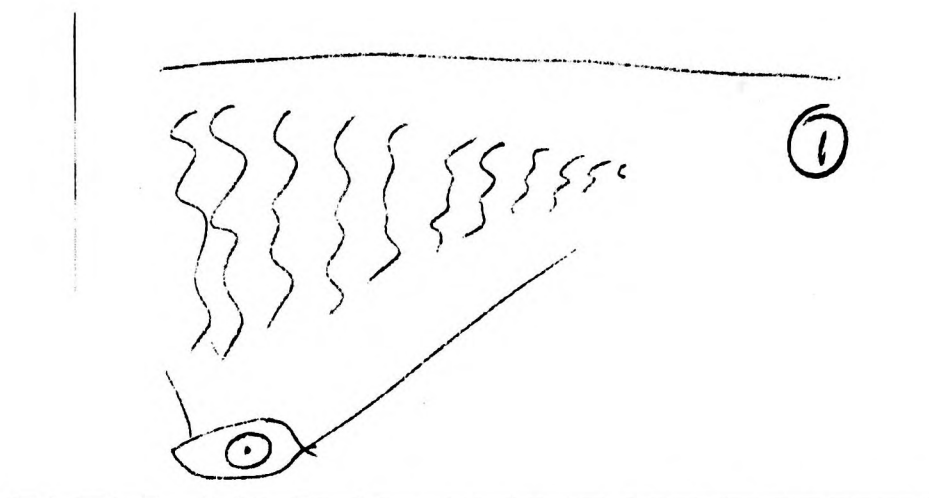
Figure 2

Pseudo shaking

When I first met Dave, he thought he may have seizures whilst asleep, as he sometimes woke up in a morning experiencing his brain and eyes telling him he was shaking. However, he denied any shaking of his body is taking place as everything around him appears static. To resolve this contradictory information Dave coined the phrase, 'pseudo shaking' to describe this perceptual mismatch of his experience:

> 'Some days I have woken up in a morning and it's like er, it, it feels like I'm coming out of a fit. And I've had that quite a few times, suddenly woken up in a morning and it's that type of shaking but I'm not shaking. Yeah just coming out of a fit because er, like I'm seeing things that are going in and out or I can see the wall, it's dead straight, I'm not shaking but my eyes seem to be telling me that I'm shaking. If you can understand that, still lying down and I can see the wall, and it's not moving but me brain's telling me that I'm still shaking, if you can understand that? That it's shaking and it's quietened down mmm, which is a strange thing, mmm. Well what I call the pseudo shaking because, obviously I'm not shaking because the wall if I was physically shaking, I'd be seeing the wall going like that wouldn't I? So it's me mind telling me

that I'm shaking but I'm not and I've had that quite a few times, suddenly woken up in the morning. If you understand that and it's that type of shaking but I'm not shaking.' D:77-126 (1).

Later in the interview, notwithstanding that most of his drawings are set in bed, Dave says he cannot really tell whether he has had a seizure whilst asleep or not. 'I tried to but er, how can I really tell that I've had one, if they happen at night, half the time I'm rarely aware or I wake up thinking, have I had one, or.' D:849-851 (1). One drawing depicted him as having up to four of these during a night.
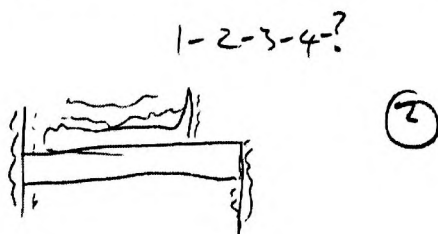
D:	Next?
VF:	Yeah, next think of going up the cycle, as you said, they get worse, what's the next worse one then?
D:	[Drawing and humming]
VF:	Why is the end of the bed wiggly?
D:	Cos the whole bed was shaking.
VF:	Right, cos you're shaking?
D:	That's right.
VF:	Right, you're shaking, so that's in the middle of the night?
D:	Yeah.
VF:	Right, it's always in the middle of the night?
D:	Yeah, er yeah.
VF:	That's the second sort of ....what's that, one two three four, what is it though, what is the 1,2,3,4?
D:	How many times I can have it in a night.
	545-572 (1)

As he continued with his drawings, Dave began to delineate between day and night occurrences and introduced day time experiences, 'I mean everything, every muscle, that can shake is shaking and erm ..... and daytime, it's back to the jolts.' D:775-780 (1).

'jolt, bang, go all over the place'

Here Dave maintains his belief in the cycle of events and how as the cycle progresses, these events can increase in number. He describes an involuntary experience of throwing a cup at the wall which came 'out of the blue' G:621 (1) tempering this with the remark, 'well in fact, maybe, just a slightly second before, I can feel it'. D:625 (1).

Figure 3

Jolt, bang, go all over the place
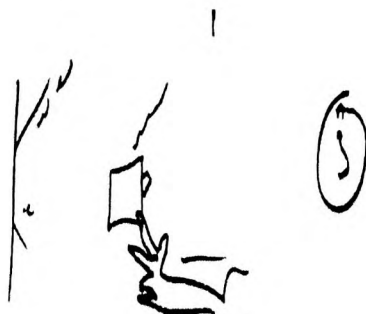
> 'that's a cup! Going on the wall and that's my hand going (gestures hand jerking cup up to hit the wall) no I threw the cup at the wall! (Laughs) just thrown out me hand. That can happen any time any amount but the worse it gets, the cycle, the more likely.' D:585-603 (1)

Dave goes on to describe in our first conversation and unprompted, the worst seizure he can remember and this description develops and shifts here into one which includes his whole body in clusters of extreme and contradictory, cenesthetic experiences including, stiffness, his whole body shaking, feelings of electrical sensations and flashing lights:

> 'Er, probably the worst one I can remember is being laid in bed, and going stiff. When I mean stiff, I mean just like concrete. Then relaxing, then going stiff again, and anything, like being in an electric shock, going through your whole body, lights flashing, every muscle in your body just

shaking. I can remember that, I can remember quite a bit, I didn't like
that one at all.' D:57-69 (1)

In terms of awareness, Dave can recall these extreme bodily experiences, he can
feel the shaking and see the flashing lights, but, he does not appear have any
'agency' over it or power to stop it (Gallagher and Brøsted Sørensen
2006)(p126). Dave went back to one of his drawings at the end of the first
interview adding in that these only happen at night now.

Figure 4

These only happen at night now

The second time I saw Dave he was having similar experiences which he then
termed as the frazzle type:

> D: Which means like the million vault going through the 'ed, its like.
>   Or if it's the erm stiff type, I might be aware of the stiffness for a
>   while, pass out, then I might come to, and be aware of the clonic
>   for a while, pass out ....
> VF: So what's passing out what's that?
> D: Blackness for a while.
> VF: Blackness for a while.
> D: Yeah.
> VF: And then you come to again?
> D: Yeah.
> 379-384(2)

Figure 5

The frazzle type
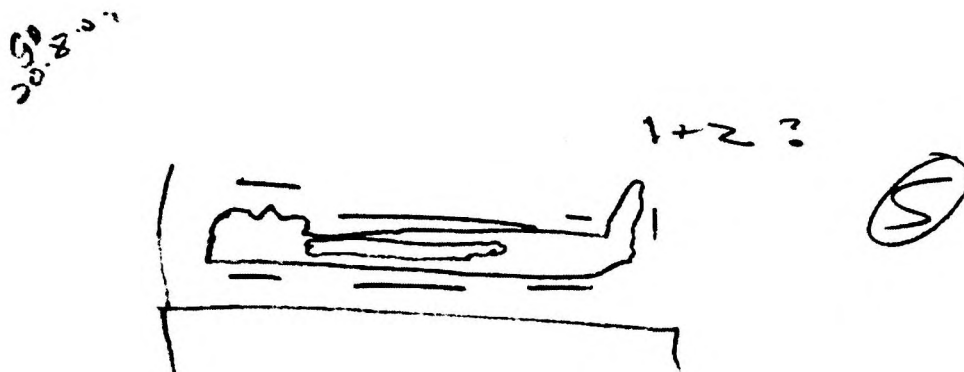
<u>The fits themselves and personal injury</u>

Dave also differentiated further between experiences and, 'the fits themselves' which he sees as being those which physically damage him, 'but the fits themselves, and that's if I've hit something when I've fallen, or damaged meself or like the last one.' D:130-131 (1). Dave mentioned bruises that he assumes he sustained during seizures he knew nothing about:

> D: But it's er when I started getting the big bruises, oh I think I've definitely had one.
> VF: Even when you're in bed, you've woken up and you've got bruises?
> D: Well the thing is I could have been sat watching TV, right, had one fallen down, hit a table, right, and without me knowing gone to bed.
> 870-876 (1)

The second time I saw him I noticed scars on his chin and mouth:

> VF: Any more major injuries?
> D: Oh yeah, you can see the stitches there and I've got some stitches there.
> VF: How did that happen then?
> PC: What happened then?
> D: Just the floor.
> PC: You hit the floor?
> VF: At home?

> D: Outside - the floor, it's hard the floor but there you go.
> 686-694 (2)

Dave also related another incident which had happened in between our two conversations, in which he scalded his foot as he poured boiling water over it. His injury did not require a skin graft however but was obviously painful and not the kind of injury one would want to impose upon oneself:

> D: Yeah I have done that before, sometimes it's that I flinch.
> Myoclonic, make a bit myoclonic. And erm I have scalded myself
> before, the worse one was 'erm I found myself er trying to make
> trying to make a cup of tea, er stood up - remember, pouring
> boiling water on me foot, and I've got me sock on – right? And I
> can *see* myself, actually seeing pouring boiling water on me foot
> and I can't, I just cannot move me foot, it's stuck, it's absolutely
> stuck... I can't move me hand, can't move me hand, and I can see
> the water dripping and I'm thinking to meself, move, move, just
> move. Then I'm thinking, if I can just get the sock off me foot,
> then it'll, it'll just make it feel better, if I could just get the sock of
> me foot, it'll make it feel better, And it just will not move.
> PC: Then what happened?
> D: It just slowly started moving, just slowly, very, very slowly.
> 153-165 (2)

Self injury is common in both NES and epilepsy – and this can be extreme (Voermans, Zwarts et al. 2005). An explanation of the capacity of some people to tolerate extreme pain is the psychological mechanism of dissociation experienced by many people with NES (Bodde, Brooks et al. 2009). However apart from burns, which are almost always exclusive to epilepsy, the occurrence of certain injuries cannot be considered a diagnostic pointer (Reuber 2008).

The black outs

> 'er another worrying thing is the black outs. D:184 (1)

Dave gave the term, 'black outs' or day dreams to periods which he can have throughout the day in his flat and he begins to talk about his levels of consciousness when undergoing these experiences:

D: Well I told you, it's on record with Dr ****, but er another worrying thing is the black outs.

VF: On top of the fits?

D: Yeah, it may not be a fit but pause, me brain just seems to turn off and I can walk around, and not know, know where I am where I've been what I've done.

183-190 (1)

He became more concerned about these as they began to happen out of doors and Dave gives examples of two of these in his poems. For example, on one occasion, he plans a shopping trip, arrives home with the planned purchases but does not remember buying them. On this same occasion he also narrowly misses being knocked over by a lorry and 'came to' just in time to avoid this. One another occasion which Dave terms, 'The Coconut Day' Dave arrives home and discovers he has purchased five coconuts. Dave describes how these experiences had come about:

D: So I'd ran through it in me 'ead, what I was gonna do ...

VF: Yeah.

D: ... so I've gone onto automatic and actually done it

VF: Yeah.

D: But unfortunately, I'd stopped right bang smack in the middle of Beverley Road looking at this lorry coming towards me.

VF: Did you stop there because you, why did you stop in the middle of the road do you think?

D: I don't know, I just came to.

238-252 (1)

D: You see, the trouble is I've got no memory in the gaps.

VF: Yeah.

D: I've tried to remember what I did, I've nero, zilch.

VF: There's only the clues of the potatoes or the cup of tea?

D: So I've done somethink, must have done somethink to there.

297-305 (1)

1.2   What it feels like .... in my brains

Figure 6

What it feels like in my brains (1)
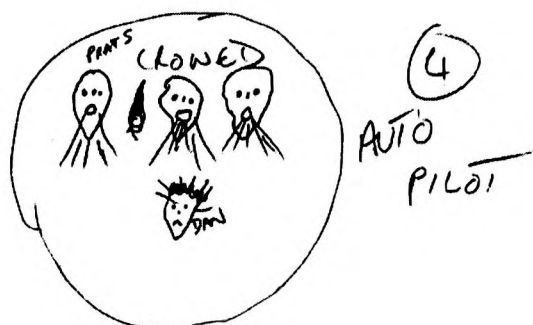
Dave drew two drawings depicting the workings of his brain and these expand on how he feels on occasions when he undertakes behaviours he can neither control nor remember. The first drawn in the first interview described how he felt immediately prior to undertaking the behaviours described above:

> 'Rough, er like something's pressing down, pulling down my head or whatever. And I can just remember it's like being in a football crowd and everybody's screaming at you for attention and you're not able to respond to any of em.' D: 214-224 (1) and,

> 'What it feels like, in my brains, that's a crowd, I'm half awake, half asleep and this part (points to the front of his head) is where the scream is coming from.' D: 650-672 (1).

When I asked Dave about this drawing the second time I saw him, he dismissed it saying that he did not feel this anymore, putting it down to the side effects of medication.

1.3   Daisy dream worlds

> D: Its like a daisy dream world where things are like weeee! It s like
> erm, its like phooo, its like erm [long pause] like a like phuf, er,
> phh Do you know anything about physics?
>
> PC: Try us.
>
> D: Black hole, if you went into a black hole, time and space gets
> squashed.
>
> PC: Okay.
>
> D: Everything's starting to slooow down, that's how it feels.
>
> PC: That experience - of feeling that you're going into a black hole,
> how often does that happen?
>
> D: Er, that's difficult to explain, you see my mind just tries to blank it
> out.
>
> PC: Okay.
>
> 545-561 (2)

Dave appears to exhibit what could be seen as components of dissociation; i.e.,
an interference with his normal perceptual, cognitive and attentional processes,
his memory is disrupted for periods of time. He has feelings of altered
consciousness and being, 'in a different world'. However, he can become aware
of other people around, 'all of a sudden somebody breaks that world, and says,
'are you alright?' 'Really, are you alright?' D: 106 (2). However, when asked
about his awareness of this other 'world', he purports to knows nothing and that
he is unable to move:

> VF: That moment you're in that other world, what's happening in that
> world then?
>
> D: I don't know!
>
> 448- 449 (2)

> D: It's basically (poses as a statue) that's it.
>
> PC: You feel you can't move?
>
> D: Yeah, basically, I'll try again (another pose) there you go!
>
> 454–457 (2)

The two scenarios depicted in his poems, are illustrations of Dave going into
what he terms 'auto pilot' D:259 (1). This explains away his way of behaving to
me and, presumably, others. These have been mirrored by similar lapses in

consciousness which have happened to him at home, 'I've had smaller episodes like that inside me flat where I'm looking at me bedroom wall the next thing I know I'm watching TV with a cup of tea in me hand.' D:253-255 (1). Fluctuations in everyday conscious experiences can result in 'normative dissociative experiences' which can happen spontaneously and merely involve 'functional shifts in attention and information processing' when individuals can shut out their external environment and perceive time as being suspended, a suspension of self-reflective consciousness (Seligman and Kirmayer 2008)(p34). However the difference between having 'normal' dissociative experiences (which can be pleasurable and contribute to enhanced functioning or performance) and abnormal ones is that normal experiences are not associated with 'clinically significant distress' (Seligman and Kirmayer 2008)(p35) which Dave does appear to suffer from.

In the world of neurology, if people do not remember things, they are often interpreted as having been unconscious (Cavanna, Mula et al. 2008) when the concept of consciousness remains elusive and, some would argue, has certainly not been defined adequately for use in behavioural neurology (Johanson, Valli et al. 2008). Dave appears to be undertaking, 'complex behaviours without conscious awareness' (Seligman and Kirmayer 2008)(p48). He retains 'cognitive consciousness' which allows his to act thus but lacks, temporarily, 'phenomenal' consciousness (Monaco, Mula et al. 2005)(p156).

Dave's periods of continuing purposeful activities whilst being oblivious to them could also be explained as him being in 'zombie mode' and this can happen in 'limbic status epilepticus'. A person's behaviour appears normal but they do not experience subjective feelings about this. Dave also managed not to get himself killed (Monaco, Mula et al. 2005)(p156) so it is arguable that some level of consciousness remained in order for him to do this. Dave's experiences of acting on 'auto pilot' are similar to those of walking or driving home without an introspective awareness of our perceptions on the journey (Tye 2003). Thus zombie like behaviour can happen to us all in every day life, for example, driving

home without remembering doing so. However, we cannot be totally unconscious otherwise accidents would occur, therefore some level of consciousness remains even if we are not aware of it (Monaco, Mula et al. 2005).

Dave is concerned about the periods where he does not remember his behaviour and, on several occasions in our second conversation, he wanted to shut out what may have even been pleasurable experiences:

> D: To you, you think, oh, perfect world, but to me I don't want to know it, I don't want to know it the thing that I've just, I don't want to know.
> VF: Where you are at that moment or?
> PC: In general?
> D: In general I don't want to know it.
> PC: Do you think sometimes you're depressed?
> D: Oh yes I do stupid things, I know I do stupid things. I don't want to know it, coconuts I don't wanna know that I done the coconut things, I don't want to know I've walked across the road that I could have killed meself, I don't want to know it.
> 562–570 (2)

His distress about these occasions is further compounded by how he thinks others see him at these points and potentially, in a negative way (Seligman and Kirmayer 2008). Early in the second conversation Dave explained through another drawing, (figure 7) how he thought his brain was functioning.

Figure 7

What it feels like in my brains (2)
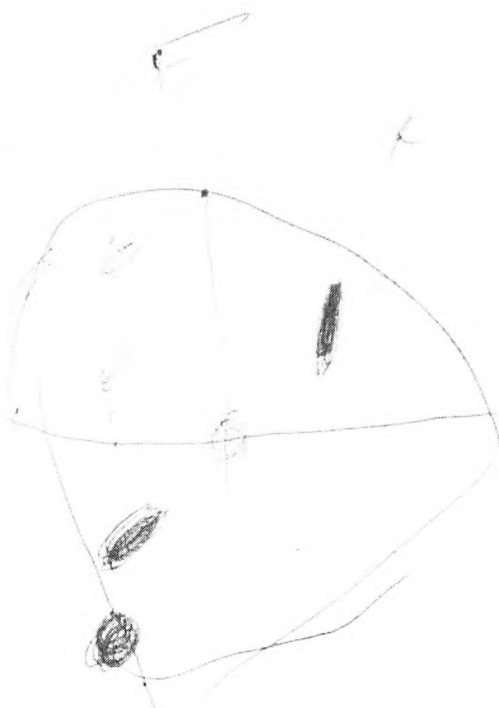
D: Divide my head into quarters. That's me front, (front of head depicted) that's me right I get headaches there, I get headaches roundabout that area and that area, (areas marked with a black/grey scribbles) these are *intensities*, like the darker it is, the more intense the pain *can* be.

VF: Yeah.

D: It doesn't mean that it *is* going to be *that* intense, but that's how it *can* be intense.

VF: Right.

D: Er, er and there ...

VF: Are they headaches or pains?

D: Headaches and pains, that there could be lower back, sort of there, (shows me the back of his neck) this part, this part here, there, seems to be the only part of my head that seems to be unaffected (the empty quartile).

VF: What made you divide your head into quarters then? [indistinct]

D: Like I said, that seems to the only part of my head that seems to be unaffected, there- seems to *feel*? Seem to have something at the time. 68–82 (2)

He remains perturbed at his periods of 'absences' and his lack of self awareness and, 19 months later, was well aware that his cognitive capacities appear to lessen during this time and he shows concern as to how he may look to other people:

> D: I think so, I think so but I think I'd be oooh, oooh sort of erm [pause] more stupider erm, more like I said that's sort of – one quart less intelligent.
> PC: You mean a bit confused?
> D: Yeah– one quart less intelligent.
> 295-298 (2)

Dave does not experience feelings that he is not real, that he is not there, his identity is never in question, indeed, he is very much present, trying to escape from this state:

> D: There's a Danny inside that's always screaming to be let out no, the good one.
> PC: Not somebody standing beside you?
> VF: Where you think there's somebody there but there isn't?
> D: Noo, silly, there's the Danny locked inside that's always screaming to be let out. Please man - let me out.
> 579–584 (2)

1.4. I want more. The Epilim's definitely helped

Figure 8

Like pure du du
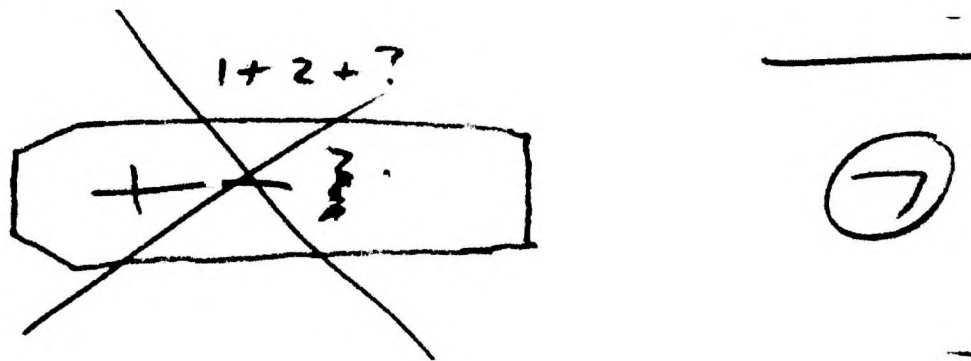
The drawing that depicts Dave as being in his coffin, having 'passed out' after the culmination of his perceived eight week cycle and having no energy and 'out for most of the day' D: 796 (1), was crossed out later when we were discussing his Epilim saying, 'But definitely that one you can scratch out now.' D:1039 (1). He then maintained that the cycle began again with muscle shaking. Dave returned to this drawing in our second conversation and described this retrospectively:

> D: There's one time, it took me three days, three days, - before I recovered, three days.
> VF: How did you feel for the three days?
> D: Like pure du du, pure and utter du du. I was in bed for two days, I had to er basically get rid of the mattress, that's how bad I was.
> VF: Get rid of the mattress?
> PC: Why was that? Sweat?
> D: Work it out for yourself.
> PC: You've been pooing, you'd soiled it?
> D   Yeah.
> PC: Or you'd been wetting?
> D: Basically speaking I couldn't get out the bed – that's how bad I was.
> 409-412 (2)

At both our meetings Dave maintained that the AED, Epilim, had improved things for him, he continued to delineate between most of his seizures occurring at night and his fits which occurred during the day. Our final discussion at the end of the first conversation was around the effect that taking the AED for 8 months had had on Dave's seizure pattern and experiences:

> 'At the end of each eight week cycle, I was definitely feeling a lot more , really really getting poorly... I mean, really, really getting poorly... being stuck in bed... yeah at least I don't get that way (coffin picture - 7) any more...still have the fits but at least it's over and done with in a day... but it doesn't really affect me that bad... from being totally absolutely, well and truly [incapacitated], medication has definitely stopped me from pegging it. The Epilim's definitely helped.' D:1026-1055 (1)

The second time we met, he had monitored the effects of various medications he had been prescribed and armed with an acquired seizure language, and he

described symptoms he still experienced which were not controlled by the AEDs:

> D: The Epilim didn't control the left hand side, period. Doesn't control the left hand side, period. Doesn't control ...the – absences doesn't really control er, doesn't really control the er night ones.
> 225-227 (2)

> D: The night ones I know I'm still having the night, the night, whether it's the tonic clonics or complex partials, I don't know. The odd time I do get night sweats, but more like as not it's probably complex partials and I do know, I clench up really tight, me teeth lock on really 'ard so could be complex partials, could be tonic clonic, so I don't know, don't know... I don't know.
> 229-233 (2)

However, the information he gave was contradictory, the first time I saw him the dose was fairly low, however, he was on a very high dose when we met again (600 mg in a morning and afternoon, plus 900 at night) and he was asking for this to be increased because other symptoms he was experiencing were not under control. Having eliminated what he now termed the 'myoclonics' G:12 (2) [101] in his right hand side, he continued to describe a wide variety of symptoms and was still searching for treatment for, 'hot poker', 'a needle stuck in the foot' D:14 (2) and 'day dreams, weird worlds' D:275 (2) and for times when he finds he cannot move.

Superordinate theme 2. Dave's beliefs about the causes of his seizures

2.1 Past events

The first time I saw him, Dave opened by telling me of the two familial deaths which appeared to have severed any family connections he previously had, 'Right let's see, well after me grandfather died - terminal cancer, me mother had

---

[101] Rhythmic spasms of muscles (myoclonus).

died previously, a year previously, erm ... and me family basically disbanded because me granddad was the person that everybody went to.' D:10-12 (1). Dave referred to his granddad in both conversations and to the fact that he had cared for him for a year before his death, after which he had not see any of his family. He intimated that he had then begun to experience sleep problems which he considered, could have been the cause of his seizures and what he believed was epilepsy:

> D: That might be the cause of me having the fits, bad sleep patterns,
> VF: Do you think that is the cause?
> D: It could be yeah. Like I said after me granddad died, me family, basically, I've not seen the rest of me family or anythink.
> VF: How long's this been for then?
> D: Well, let's see, my granddad died two years ago, and the epilepsy started a year ago but I think they may have been some episodes earlier than that, but I can't be certain.
> VF: What sort of episodes?
> D: In the night time and blackouts.
> 379-395 (1)

Dave returned to the idea of events occurring before this when he wrote back to me about his poetic interpretations (see box 6).

Box 6
Dave's recollections

I was asked about déjà vu in the interview my earliest recollection around the age of 8 years of age. One that sticks out is being on a school trip and being on a bus. Can't remember where and thinking, I know all of this.
At approximately the same age we had Christmas dinner at me grandparents and I must have had what I now know to be a Complex Partial because apparently I had a dazed look in me face tried getting into me grandparents gas cupboard and had a good chat with no one in particular of which I have no memory!
My mother noted later about this period and me she said I just suddenly went cold towards her and my memory seemed slightly different.
At the age of 14-15 I was tearing apart sheets and blankets in my sleep and waking up very tired. Doc gave me iron med.

D: Personal written communication (29/01/2009)

In the second interview he had already alluded to this, 'I've noticed that since I was a kid, I've had that quite a lot since I was a kid actually, déjà vu.' D:548 – 549 (2). And when asked directly by P.C., about what he considered caused his seizures:

> 'It might have been me granddad's death actually, cos I was looking after my granddad and it would be about year and a half after he died that's when I went - but, I was, I'd noticed it.
> D: 653–654 (2)

Coda - Déjà vu.

The first time I saw Dave he was unkempt and dirty, however the second time we met he was clean and spruce but felt two years on from the onset of his seizures, despondent about his prognosis and future:

> D: Yeah, then its going downhill.
> PC: Is that what you feel that you're more down hill now than when you first spoke to us?
> D: Yes, it seems to be getting worse and worse.
> 670–672 (2)

He returned, at the close of the second interview, to the time he had his first seizure:

> 'I'd done me back in and I was laid on me couch, I'd got some painkillers from me doctor, the hyrocodeine, erm and I remember thinking, laid on me couch and I remember thinking 'that's a bloody big train going by!'
>
> D:628-630 (2) [102]

---

[102] The rumbling of the cargo train remined me of a study where people with epilepsy were found to be more likely to think they were having a seizure during an earthquake then did people with NES. Watson, N., F, M. Doherty, J, et al. (2002). "The experience of earthquakes by patients with epilepsy and nonepileptic seizures." Epilepsia 43: 317 - 320.

Addendum: Information obtained from the Consultant (A.M.,) after the completion of the research.

Dave was diagnosed with idiopathic generalised epilepsy. He has normal CT and EEG scans. He explained his experiences at the epilepsy clinic very much like he did to me and was first diagnosed with myoclonic jerks and prescribed Epilim which decreased his seizures. He presented in A & E after his chip pan fire. Following this, the Epilim appeared not to be as effective and he then experienced the 'near miss RTA' (depicted in poem one, 'Being in autopilot' in chapter 5.6.). He was then prescribed other medications in order to control his seizures. The Epilim remains effective for seizures but not for his myoclonus. D*** presented in A & E a second time following an assault which he remembered nothing about. He continues to try different medications to control his three different experiences. He was experiencing jerks more or less daily, absences around ten times a day and nocturnal fits where he wakes up exhausted, has sometimes bitten his tongue and been incontinent of urine. His absences and myoclonic jerks had been witnessed in the clinic by an epilepsy nurse.

5.3 Vince: I'll let you try and work that that out - even though that looks like a fish

Mini biography

Vince (V), in his early sixties, had experienced around seven seizures in the fifteen month period prior to our first interview, and had commenced taking anti epileptic drugs six weeks before I first saw him. Vince appeared to have had a seizure a year before he visited Dr M***, one which his family described at the time as perhaps being a stroke. However, looking back, they considered that this could have been a first seizure as Vince told me that the specialist had told him he had epilepsy. Vince lived with his wife in a council property in an area of high deprivation and his young life had been 'absolutely chaotic' V: 825 (1) and he had spent periods of time in prison at various times in his life.

Vince was involved in a car crash nearly 35 years ago, in which he sustained head injuries and was the sole survivor, and experienced a second car crash later in adulthood. He was also knocked down by a car as a child and remained in hospital for six months in a coma. There is the potential for him, therefore, to have acquired a traumatic brain injury in all of these accidents, seizures (both epileptic or NES) arising from traumatic brain injury being common, (Hudak, Trivedi et al. 2004). Vince links his present condition to the first car crash and after a recent brain scan which, he was told, showed damage.

Vince had prepared me a written description of his experiences in advance of the interview (see box 7, below) and later supplemented this with a drawing (see below, figure 10). Vince talked about what he termed 'his situations' early on in the interview, launching straight into his own personal 'bodily' experiences. He was articulate and described his experiences in such a way as to give me a very clear idea of how he felt during his seizures, particularly in the way he attempted to describe his feelings of awareness. His wife (W), present

throughout both interview conversations, added to these descriptions being a witness to them.

Vince's 'situations' (his term) were his main topic of conversation throughout his two interviews, what they were like and how they had come about. However, bound up with these were constant ponderings about the car crash of nearly 30 years ago in which a girl whom he was 'very much in love with' V: 965 (1) had been killed, and who, nursing staff had told him, was pregnant, the whole situation resulting in a break up of his first marriage soon afterwards. Vince's experiences were tied up with past events as he strove both to remember the accident, never accessing, 'the whole truth of the accident, I've no idea'. V: 246 (2) and also, to understand how this event could be at the root of his present problems.

Superordinate and subordinate themes
Table 9

Super ordinate theme	1 Threats to Integrity of Self	2 Reformulations of embodied experiences of awareness and consciousness
Subordinate themes	1.1 Fear and sense of agency 1.2 Conquer and accept 1.3 The fullness of the accident 1.4 Identification and acceptance	2.1 Loss of insight

As it became apparent that Vince's experiences posed a significant threat to him in terms of his bodily integrity and its functionality, a super ordinate theme was that of, 'Threats to Integrity of Self' which is taken directly from a developing model proposed by Morse (1997), which identifies stages of response to serious

injury [103]. This can be used to understand and support someone's response to illness experience, specifically incorporating strategies used by individuals to process changes in, and maintain the integrity of, the self.

Although Vince's experience does not always match the linear progression in Morse's model, it remains a useful framework for tracking the process Vince goes though in coming to terms with his 'now reality.' V: 258 (1). The main stages of Morse's theory with responses and strategies are outlined below, a full explanation of the model being in (Morse 1997)(p29). Vince's individual process is reformulated for this interpretation, see table 10 below. Subordinate themes to this main theme are in table 9, all of which encompass various aspects of Vince's coming to terms with the fragmentation of himself, 'Conquer and accept', V:257 (1) and, 'the whole truth of the accident' V:246 (2), being in-vivo themes, that is, being taken from the spoken words of participants.

The stages and responses in Morse's model consist of five stages each with different possible responses. Stage one, Vigilance: has responses of suspecting, observing and reading the body, becoming overwhelmed, maintaining emotional control and accepting assistance. Stage two, Disruption: Enduring to survive has possible responses which can include, holding on, being in a shattered reality and experiencing a haze of disorientation. Stage three, Enduring to live: Striving to regain self, can involve responses of self living through pain, trying to bear it, learning to take it, accepting dependence, recognising physical change and loss of function, fearing isolation, grasping the implications of illness and injury and recognising the uncertain prognosis. Stage four, Suffering: Striving to restore self can move onto responses of struggling with grief, doing the work of healing and making sense. Finally, stage five, Learning to live with the altered self has reponses of getting to know and to

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[103] The Threats of Integrity of Self theory was developed from undertaking a qualitative meta synthesis of studies which then incorporated and encompassed the other models in these studies, in order to develop the new model.

trust the altered body, accepting the consequences of the experience, revaluing the experience, attaining mastery and revising or modifying life goals.

A second super ordinate theme is the one of, 'Embodied experiences of Awareness and consciousness', which served to illustrate how these were captured before Vince's understanding reached a stage when he could not relate to these (earlier) descriptions of his experiences. The subordinate theme to this, that of, 'Loss of insight' came about because, by the time I met Vince again, his descriptions were *linguistically* very different the second time I saw him. Vince also provided me with some 'non linguistic' data (Gillies, Harden et al. 2005) in the form a drawing of his initial seizure experiences combined with his explanation of this. This will be explored in the final section of this interpretation.

Vince – pre interview thoughts

Vince's descriptions of his experiences began before the interview with a written description he had prepared and gave to me when I arrived for our first interview (see box 7, below). This represented his inner dialogue and served as a précis of his process of understanding his present condition.

Talking to neurologists about the project, it was suggested that Vince's description, compared to many they had experienced, is unusual in its clarity and brevity:

> 'The problem is when patients come with writing you never get their experience, you just get the list of symptoms and physical events, they will not put in writing, they wouldn't mention about their brother being murdered, they put, this is my problem, these are my symptoms, you give me the cure. There may be twenty pages but it will still be along those lines.' P.P.K., (504–510). [104]

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[104] Please see thesis appendices, document C.

Chapter 5.3. Vince: I'll let you try and work that that out - even though that looks like a fish

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Box 7

Written description from Vince

The feelings that I have had apropo [apropos] no as to what I now have, I have had for 12-13 months ago. These incidents I first believed where these feelings were concerned that I had mini-strokes but after explaining them to my Doctor he wrote to Dr M*** for an appointment with him. After seeing the doctor's assistant I was sent for three different tests which, I went through and found out that I am now epileptic!
At first these feelings were difficult to understand and even harder to explain. You see I felt that I was drawn away the company I was with and talking to; there was this feeling of being with, but totally apart from. It seemed to me to be quite inexplicable! You see I was there but, indeed, I wasn't. Even now I find it hard to explain the reality of what was going on; it is still confusing to me.
The feelings of these moments are in fact quite altruistic (!) to me and yet, like cubism, not really understood.
Vince (2008)

Superordinate theme 1. Threats to integrity of self.

'In sickness one confronts the inchoate. Bodily suffering disturbs the language of thought, rendering our previous construction incoherent and incomplete' Kirmayer (1992, p329) in (Gibbs and Franks 2002)(p141).

The philosophy of Merleau Ponty and his representation of the subjective body as lived, i.e., one in which a person *is* his body and not aware of it as a separate entity, shifts, for Vince, to it becoming an objective body, one which he becomes aware of as it begins to be disruptive and demand attention (Wilde 2003). that one's body is no longer behaving reliably results in, 'the unity of our existence in the world [being] broken' (van Manen 1998b)(p12). Vince was beginning to experience the body he possessed, once silent, as an object no longer silent, no longer trustworthy and he began to formulate a response to this (Wilde 2003).

Figure 9

Chapter 5.3. Vince: I'll let you try and work that that out - even though that looks like a fish

___

Photograph of *Portrait of Picasso*, 1912, oil on canvas

1.1 Fear and sense of agency

Vince's safe reality of the body he once knew is shifting towards a loss of agency and feelings of disempowerment over its behaviour (Wilde 2003) and Vince is threatened by something he does not fully understand yet. Although Vince may have been given some level of physiological explanation of why this is happening, he has yet to understand and resolve this on his terms. That the brain has a role in Vince's problems is mirrored in Vince being aware that, 'The fear comes from the fact that it is something within *yourself*'. V: 777 (1) and that his condition could deteriorate over time. Vince's deliberations about brain functions leads to him to consider just how much control or agency he actually has over his behaviour, admitting both a fear of his condition and its unpredictability, and well as something he needed to overcome and accept:

VF: Mmm. You don't know when it's going to happen next.
V: No. Because of that I now have a bit of a fear of it...
VF: Mmm
V: ...which eventually I will have to have conquer and accept that it is
      - a part of my now reality. Takes a bit of doing. 251-258 (1)

Chapter 5.3. Vince: I'll let you try and work that that out - even though that looks like a fish

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Vince reaches the stage of recognising a loss of some function and physical change, early in comparison to Morse's model, where this is not accomplished there until stage 3:

> 'I've been in no control in what's happening at all. That's the point that actually frightened me, the fact that I am *not* in control.' V: 247-249 (1).

This fear is well founded and related to the uncertainty of an epilepsy trajectory and he recalls his neurologist confirming that things *can* worsen. Vince told me that he welcomed this forthrightness however, and is aware of the worst scene scenario.

Vince begins to consider what caused the onset of these present experiences and whether he had, in fact, had previous less noticeable events which could have been epileptic seizures. He related past, nocturnal events:

> 'Sometimes I'd be lying there and go absolutely stiff as a board, squeezing my fists, I wouldn't wake up, I'd be still unconscious and exactly what, that was, whether it was dreaming about the car accident - because I spent a lot of time trying to find out what exactly what it was that happened.' V: 186–189 (2),

> 'It went on for about half an hour or something like that. Exactly what, I thought it was because I was thinking trying to work out what it was actually happened in the accident.' V: 224-225 (2).

> 'Yes or maybe in some other way, I was in fact having fits in a sort of totally unnoticeable manner.' V:1069-1070 (1). 'Yes because em [pause] they didn't seem to be, have that effect'. V: 1074-1075 (1).

Vince told me in both interviews of comments made by his neurologist that bore out this idea, 'yes, he *has* had one - he has had a big one and it's been when he has been asleep' V:222-223 (1), and again when I saw him the second time he reiterated this, 'Dr M*** said, things could have actually happened while you were asleep'. V: 219 (2). He processes this information recalling two different people telling him about such events around twelve years after the accident:

Chapter 5.3. Vince: I'll let you try and work that that out - even though that looks like a fish

_____

> 'I know somebody said, in prison one night, what were you dreaming about last night? I said what? He said well, your whole body was absolutely tense. I said, a girl told me about it. I've no idea what it is exactly what, whether that is part of that, (pointing to the centre of his drawing) I've no idea'. V: 198-201 (2).

1.2 Conquer and accept

When I asked Vince how he felt about the diagnosis he said the neurologist had given him of epilepsy, integral to his understanding of his condition was his relief that he had not had strokes, which he compares with epilepsy and perceives as having a worse outcome:

> VF: When you thought you were epileptic how did you feel about that then? Were you disappointed?
> V: No, no I was aware it was something explicable.
> VF: That's right, that you could understand.
> V: Because 9 times out of 10, anything in the brain area is very, very difficult.
> VF: Yeah so you were relieved that he said it was something like that, something you could name.
> V: And it wasn't strokes. Because the difference between the two is amazing – you know a stroke you can end up paralysed for the rest of your life.
> 1192-1209 (1)

This comparison is interesting because at some point in both interviews he alluded (in the second person, hinting at a distancing from this event happening to him personally) to the condition worsening and what a blow this would be to him:

> V: Because eventually, the brain might weaken and I end up where I _am_ collapsing, but when I _do_ it is far more severe....
> VF: You think brain might weaken up what do you mean do something different?
> V: It might, instead of just being there and sort of drawing back ...
> VF: Going away for a bit and then coming back?
> V: You end up losing control of other parts of your body as well.
> W: I hope it doesn't come to that, (very quietly!)

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VF: Mmm?
W: I am just saying, I hope it doesn't come to that.
V: But you know, when you do collapse, something which I thankfully
       I am not at the moment, doing but if it comes to that and I do
       collapse – the difference will be sort of magnitudinal but that is
       the simplest I know.
1503–1523 (1)

Again, here Vince returns to what he perceives as the dynamic qualities of the brain and the damage it received, postulating that the whole thing may weaken and surrender to the superior, damaged part and again, relating this to how much control and agency he had over his body, 'And how much worse it will get I don't know.'V:603 (2).

Vince thus reaches another stage of Morse's model and one in which there can be a refusal 'to accept the [new] damaged self' (Morse 1997)(p29). Instead, Vince struggles to make sense of this new self which has emerged by examining the past, 'I know the whole thing is looking back, trying to collect all of it together... to make sense out of it'. V:327-329 (2).

The question of how and why this new self had emerged and taken so long to manifest itself is resonated in Vince's ruminations that his fundamental self had altered and, unseen until now, an alternative self was fighting to show itself:

> 'I can't understand why is it taking so long ...before it has become - what I've become.' V:719-720 (1).

> 'You don't think that erm - the brain damage you received in a car crash several years ago actually started something which took a while to break through.' V:606-608 (1).

He told me that his neurologist had confirmed that this could be the case, 'He thinks it can go back that far - all it has done is build up slowly. ' V:859 (1). This brings Vince's reasoning to a point where he begins to considers how vulnerable we all are potentially, 'and probably 'cause no one usually is, ever, in full control of their abilities'. V:371 (2):

V: Yeah and it can be *really* frightening.
VF: Yes I have heard people say this before yeah.
V: The fear comes from the fact that it is something within *yourself* – it is something which has happened which has caused....
876-881 (1)

1.3 The fullness of the accident

When I saw Vince a second time he returned to the car accident, and the trajectory of events since then relating this to his brain injury, its earlier effects on his body's physical functioning, the epilepsy and that they are one and the same:

V: At the car accident, er, I did whack my head.
VF: The original car accident?
V: Yeah I did whack my head left side, er right side, when I've done that the brain – come forward very fast, then shot back.
VF: Is that what they said to you?
V: Yeah, the guy who was in charge of me.
V: Said what's happened, your brain's come forward, shot back and its shooting back that it actually (slapped his fist) ...
VF: Damaged it.
V: And that was because of the weakness, I actually got on me right hand side but as far as epilepsy ...
VF: It didn't show up?
V: No
VF: What was the weakness then that you had?
V: Well the whole of my right hand side was sort of weakened. For a long while - walking, people used to say, is he drunk?
VF: Yeah.
V: It was the way of walking, it was the instability on this side.
VF: Yeah.
V: It was also the instability and of course, that, add *that* to the epilepsy, they're all part of, they're all in or out the same pool sort of thing,
VF: What do you mean?
V: They're all together, the instability, the epilepsy,
336–359 (2)

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'I *never* really got to understand the *horrors* of what happened, exactly *how* it happened and *why* it happened. I've never found that out.' V:695–697 (1). Trying to remember the details of the accident was a continuing struggle for Vince. He was facing the challenge of both trying to remember events leading up to a fatal accident, whilst at the same time also trying to make sense of his behaviour which could be a direct consequence of these irretrievable events.

In addition he had been given at one point, some responsibility for his girlfriend's death from hospital staff, 'One of the nurses, has a go at me, the girl we'd killed - she was pregnant and I couldn't think who it was – I couldn't even remember being in a car'. V:268–269 (2). This statement that must have been difficult to accept and process, given that he had only just regained consciousness himself.

Making sense of what is happening to self is another late stage of Morse's model. Vince, however begins his attempts to understand the onset of his situations very early in the interview, almost immediately accepting this diagnosis and drawing attention to the early car accident, guessing that he suffered brain damage from this:

> V: I have had – first of all a car accident I was in quite a few years ago.
> VF: Oh right.
> V: I had suffered brain damage.
> VF: Right.
> V: It weakened the whole of my right hand side and I knew that brain damage - quite a few people who *did* have brain damage had epileptic fits.
> 161–171 (1)

His lay knowledge informed him that people can develop epilepsy after such trauma, 'That's basically what the signs or symptoms are if you get clocked on the head anyway.' V: 396-397 (1).

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Vince's belief that he sustained brain damage is both plausible (there is evidence to support this), and borne out by his neurologist's comments on a recent brain scan, 'He said somewhere up here there is damage - and, exactly what he meant, I wasn't too sure.' V:419-420(1), later attributing this as a reason for his epilepsy, 'the reason I now have this is because of damages, brain damage that I had'. V:163–164 (2).

Vince's pre occupation with brain function was justifiable given epilepsy's organic roots. Vince had own ways of making sense of the mechanics involved in damaging a brain, and which was described to him by a doctor at the time, arguing that the damaged part of his brain was stronger than the undamaged part during a seizure:

> 'And that's probably because my brain and, one part of the brain is being overruled by the other and that's the part of the brain which is damaged – it's actually been - during that period been stronger.' V: 1624-1626 (1)

Vince describes a dichotomy in his brain, one part of it has been affected by damage and acts in a seizure, and another undamaged part shuts down during this period being overruled by the damaged part. One part is malevolent, the other good, one part is strong, the other part is weak, one part is epileptic, the other part not.

1.4 Identification and acceptance

Although Vince accepted that he had epilepsy, at one level he could not identify fully with others with the same condition as his physical experiences were not similar:

> 'That's the thing about it I've seen crashing epilepsy, bumph collapse on the floor.' V:280 (2) and, 'Although I've had this funny feeling, you know where, as I say, I've known people who've been epileptic quite a few people [Pause], I've never been – like them'. V:415-416 (2).

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> 'So of course when you're told it is epileptic, your *understanding* of what epileptics are - and if mine's an epileptic, why is it so different?' V:583-584 (1)

However, he did begin a shift in this view as a shared physical symptom emerged, in this case the headaches he had begun to suffer from, 'I've known people (with epilepsy) when they actually come out of a - you see them holding their heads – every time.' V: 531-532 (2), identifying with them in terms of fighting *something*, be it bodily or emotional stability:

V:	Probably, one of the things I know about epilepsy because I've been told by other people who have epilepsy is that you're in there and you're fighting.
W:	You frightened your Kathy didn't yer?
VF:	Fighting, or frightened?
V:	No you're fighting, you don't know what you're fighting.
VF:	Right, you're fighting but you don't know what you're fighting, so, are you any clearer about what you're fighting now?
V:	Erm ... probably stability.
VF	Stability yeah of, of your body or ...
V:	Yeah of, mental emotions, everything you say and do are all part of your mental emotions, they're all from the mind. 426-437 (2)

This idea of fighting something was identified in the Bethel project as being a concept that people with epilepsy utilised. That the future could involve him in more behaviour reminiscent of what he sees as typical epileptic behaviour is a threat to Vince, and he is fighting not only the loss of his stable body functioning but also the emotions which have arisen in him from this loss and of a potential, future degeneration.

In terms of Morse's model, this is an early process whereby individuals attempt to 'maintain emotional control' with the use of various strategies to become calm about what is happening to them (Morse 1997). Vince is interested in the brain mechanism involved in epilepsy 'It's a brain connection.' V:555 (2), ' it seems to be a weakness somewhere.' V:609 (2). His ruminations about this

illustrate that he is aware that body and mind are linked, and he also wishes to maintain some control over how he copes with the effects of epilepsy, and retain some power over the condition.

Richards in her attempt to understand her personal experiences of being diagnosed with epilepsy at 26 years old and needing to understand her condition in terms of how her body functioned physiologically quoted thus:

> 'A complete treatment of epilepsy is not just the administration of drugs; rather, it also includes (a) teaching the patient about his brain and its functioning and (b) how the patient's feelings, thinking and behaviour can all be used in the control of his epilepsy.' Fenwick (1991) in (Richard 1993).

By the time I left Vince the second time we met, he could be said to have reached the final stage of Morse's model, that of 'Learning to live with the altered self' in that he was, 'accepting the consequences of the experience.' (Morse 1997) saying to me, 'I have to accept it because it's real'. V:514 (2). I believe this understanding could have been furthered for Vince in that, after his neurologist informing him of damage incurred to his brain, some education about the implications of this and the fundamentals of epileptic physiological processes may have been useful for him.

Superordinate theme 2. Reformulations of embodied experiences of awareness and consciousness

Vince articulated his descriptions as a person who knows the world through their body, and whose body is informing him of changes (Wilde 2003). Whereas Vince described hallucinations, illusions and self transformations (Parnas, Møller et al. 2005), his wife confirmed to him that he had remained static:

> V: OK well basically it started off - I was having these 'situations' and
>   they started last year – where I was talking to, talking to people

> and suddenly, I seemed to be totally removed and well, Eileen'll be able to tell you much better, how my voice went -. How did my voice go Eileen?
>
> W: Well, just went funny - couldn't understand him.
>
> VF: Couldn't understand him? Incoherent sort of – you couldn't understand the words?
>
> V: And basically that is *is* what happened and - when I came back I knew I'd been – it almost felt as if I'd had been somewhere else – I hadn't been - *there*, but when I came back I realised that I hadn't left.'

25-37 (1)

> V: I can't really describe it any better, other than the fact that I – as I pulled away, I seemed to be suspended – I was slightly moving away from - and that I can't comprehend at all.

41-44 (1)

He began to describe an awareness of a shift in his conscious state, having the illusion that he has been somewhere else but is cognisant that physically, he had remained where he was. Vince talks of out of body experiences, differences in his self awareness (Parnas, Møller et al. 2005) with illusions of being pulled away, moved away, suspended, slightly moving away from - all perceptual and attentional anomalies (ibid), his wife reinforcing that he was verbally incoherent when in these states.

Vince could be seen to be experiencing what amounts to an, 'anomalous self-experience', including visual, auditory, tactile and motor perceptual experiences as well as 'coenaesthesias' (which can include migrating sensations, sensations of movement, lightness, levitation, elevation and somatic depersonalisation) (Vollmer Larsen, Handest et al. 2007)(p346).

Sufferers of schizophrenia, a condition which straddles the boundary between the categories of organic and functional, experience similar phenomenological attributes, particularly anomalies of self awareness (Vollmer Larsen, Handest et al. 2007). Certain subjective experiences or 'basic symptoms' uncovered in clinical interviews can assess, and may accurately identify, people at risk of

future psychoses - these being 'pre-psychotic antecedents of full-blown psychosis' and hence 'proximate to the underlying hypothetical causal biological dysfunction' (Vollmer Larsen, Handest et al. 2007)(p345). This innovative work in schizophrenia, was inspired by Husserlian phenomenology and the work of Janet and undertaken by German psychiatric scientists who study patients' subjective views and experiences systematically (Parnas, Møller et al. 2005).

Vince did not seem able to focus his attention on anything else but on that which he was experiencing, but was still aware that events were ongoing around him. Vince reformulates his descriptions further, expanding on his awareness in terms of being unable to converse with other people around him:

> V: And then suddenly this thing came along and I lifted away.
> VF: Lifted away?
> V: Yes that's what it felt like as if I was lifted away. I could *see* the people I was talking to, ... but as the ... em what's the word? – the *contact* seemed to be broken and that's one of the points that erm, I *don't* understand – it didn't seem to make an awful lot of sense.
> VF: Did the, the fact that you broke contact with somebody – that didn't make sense to you?
> V: What – was the fact that I seemed to have been taken away - and the contact I was making - even though I could still see .....
> VF: You could still see them?
> V: Yeah ...but the contact with them was no longer there.
> VF: By contact you mean you couldn't speak to them?
> V: I mean I was *trying* to speak but as Eileen's just told you, it was mumbo jumbo.
> VF: Mmm.
> V: And the contact had been broken because I failed to realise just what was actually going on.
> VF: You failed to realise.
> V: Yeah.
> VF: That you were – because you said that you had been lifted – felt as thought you had been lifted away.
> V: And I couldn't understand the reality of why – you know, what it meant.
> 76-113 (1)

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It is these subjective, qualitative descriptions of experiences which are rarely studied, in part because of issues of reliability (Parnas, Handest et al. 2005; Vollmer Larsen, Handest et al. 2007), but which need to be reified - and in their own terms, which is what IPA does. When studied, systematically and with a phenomenological approach, i.e., giving the patients space and time to verbalise what may be to them real albeit, 'fleeting' and 'ineffable' experiences, these could serve to enhance and inform other measures of experience (Parnas, Møller et al. 2005)(p237).

The concept of defining consciousness or, impairment of consciousness, is a contentious one and will be returned to later. Briefly, however, one way of thinking about whether someone is 'conscious' or not, is to consider the various degrees to which someone can be self aware. Some argue that a conscious mental state is one which is accompanied by 'higher order states' that is, an individual is aware of being in this state and can consider for example, thinking about some thought or being aware of their mood or a bodily sensation (Kriegel and Williford 2006). This constitutes the self representational theory of consciousness – that is, a conscious state is only that if the individual is aware of their own conscious state, external stimuli, themselves, and their awareness of that stimuli (Kriegel and Williford 2006). If we think of Vince in relation to this theory, he is in a state aware whereby he is aware that he cannot communicate with others, (i.e., conscious) however, others perceive him as being unresponsive.

Another way of thinking about consciousness, is to think of it as involving a person being able to interact empathically with others in the social world at a given time notwithstanding they are receiving a constant flow of altering mental activity (Kalamangalam 2001). In these terms, Vince is *not* able to communicate with people around him. Although people experiencing seizures may *appear* to be unconscious, this may not be the case. Just because they do not respond during a seizure does not mean that they are 'unconscious' to, or

unaware of, other input, they simply may not be able to articulate this at the time. A perceived, loss of consciousness observed during a seizure may be due to a person not being able to perform voluntary movements, or they may have diverted their attention to a hallucination or illusion they think they are experiencing. Thus, such behavioural disturbances often seen as a loss of consciousness by an observer may not be what the individual personally experiences (Gloor 1986).

In neurology the understanding consciousness - which leads to defining seizure types (Johanson, Revonsuo et al. 2003), is centred around how responsive a patient is during a seizure. This understanding assumes that, 'behavioural, constituent functions of consciousness' (i.e., defined as operational definitions of behaviour) can be reliably measured by someone else, (given that this would be dependent on both the patient's and observer's level of articulacy and language skills), as representing what is, essentially, a patient's subjective experience (Cavanna, Mula et al. 2008).

The philosophical understandings of consciousness however, *is* about people's subjective experiences and the phenomenal nature of that conscious experience described by an individual, to the best of their ability, again often in terms of their linguistic skills. This experience actually consists of unifying experiences from various sensory modes into a new simultaneous experience, existing as a state of consciousness in its own right - phenomenological consciousness (Tye 2003).

A suggestion that the concept of unconsciousness is not a useful in seizure experiences (Gloor 1986) is illustrated by the above comments, i.e., attempting to assess whether Vince is either conscious or unconscious, aware or unaware is not tenable here at this level of analysis. He is however, in a state somewhere between these descriptions at different stages of his experiences. Vince offered

me a first hand account of a his experience of consciousness which involved his perceptions of his body in an external world (Velmans 1996).

Seizure experiences can be 'bizarre' and are ones which do not occur in a person in their normal awake state, thus finding the language to describe these is not easy (Johanson, Valli et al. 2008). However, even without recourse to a language to express his experience, Vince managed to articulate many details of this awareness. He described, bodily and modality specific sensations, hallucinations, his cognitive functioning, alterations in levels of consciousness, his absorption and where his attention was directed (Johanson, Valli et al. 2008). It is this first person perspective that I accessed, second hand through the language he had at his disposal.

Because of the clarity of Vince's experiences, and in order to link these with the understanding of him being in differing states of unawareness and awareness rather than being simply consciousness or unconsciousness, the following are extended excerpts from his descriptions which illustrate this as we both attempted to gain an understanding of what he was feeling:

V: The way it actually happens when - I am talking normally and I *still* think I am talking normally - but I seem as if I'm got lifted up and away and I am looking at.....

W: You're in a world of your own.

VF: Mmm.

V: Yes, you know in a sort of - almost in an empty atmosphere.

VF: An empty atmosphere? How do you mean - What does that feel like - is there - cos there's other people there? How is the atmosphere empty?

V: Because you seem to be lifted as if - the atmosphere that keeps you held down.

VF: Keeps you held down - so it lifts you up and keeps you held down?

V: No - it lifts you up and you almost feel as if you're floating ...

VF: Mmm.

V: ...if you're floating then - the normal atmosphere that keeps you held to the ground ...

VF: Mmm, normally, yes gravity.

V: Yeah gravity, that's the word.

VF: Yes (both laugh)
V: The gravity seems less restricting because you seem to lift up, you can *see* who you're talking to - but even though you can *see* them, they seem to be a long way away, and you know, you sort of come back down and when you come back down, you don't really understand what it was.
462–498 (1).

V: Well it seems that where I'm concerned it's this thing where I seem to lift away and, I'm not me.
VF: You're not you? Who are you then?
V: I don't know, but I'm looking at the people and even though they haven't changed, *I* seem to have changed.
VF: Changed?
V: Yeah, when so I come back down, it seems ...
V: ...as if it's only natural
VF: It seems ...
V: That this happened although I don't understand it at all - it doesn't make any sense.
VF: Natural - not natural, what do you mean? Because you said you felt as though you were lift up and then held down but then you said you're floating.
V: Yes, you float away and as you're floating you're looking - they seemed to have gone further away from you and - you're thinking - I can't really say whether the thinking is positive or negative.
509–534 (1)

Vince's experiences are complex at this point, he describes himself floating above and apart from people, his wife interpreting the same time period as him being in a world of his own. Vince is again, describing various anomalous experiences similar to those people with schizophrenia experience; physical and visual delusions, illusions and derealisation, whereby he is moving in space, moving away and returning, looking down on people and self transformation. He is then trying to put these experiences over to me verbally, using particular linguistic strategies in order to help him do this (Tye 2003).

Vince utilises embodied language and 'conceives of abstract concepts in physical terms' (Gibbs 2006)(p440). Because, as human beings we have shared experiences such as, what it feels like to float, to look down on other people from a height, or to day dream, the approximations Vince uses to describe his

experiences (see box 8) are rooted in, and are simulations of, these shared experience (Gibbs 2006). The listener, therefore, can 'understand something of what other's experience' (Wilde 2003)(p171).

> 'I can understand the function of the living body only by enacting it myself, and insofar as I am a body.' (Merleau-Ponty 1945/62)(p 75).

That is, we can *imagine* what Vince's experiences feel like for him, from his descriptions whilst knowing that these things did not literally happen.

Box 8

Approximations of experiences by Vince

it <u>almost</u> felt as if I'd had been somewhere else
you seem to lift up
<u>as if</u> I got lifted up and away and
<u>almost in</u> an empty atmosphere
<u>as if</u> - the atmosphere that keeps you held down.
it lifts you up and <u>you almost feel as if</u> you're floating ...
it's this thing where <u>I seem to</u> lift away
<u>they seemed</u> to have gone further away from you
I'm not me, <u>*I* seem</u> to have changed
I can't really say whether the thinking is positive or negative

Vince speaks of still being able to see people but also realises that his contact with them has been, temporarily, broken off. Vince, for this period of time, *appears* to others to be unresponsive and he and his wife come to a shared agreement of how this appears to others:

> VF: And do you agree with him how he described his seizures?'
> W: Yes I do really. He does seem to be – away.'
> 1264-1266 (1)

Vince however, is also aware that he has lost this ability to show to others that he is in fact, perceiving *something* and he reiterates this later in the conversation comparing it to others who have epilepsy:

> V: Cos there are some who just, they have no idea what they do because they totally collapse, they are unconscious. Whereas I am still, to a certain extent – conscious in that ...
> VF: Yes you are
> V: ...if not fully connected, I am conscious about what is happening and to a certain extent that, I suppose, is good luck.
> 1492–1499 (1)

Towards the end of our first interview, Vince begins to have some insights in terms of becoming aware that some of his own behaviour was not always within his control (he did not remember dropping a fork, for example during one experience, but remembers leaning down to pick it up again, so at some level he

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has 'remembered' that he had done this). He is also aware that, what *he* thinks is happening is not perceived in this way by onlookers:

> V: And that is the thing about epilepsy, it is totally unconscious.
> VF: Mmm.
> V: Even although you can *see*, when you're speaking you know what you are saying - but from there to there the translation goes totally different, because you're not saying what you're thinking instead of coming out with understandable, understandable, words it's coming out (laughs) as absolute rubbish.
> 1612–1620 (1)

Vince process is not linear within Morse's model and the two passages above illustrate his movement between stages. For example, lines 1492–1499, above indicate his location in both the first and second stage. Stage one, as our conversation allows him to incorporate his new experiences as being a part of himself and stage two, Disruption: Enduring to Survive, whereby he realises that life has changed for him. He also comes to the realisation that his version of events differs to others. In lines 1612-1620, Vince moves onto stage three where he is 'grasping the implications' of his condition and 'learning what happened' through his inner dialogue, his dialogue with me and his wife's observations.

2.1 Loss of insight

Vince's initial, complex descriptions quoted above are invaluable because, by the time I met Vince again, they were irretrievable. That is, although these initial experiences which he had described in terms of embodiment and which were very meaningful for him at the time, something had altered. Upon looking back at this, the original filter or lens he had used on this experience, did not make as much sense to him (Smith and Eatough 2008).

Vince did not 'feel' these experiences anymore, he described them as altering into one where only a physical headache prevailed, during which he was not

conscious of anything else. He did not use embodied language to describe what he was experiencing, but shifted to describing them in terms of basic, everyday experiences:

> V: No, what seems to happen is that, basically I get pretty hot.
> VF: Hot.
> V: Yeah, end up with a really stinking headache, which I can't get rid of for at least half an hour.
> 29–32 (2)

However, he questions whether things still appear to *others* as they did before, i.e., people being unable to understand his speech which his wife confirms is the case:

> V: I'm wondering instead of, at a point when I'm talking to them, they hear me talking gibberish.
> VF: That's what you said before, but you don't do that anymore or that does still happen?
> W: It does happen now and again.
> V: I don't really notice it.
> 44–48 (2)

Vince is still not (as he was not before) aware of this but also, he does not – indeed he cannot anymore verbalise the complex feelings and sensations described in his initial descriptions. This loss of insight and introspection is replaced by other descriptions which are grounded in real life examples and, for people not experiencing seizures, actually easy to relate to in terms of the disorientation he felt:

> V: Yeah I remember all that - but that was the weird thing about it I could *see*, I could see, feel, but not totally understand. Becoming, you know getting on the train or a tube in London and going towards somewhere but going the wrong way.
> VF: That's what it feels like?
> V: But getting on the tube, you're suddenly thinking, I'm going the wrong bloody way, get the tube back, but how often would you actually get on and get a tube back, how often would you actually think like that? That is the thing about epilepsy.
> VF: So you still feel a bit like that? (the picture)

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---

V: Yeah.
542–550 (2)

V: When that happens, it's like a loss or its like, you come out you going to get in your car, another car, there's another car, the exact same car, put your key in, you wonder why you can't open it.
VF: And that's what its like?
V: Yeah.
561-565 (2)

This is a common strategy for people when describing their gaps in consciousness, this is not a normal state for them to be in and they attempt to relate it to common experiences that they and others have had Gallese Vittorio, (2001) in (Thompson, Osorio et al. 2005).

Vince's process of integrating a new self is reformulated below with some differences to Morse's trajectory in terms of differences in some responses and strategies. Where strategies are employed by Vince, these are in the original model. Other responses not made by Vince are omitted. For example, stage one did not involve as strategies, Vince becoming overwhelmed and accepting assistance from others. The dependency element was also missing in stage three, as was a fear of being isolated. An extra response was added to stage 4, that of reflecting on the past because, in striving to integrate a new self Vince's response was to make sense of his situation by reflecting on his past. Stage five saw him at one level accepting his condition and trying to know his 'new' body, whilst not wholly trusting it. Vince had an additional major response in learning to live with his altered self - that of feeling disempowered by his seizures. Vince went through a process of accepting a new self but had a strong sense of disempowerment about his control over his emotions and his mind. It is arguable that 'disempowerment' could be added in as a final stage in an adapted model.

Table 10

Vince's progress of integrating a new self

	Stage	Response	Strategy
1	Vigilance	Suspecting, reading the body	Observing, noting and recording changes
		Observing	Imprinting the experience
		Maintaining emotional control	Staying calm
2	Disruption: Enduring to survive	Being in a shattered reality Experiencing a "haze of disorientation"	
3	Enduring to live: Striving to regain self	Trying to bear it, learning to take it	Focussing on the particular
		Recognising physical change and loss of function	Discovering limitations
		Grasping the implications of illness and injury	Learning what happened
		Recognising the uncertain prognosis	Focussing on the present
4	Suffering: Striving to restore self	**Reflecting on the past**	
		Doing the work of healing	Living with setbacks and discouragement
		Making sense	Piecing reality together Reiterating the experience Seeking information Examining events Searching for meaning Accepting the losses Recognizing " it could be worse"
5	Learning to live with the altered self	Getting to know the altered body	Learning limitations
		Accepting the consequences of the experience	Learning to live as a disabled person
		Disempowerment	

Nonlinguistic data: Vince's explanation of his drawing

I'll let you try and work that that out - even though that looks like a fish. V:1536-1537 (1)

Using non-linguistic forms of data has been used to try and gain descriptions which bypass conventional ways of making sense of things and can be useful if people are not verbally articulate. However, they can still be read in different ways by different people (Gillies, Harden et al. 2005). The drawings that were produced by my participants were serendipitous in that, although I took

drawing materials along with me 'just in case' an interview should falter, they were not an expected outcome and welcomed as another mode of interpretation to explore.

When I first offered Vince writing implements, he did not think he could depict his seizure in a drawing:

V:	It was all – to draw it, all it would be would be a question mark.
VF:	Would it – do you want to try or and just put a question mark you think.
V:	Yes, a question mark – because, it is something I so definitely don't understand so what exactly is happening is totally questionable.
VF:	Well you *know* what's happening because you have described it haven't you – it is *why* isn't it really?
V:	Yeah, and that is the obvious question mark and to say it goes back as far as ...
VF:	To the car crash?
V:	... where I had the brain damage in the car accident, yes.

1133-1149 (1)

However, whilst his wife was talking to me about unrelated, family events - which could have been problematic in terms of an unwanted diversion, this worked the other way and Vince produced the drawing below while she was talking to me. The physical process of drawing and explaining it to me verbally (see box 9, below) appeared to help Vince make more sense of his experience in terms of clarifying what happened to him in his early seizure experiences.

Chapter 5.3. Vince: I'll let you try and work that that out - even though that looks like a fish

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Figure 10

Vince's drawing
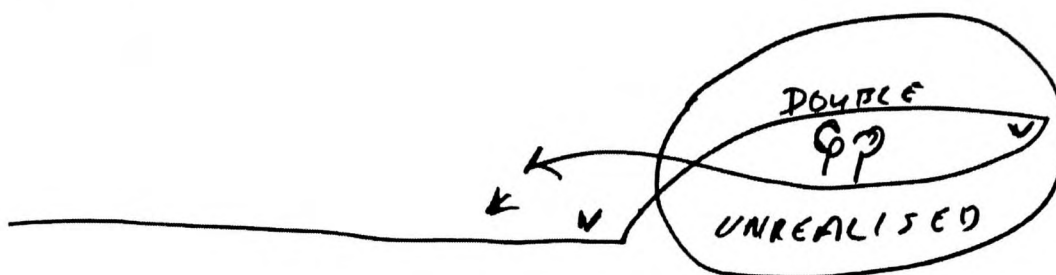
Vince's drawing can be read in several ways and one can move between these readings. It tells us something about; the phenomenon being explored, something about the person who drew the image, something about meanings and resources available to them, and it can act as a resource to encourage further discussion (Gillies, Harden et al. 2005):

> 'The whole circle around that there that's me - questioning going in, questioning coming out. But still...... mmm, still unrealised because you don't really feel and if you don't really feel, then the realisation is minimal. No the realisation is, if you feel exactly what is going on – but you don't, so that makes it unrealised. Well that's probably why it's so bloody confusing. You are going in with something and you are coming out and other people realise you have gone in – you come out without any real realisation.' (Vince, 2008)

The drawing is a much simplified depiction of his initial, verbal descriptions but confirmed and consolidated it. The drawing symbolises Vince being completely enclosed, within another enclosure where things are ongoing but he has no knowledge of these. Vince's 'spanish' question marks, depicting before and after the experience, illustrate Vince's constant striving to doubly understand, both the experience itself and what led up to it.

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It extends Vince's experiences of his awareness in terms of the relationship between his subjective experience and his external environment (Johanson, Valli et al. 2008).

This drawing, like his early descriptions and his poem, (see Diamond Cutting section) could not have been constructed the second time I saw Vince. His experiences had altered to one of just experiencing a headache, which he had to sit through until it abated.

When I asked him in the second interview, if the drawing was symbolic of his experiences as they stood now, he recalled what the drawing had meant at the time but had no idea of whether this was actually happening to him at this later point. He found his two experiences difficult to relate to each other and when we looked again at his drawing of his initial experiences he seemed to lose his ownership of it, 'Well I don't seem to be getting affected the way I was (pointing to the drawing) there'. V:38(2), 'whether that is to do with this (flips drawing) I've no idea'. V:152 (2) so it could be argued, was not a fixed representation of his experiences but one which was captured as being representative at the time.

Box 9

Vince's verbatim explanation of his drawing

V:	Do you understand that? (the drawing)
VF:	Erm, This is you – one, minute you are there –
V:	The first I am there, then I come to there and then I come back coming back, coming back, heading back to where I was before...
VF:	Where you were before.
V:	...on level ground and suddenly I seem to be *above* ....
VF:	Mmm, looking down on people.
V:	Yes above, almost beyond and *then* I come back – but exactly what is happening during *that* period is ....
VF:	Is inside there? Mmm. What's that?
V:	I'm doing it wrong.
VF:	Do you want a question mark?
V:	Yeah.
VF:	It's like that isn't it –Yes. But you don't know what is happening in that space of time?
V:	Yeah, That's a Spanish question mark –
VF:	Is it really?
V:	A Spanish question actually starts *before* the question and you have that – you have – sort of - this.
VF:	Have you done Spanish?
V:	Yeah, a little bit.
VF:	What does that say - double, double, double?
V:	You're doubling, and in, while you're in, while you're in there is a question going in and a question coming back out because they're unrealised.
VF:	The questions haven't been answered – yes.
V:	Yes, basically (more drawing)
VF:	Unrealised questions or.....
V:	Yes. The whole lot there...
VF:	Mmm, mmm
V:	...*is unrealised* – to me. *Other* people see it but I don't.
VF:	Yeah.
V:	All I see is - sort of coming from there over there and then going back...
VF:	Going back. Yeah I understand. So you *could* draw it.
V:	I have been thinking about how to do it.
1396-1460 (1)	

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Reflections on Vince's experiences

Although I analysed and interpreted Vince as a case in its own right, much of what I heard from him did resonate with me as being similar to what the Bethel study had described in people with epilepsy, and given that the IPA researcher is an integral part of the interpretation and can speculate on their interpretation, I offer some reflections in these terms briefly here.

Vince did not need prompting to tell me of his experiences, he had long thought about them, written them down in advance of meeting me, drawing and talking at length about them, even managing to replace his loss of phenomenological insights with other useful analogies which lay and professionals could relate to. In an interview with Vince in the Bethel work, this would be a significantly factor in terms of a positive epilepsy diagnosis.

Most striking was the complexity and insightfulness of Vince's initial descriptions contrasted with later ones. Vince never wavered from these, formulating and reformulating his descriptions including offering a visual form, in order to put them across to me. He demonstrated an acute awareness of the levels and contents of his awareness, knowing when he moved from being able to communicate with others to a complete inability to do this, recalling, like many of the Bethel participants, this move from 'dynamic to static' state. He also attempted an complex reconstruction of his time spent in this state supplemented by observations from observers (Fuichner 2002). He describes to 'out of body experiences' (autoscopy) which occur in dissociation, (LaFrance, Gates et al. 2008)(p318), and mental illusions of derealisation and depersonalization (Wolf, Schöndienst et al. 2000; LaFrance, Gates et al. 2008)(p318), along with visual and auditory illusions which the Bethel studies found can point to an epilepsy diagnosis.

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Vince used language which approximated his experiences, not making great use of metaphor although he did verbalise perceiving epilepsy as something to be fought with which again, was a significant diagnostic pointer in the Bethel studies towards a diagnosis of epilepsy (Surmann 2002). The implication that the seizure was external, an enemy and a threat and Vince was a victim of it also relates to the concept of agency and of the seizure being an independent entity which acted upon him from outside of him and of its own volition (Plug, Sharrack et al. 2009i).

The rapid loss of Vince's insights into his experiences occurred between the two interviews, possibly since he began his AEDs and may be important to note. Although these experiences were real to him at the time, Vince was unable to relate to these earlier descriptions. Epilepsy is experienced variously by different people and it is important to capture these initial experiences and their subsequent temporal progression (Andermann 2000).

Brief resumé of Vince

In order to make some sense of his present experiences, Vince re-examined his past, relating serious past physical injury to his present condition, that is, how a car crash many years ago and subsequent head trauma could cause his present seizures. He eventually linked the effects of the accident with his present condition. One thing he never resolved or remembered however, was the run up to the accident which both caused the death of his girlfriend and, arguably, his present seizures.

Vince had explored and considered alternative explanations for his experiences, and was relieved when the neurologist told him he thought he had epilepsy comparing the outcomes of what he thought were 'mini strokes' to those of an epilepsy diagnosis. He ruminated about the 'brain connection' and conjured up pictures of how the weaker, good part of his brain could succumb to being taken

over wholly by the damaged, stronger, epileptic, malevolent part which could lead to further damage to and, potentially, to further loss of bodily function.

Vince's extensively described his seizure experiences in terms of consciousness, using language which facilitated powerful images of them, which included illusions, hallucinations, bodily and modality specific sensations, cognitive functioning during a seizure and alterations in levels of consciousness, i.e., where his attention was directed and may have, in another study, hinted at a diagnosis. Equally, some experiences may have been missing, people with seizures can have sexual and erotic experiences (Johanson, Valli et al. 2008) and Vince may have chosen not to tell me about these given I was a female researcher.

Coda

Vince gave his reasons for taking part in my study as being both to help other people and for his own understanding, 'you know I'm perfectly willing to go through the whole thing, because it will actually help *me* to understand'. V:259 (1)

> VF: What - talking to me you mean?
> V: Yeah, [pause] because by talking about it, I *may* get a better understanding of exactly what it is.
> 347-350 (1)

Vince was also aware of the very subjective nature of his experience and how difficult it was for others to understand this. When I asked him at the end of the interview if he had any ideas for additional questions for me to ask other people he said, 'all I say is please attempt to be totally self descriptive'...'because doctors can give you an idea but the reality must come from the sufferers, because they are the only ones who can or cannot,' V:1482-1488 (1). This notion of the patient being the expert, and mentioned by Gülich in the context of the

Bethel work, accepts that patients and doctors have different expertise and neither are superior or inferior (Tuckett, Boulton et al. 1985).

It is argued that bodily experiences can shape participants' narratives (Öhlen 2003). My findings illustrate that these are often poetic and evocative. Vince's interpretation is concluded with two poetic interpretations of his experiences in section 5.6.

Addendum: Information obtained from the Consultant (A.M.,) after the completion of the research.

Since I first saw Vince neurology services were considering whether he had post traumatic epilepsy from his RTA. It was also considered whether he had suffered a stroke. After being prescribed the AED, Tegretol, his seizures lessened considerably and his diagnosis then became 'probable temporal lobe epilepsy'.

Vince was finally diagnosed with complex partial seizures with and without generalisation. Scans showed the presence of some old injuries in the right frontal hemisphere and there was correlating epileptic EEG abnormality.

5.4 Graham: Metaphor analysis

Mini biography

For his first interview, I collected Graham (age 51), from the hospital where he was visiting his wife who had terminal cancer (she died soon after our first interview). Graham's son, in his early twenties, had autism and epileptic seizures, and his 18 year old daughter was unemployed, trying to improve her employment chances by taking a computer course. They lived in a small end terraced house in a poor socio-economic area of the city. Graham's daughter shared a bedroom with her brother. Their home was under threat of being compulsorily purchased at the time, and he was concerned about where he could then live, as he could not afford to buy a house. However, when I saw him a second time, this threat had been removed, the surrounding streets were due to be regenerated, and his daughter could now have a room to herself. Graham had been involved in a car accident some 38 years previously in which, he told me, he had sustained head injuries. His right side is slightly paralysed, so that he walks badly and does not have full use of his right arm.

I experienced the first interview as exhausting. Graham was extremely difficult to understand, mainly due to him shifting from one topic to another as I struggled to, keep track of what he was saying and, to gain an impression of what his experiences were like. I also had to orient myself to the language he used, which was sometimes strange, [105] although his constant use of metaphor helped him to describe his experiences and helped me to understand and interpret them (Finch 2004).

Graham's biography was not in the form of a coherent story (Miczo 2003), The trajectory of his interview [106] continually shifted between what was happening to

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[105] Examples of these are, 'Sorry. Rephrase that I will.' (357). 'These absences will spark things out and about'. (359). ' So I was sat, sat there, be having fits with it.' (411), I sound a bit grotty that (851).

Graham in real time, what had happened to him in the past, (particularly in relation to the car accident - a major theme throughout his interview) and projected into the future with his concerns about his wife and son. It was difficult to keep track of his thought processes, Graham was clearly nonplussed about what was physically happening to him, and how he was going to cope with his immediate family circumstances if the situation continued, 'but I'd like to know [long pause] about why things like this are happening. I'm just really confused.' G:815 (1). What was then required of me was to piece together Graham's story to make some kind of coherent whole, in terms of offering a description and interpretation of his experiences (van Manen 2006) (Thomas 2005).

This shifting trajectory and one which my unscheduled interviewing style accommodated was useful in that it allowed Graham to add into the interview at various points things which were significant to him. For example, perhaps because we had already talked about this in the car pre interview and on the telephone, the gravity of his wife's condition only emerged later on the interview.

Following his first meeting with the neurologist, Graham took the offer of a chance to talk to me about his situation:

> '... and have a chin wag you know, to have a talk of what's actually happened, so I says, if you don't mind Mr M***, cos it's scaring me, it really has put me hairs up. Do not want it to happen again, you know, I'm scared as I said about the family, and me wife can't cope.' G:580-583 (1)

Graham, in the main, talked about himself the greatest number of times, and his wife and son second. He spoke very little of his daughter at both interviews. She was almost invisible within his talk about his family, not appearing to need

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106 Interview one trajectory outline and more detailed representations of this in the thesis appendices file entitled, Graham - representation of interview trajectory, 1-5 .

Graham to care for her, later registering herself as an official carer for him. Graham had been made redundant just over a year earlier, after being in a job for nearly 25 years, and found himself a year on in a very different situation from being in full time employment, 'Now a year after that, me wife having cancer, and me son starting epileptic fits.' G:1296(1).

Graham's son had been seeing the neurology services for two or three years and had 'funny dos'. Graham did not expand upon why or when his son's original need for AEDs had begun, or whether he had epilepsy or not (although he appeared to have been instructed to administer a small dose of an AED, Clonazepam, when a seizure in his son appeared imminent). Graham brought the interview to a close himself by reiterating what the research was about and what it could possibly uncover. What was required of me was to piece together Graham's story to make a coherent whole.

Structure of interpretation

Graham's interpretation will be structured around the metaphors he uses because his constant recourse to metaphor as a rhetorical device aided him in imaginatively conceptualising his thoughts and cognitions about his situation (Deignan 2005). Like Surmann's work, the cognitive theory of metaphor is the one which underpins this interpretation. That is, metaphor is an intuitive, unconscious way of attempting to express complex experience and the essence of metaphor is understanding and experiencing one thing in terms of another. Cognitive metaphor theory argues that how we think and act is metaphorical in nature, that our conceptual system is automatic, i.e., we think and act automatically along certain lines. Metaphorical concepts can be extended beyond the range of ordinary, literal ways of thinking and move into figurative, poetic, colourful, fanciful language and thought and concepts can be uncovered by examining the language used by someone (Lakoff and Johnson 2003).

The experiences Graham describes in his interviews are clustered into four superordinate themes. The first being set within the backdrop of his new role of being a significant presence in the family in the caring of his terminally ill wife, his autistic son and the stresses related to this. The first superordinate theme, 'I gotta be there', G:1085 (1) is an interpretation of his life situation at the time I saw him and sets the scene in order to understand Graham's physical experiences. Each person has their own way of making sense of what is happening to them and this is bound up with their personal life, circumstances, social and cultural milieu, and other economic aspects of their lives. It was important, therefore, to put Graham's experiences into the context of his everyday life (Stelter 2000), as they constituted a major part of what he talked about in his interview with his seizure experiences inextricably related to these.

There follows three additional superordinate themes, 2) 'spitting images', 3) 'understanding multiple beginnings', and 4) 'distancing', all of which reflect the confusion Graham felt as to where and when his physical experiences had begun and whether they were a reflection of what was going on in his personal and family life.

Table 11

Superordinate and superordinate theme one

Superordinate theme	1. I gotta be there
Subordinate themes	1.1 Stresses and strains 1.2 Maintaining emotional stability 1.3 Coping strategies 1.4 Sentry work and isolation

Gibbs argues that people make sense of their own metaphoric constructs in a process whereby they imagine that they are performing these bodily actions, (even though some of them are impossible to do physically), and this helps them

understand their situation and put it over to others. People will recruit verbal, embodied metaphors because they can 'recreate what it must be like to engage in similar actions' (Gibbs 2006)(p438). For example, metaphorical expressions such as 'grasp a concept' or 'get over' an emotion involve simulating what it must be like to engage in these specific activities, even though they would be physically impossible to perform. This process of building an embodied simulation is both facilitated and constrained by past and present bodily experience and, consequently, for how verbal metaphors are understood (Gibbs 2006). The concepts behind the metaphors Graham employed encompassed elements of his day to day pressures appearing to act as props in maintaining his emotional stability and in helping him formulate coping strategies. The sections below will explore Graham's use of these.

1.1 Stresses and Strains

The pressures upon Graham were immense the time I first saw him: as well as his wife being terminally ill, his grown up son had autism. Graham was beginning to realise that he was now juggling and negotiating new roles, as a carer, husband, and full time parent which were, it could be argued, more predominant now given his wife's condition, and very different from his traditional, recent one of 'bread winner'. His life had changed irrevocably since his redundancy and ensuing events, and he had been launched into a situation he had not envisaged (Sadala and Adorno 2002) responding as well as he knew how, beginning with his ability to at least be physically present:

> G: For their sakes,
> VF: Yeah.
> G: I gotta be there, you know what I mean?
> VF: Yes.
> G: Sorry, that's, (re) phrase it, I've got to be there, it's a, parent
>   husband's duty, innit?
> 1081-1089 (1).

That this is both new to him and exerting its effects is illustrated by the metaphoric concepts Graham uses which, throughout his interview, served to trace and illuminate his thoughts and helped me in the hermeneutic process (Finch 2004).

I assumed that emotions must have been running high at this point and as such, were an integral part of him 'being in the world' (Thomas 2005). However, that he experienced emotions were only voiced by him once when Graham told me of his wife's prognosis and which hinted that public, uncontrolled displays of emotion were not, to him, acceptable:

> 'Well, I've got to, cos, er, me wife the way she is, and I told yer she, I sat in, M*** W***** from oncology on Friday, will I last 'til Christmas? I broke down, I was crying me eyes out, you know, so did she, and it's, something I don't want to happen again, you know what I mean.' G: 1074-1077 (1)

Graham hinted at the direct stress caused by the demands of caring for a palliative patient, their physical needs and how it affected family and domestic life. For instance, he mentioned sanitary supplies that were delivered in bulk to his home, which he hinted took up precious space in the house:

> 'Second day I think it was. Dove House sent a sort of napkin and there was, I don't know how many there was but there was say about five hundred in about, I don't know how many boxes but it was like Father Christmas come early in the kitchen, in there, you couldn't hardly move you know. Wife in tears, crying her eyes out like, oh dear.' G: 204 - 207 (2)

This delivery signified his status as a carer, and his wife's of being dependent on him along with a reduction in her functionality and her mortality. Graham had visited his own general practitioner about his wife being at home, who immediately visited him to assess his home situation and to support him as his home environment was transformed into a palliative care ward for his wife:

> 'Dove house get a bed in here and oh er everything was shoved all over the place, like Steptoe's back yard in here borrowed me mother in laws commode, and lady from Dove house bought some like a cabinet what have you to use, and, I was getting a bit tensed up then.' G: 195–196 (1)

It could be considered that Graham was also suffering from 'vicarious stress' (Thomas 2005)(p64), as his son and daughter were grappling with the situation in their own individual ways which, in turn, may have impacted upon him.

Graham was moving towards the realisation that he is solely responsible for the family, his wife being beyond supporting him in this and hoping that he has the personal resources to do it. The metaphors of being 'put into gear' and wanting to 'see' what was going on in his head indicate his desire to understand this:

> G: What's exactly going on you know, is there anything I could,
>   anybody I could talk to, put me in gear, please, I want to know.
> VF   In gear?
> G: Yeah, I wanna know what's between my two ears. Have I got a
>   brain? Do you know what I mean?
> 718-724 (1)

1.2   Maintaining emotional stability

Graham's stress did not appear to have any other outlet for channelling it other than his use of metaphor in order to understand and 'visualise' this in various ways (Finch 2004) or in his physical manifestations of seizures.

For example, when talking about a time when he thought he was going into a fit, Graham's statement below could be construed in two ways. In one sense, he could be describing how he feels when attempting to manage, inhibit or stall an ensuing fit. Alternatively, this could be seen as a metaphor for a fit, whereby he is describing a way of behaving which allows him to withdraw from the immediate needs and demands of his wife. The fact that he entered into a discussion with me about his non verbal signals to his wife that he needs some time to respond to her, lends some support to my second interpretation:

G: Yeah, cos it feels, you feel like you're, er, an outsider cos you feel so guilty that you, if your wife is trying to talk to yer, you can't really express, any, er, emotions, to what she's saying, you can't really agree or disagree, or conversation onwards, you sort of like sit there, and you put your hand up and say, whoa, whoa, whoa, you just -

VF: Oh!

G: Close off a bit will yer, in a way of putting it, just go, hang on, you know, a couple of minutes after that, what were you saying and explain to her what I've just had -you know what I mean.

VF: But she knows about them, so she understands. Maybe you could have a signal or something, well you do have one, don't you?

G: Yeah, I put my hand up and go, 'take five' in hand signal, take five you know, I don't use hand signal like deaf people do, but it –

931-946 (1)

The feelings of guilt alluded to in the quote below from his first interview, appeared to be associated with him coming to terms with his new role and the tasks he was now obliged to undertake in order to fulfil this. For example, something being on one's 'conscience' implies feelings of guilt and, when I queried this by asking him what he meant he rephrased this:

G: I've got that much on my, that much on my conscience.

VF: On your conscience? It's not your, what do you mean by?

G: On me *mind*.

VF: On your mind, yeah.

1283-1289 (1)

His description of things being *on* his mind, rather than *in* his mind inferred some element of pressure and it was in the second interview when Graham expanded in retrospect and coherently, on what was going through his mind at this time. He also related what could be seen as the beginnings of his grieving process as he began to consider what his life would be like when his wife had died:

'Yeah alright me days were all planned out like visiting times twice a day, washing, taking stuff to and fro from the hospital, pay your bills, do shopping, and you know such as like, such as er life's chores aren't they really? Say in your mind good grief, it is tiresome and it is jiggering, but you've gotta cos it's your other half innit? It's your missus, wife like. So you do think of what's gonna be, going on at the moment, picture what's

going to be in the future so you do like to, get stressed up [pause] depressed and that I suppose.' G:132-137 (2)

He described the distressing practicalities he had had to cope with and what this had actually meant for him to manage alone. The metaphor of going into overdrive below, illustrates Graham's embodied relation to this concept in that it simulates how his mind, when not dealing with the immediate demands of his wife's situation, feels overloaded and out of control (Gibbs 2006) as he copes with a multitude of thoughts and practical concerns:

> 'That's the stress side of cos when P** got her head down, go to sleep for a couple of hours, my mind goes into like overdrive, what's going to happen next, what do I do, who do I see, who do I negotiate with you know, like for instance, the day before she died, went to the undertakers, booking find out what's going on and how you do things. So the day after she died I went back to him I said, to make arrangements for her crematorium you know what I mean.' G: 287-291 (2)

1.3 Coping strategies

'So we're using it, like as a little brain.' G:1458 (1)

Graham brought to the first interview a bag which contained his main, everyday tasks and concerns, medications, details of the dates of his own fits, and a large calendar that he has on the wall at home to note various appointments on, thus showing me concrete evidence - 'proof', as he termed it - of the stress he was under and how he was managing this:

> G: But I'm sorry, sorry to say it though Val, I've had to bring these on board, as proof, about what I am trying to talk about, you know, I am not trying to
> VF: Because you feel so busy, it feels so busy?
> G: Yes.
> VF: And that's like it's showing me, how busy it is.
> G: In a way, yes. It's, erm, you know, it's constantly, like prescriptions, and things like this, it might be in me head.
> 1438-1448 (1)

Graham's allusion to the notations on the calendar as being akin to a difficult foreign language which had to be explained and translated, illustrates the newness and complexity of this new experience for Graham, that of having to negotiate someone's illness trajectory and all that this entails:

> G: But, been putting them down on the calendar, you see [gets calendar out of bag]. We have to, em, to be sure, we have to get these big box calendars.
> 1408-1409 (1)

> G: That much things happening in our house you see, we've got to er, it's a bit like Swahili. 1413 (1)

> G: Yeah, so that's our little, our Encyclopaedia.
> VF: Busy June is that.
> 1434 - 1436 (1)

Perhaps Graham's busy calendar acted as a metaphoric focus for the whole family in order for them to work things out together, as he used the plural to describe its usefulness, (as in the quotes above). 'It's a form of interest, but it's, it's mind boggling, it's really ooh.' G:1491 (1), or at least for them to see what was involved for him in the logistics of caring. It also served to illustrate visually to outsiders, unlike a small electronic diary in one's pocket, just how complex life had become for him and the juggling acts he now had to perform. These included his wife's deteriorating condition, her various medical appointments and treatments, his son's daily routine, medication and his constant surveillance for signs that either of them may be going to have a seizure.

He also brought along a notebook containing details of his son's seizures, 'So when we go, to see A.M., we'll put this in front of him so he can have a look, at how we express it,' G:1387-1388 (1). The calendar, itself a metaphor, the 'little brain' - was still there on the table, eighteen months later, still displaying life's tasks, when I visited Graham again at home.

Graham admitted that his head was full of what he has to do even at night and he needed time out to reflect in order to cope with the events in the past and coming days. This time however, was only available when the rest of the family were asleep, and having the luxury of this time alone resulted in him forfeiting his own rest and possibly resulting in him being deprived of sleep. This time of day was predictable for Graham, and he told me of his late night ruminations:

> 'I can watch some bloke on television, thinking of what's to be done next and, maybe at midnight I might go out and empty the bin, something like that, you know, something like that, you just, funny little world you go into.' G: 1573-1576 (1)

Graham returned to this personal reflection when I saw him a second time, 'I was sat here all hours of the morning, not going to bed sometimes, thinking, thinking things over, yeah.' G: 270-271 (2)

His son's life and movements appeared to be important to Graham's own stability was apparent both times I met him. On the one hand his son was predictable in his movements, on the other there was the possibility of him having unexpected seizures. His son's daily routine helped give structure and meaning to Graham's day, and the last sentence of the extract below, which addressed his son directly, points to the importance of his son's presence in Graham's life:

> 'No, it's er, you see I've gotta be up routine, what was it, half past five this morning, yesterday it was a quarter past five, the day before that, to get the day rota going you see. Me son gets up about five, ten past seven in the morning. With having autism, they stick to their own routine, don't they, rota you see, so it's ten past seven I shouted him to get up, he gets up and does breakfast, so I'll get up in the morning. You start the day off for me like you know.'
> G:1584-1589 (1).

This final sentence is symbolic in that Graham meshes himself and his son together as a single entity. A comment Graham made about himself inheriting his son's epilepsy, resonates here and one wonders whether Graham and his son

share an element of autism also:

> G: Yeah. I once asked Mr M*** "Is it hereditary?" I said.
> VF: Mmm.
> G: But he can't pass it down to me, can he? I've got to pass it down to him.
> 1328 - 1332 (1)

1.4 Sentry work and isolation

Graham's term for his constant surveillance of family events was 'sentry work' G:649 (1), another metaphor, one of being on guard in a small hut, as he juggled his various roles, and gave me the impression of him being isolated from any other forms of social support. Graham was this nuclear family's mainstay, and I perceived him as being a solitary figure much of the time, although how much of this was self imposed was not clear. He mentioned a rift with his one sister and he did not mention anyone else in terms of help, saying he was independent, 'Cos none of her family want to know, and I have no family to support meself so I've got to do things independently.' G:1097-1098 (1)

However, at the second interview he expressed surprise at how many of his wife's family actually attended her funeral, the whole room was, in fact, as Graham put it, 'heaving' G:9 (2). This brings into question whether looking after his family was, to Graham, a replacement role for the gap left by his redundancy and that to manage this alone was something Graham needed to do as he had once supported his family financially. Following his wife's death, his son became Graham's main priority and, when the family doctor recognising that he was still under some stress, offered him counselling which Graham declined reiterating his, perhaps chosen, position of needing to assert his ability to cope alone:

> G: I said no, I've got to fight it meself I said, got to get over that hurdle.
> VF: Mmm.

G: On me own terms, so can't do it. No well I can do, but I don't
       wanna do that, I'm too independent, you see, gotta fight it meself.
173-176 (2)

Graham's concerns above were practical ones which required problem solving
and management skills of a different nature to those used in paid employment.
The metaphors he used illustrated and highlighted the nature of his concerns.
However, his physical experiences, also something not envisaged by him, were
not of the same nature and not resolved with practical solutions needing a
deeper conceptualisation on his part.

The following section is an interpretation of Graham's physical experiences
which I am reticent to call seizures as this is not a term he uses, preferring other
terms. He did allude to some stigma being attached to this term:

G: Yeah, sometimes, I suppose, yeah, some people don't like that
       expression 'fits' do they?
VF: No, no they don't, no.
G: Yeah, we found that out, so we use, em,
VF: How did you find that out then, from other people?
G: Yeah, yeah. If you mention, like a seizure then they'll go,
       [expression –part of the conversation unintelligible]...oh, yeah,
       and if you mention having a seizure you've probably hit a sore
       point there you see.
VF: With other people that have them, or?
G: Well, aw no, just other people sometimes, and talk about it, like so
       you think well, OK then, maybe they know more than what we do -
       we use the expression 'seizures' you see, that's why we have to,
       sorry to interrupt you, that's why had to, er, use from the book –
       'absence' [label on front of son's notebook].
1521–1538 (1).

Superordinate and subordinate themes 2 - 4

The second cluster of experiences are encapsulated in three super ordinate
themes, which linked together in that they serve to go beyond the first cluster of
by offering Graham routes of explanation by which he could link these
'precursors' to later understandings of his experiences. The first superordinate
theme, 'Spitting images', an in-vivo term rooted in Graham's comments about

his experiences, 'The spitting image all the time, of these absences, and it's that's having fits.' G:422- 423 (1), with subordinate themes of, 'Confusions' 'conflations', and 'contradictions' in terms of his awareness, unawareness and gaps in his experiences'. The second superordinate theme, 'Understanding multiple beginnings', describes Graham's process of decision making about his experiences, having subordinate themes encompassing, concepts of war, fear and fighting, and of journeying. The third, final superordinate theme is, 'Distancing', which explores Graham's use of second person narrative as a subordinate theme.

Table 12

Superordinate and subordinate themes 2 - 4

Super ordinate themes	2 Spitting images	3 Understanding multiple beginnings	4 Distancing
Subordinate themes	2.1 Confusions in terminology 2.2 Conflations 2.3 Contradictions in awareness, unawareness, gaps in experience.	3.1 Concepts of war, fear and fighting 3.2 Concepts of journeying	4.1 The use of second person narrative

Superordinate theme 2: Spitting images

2.1   Confusions in terminology

Graham's story was one where the terms absences, headaches, flutters were used interchangeably in describing what appeared to be the same experiences;

> 'I've had these little absences and they've led to these fits. Is that the same things that are happening?' G:395-396 (1). 'With having the stroke, now the seizures, I wondered, could they have run in, could they clash? And that's all up to fits. I've had to ring a few bells, you know what I mean?' G:463-464 (1)

Graham's terminology for his physical experiences was an amalgam of 'epilepsy'
based terminology (he was not completely naive to seizure discourses having
already been in contact with neurology services with his son), and his own
personal formulations. It was confusing as to whether the terms related to him,
his son or both of them. It was also difficult to divide them into discrete
experiences in terms of semiology because, as his narrative progressed, they
appear to settle into, and represent, one and the same experience. Descriptions
from Graham of his first experience, which was seen by him as signifying a
beginning, included a flurry of mixtures of terminology which distanced him
from the company he was in:

> G: Yeah, the first one, when I was sat on the settee in the front room,
> and erm, talking away to the missus, and these little, little, I think
> you call em absency things, I think you call 'em, where you have
> your little flutters, little, well your ears start buzzing, it seems, it
> can't really ...
> VF: Your ears start buzzing?
> G: Yeah, you can't really take in what people are talking to you about.
> VF Right.
> 99–108 (1)

Graham later shifted to adding in more epilepsy related terminology, 'shall we
say fit, absence, seizure I don't know what you call it really if it's a seizure,
innit?' G:321-322 (1).

'Like gulping, gasping for air, and me eyes went like, I think she used the
expression, like a cod.' G:569-570 (1). Graham's second experience added in his
wife's description and this, repeated at his first neurology appointment, acted as
a trigger to the neurologist to consult with A.M., for Graham to be considered as
a participant for my study. His experiences then being reformulated using some
seizure-related terminology and adding in Graham's personal formulation of
immobility:

> 'I was sat there, all of a sudden this... absence call it again, happened,
> and then my wife told me, said you was like, making like, gulping air
> sounds and you've had another fit again, she said. Well, I said, it's funny

I said, that's absence, where I sort of like freeze'. G: 655-658 (1),

'And me eyes, I use the phrase like 'cod eyes', you know, I'm looking up'.
G:1020 (1).

At this point Graham describes being surrounded by his whole family, and the
becoming the centre of attention, 'Yes, and me son didn't go to, er, tech college
that day because me wife, had to look after him, he got a bit stressed got a bit
upset with himself.' G: 663-664 (1). This attention Graham receives relates to
the notion of secondary gain in illness behaviour whereby people are rewarded
for such behaviour (Reuber 2008i).

Though Graham's experiences were novel to himself and his family, descriptions
of them took up a fraction of Graham's interview. When he was prescribed
AEDs for these, he was primarily concerned that they may cause weight gain,
and only secondarily that his experiences may cease with this medication.
However, he was willing to take this particular 'risk' so that he could fulfil his
role as a husband and father:

> 'But I said if it's gonna, if it's gonna make me ... not have these little
> absences, I'll go for it, cos I've go to, try sommat, I've got to try and be
> there, say it again, on account of me wife and me son you see. I've got to
> support them one way or another'. G:513-515 (1).

2.2 Conflation of Graham's and his son's experiences

'So there's two of you really then?' VF:1316 (1)

People who have observed others having epileptic seizures can use these as a
model for explaining their own experiences (Kuyk, Van Dyck et al. 1996). It was
early in our first conversation when Graham told me of his son's three year
involvement with neurology services and, according to notes his wife had made,
his son's seizures had begun around the same time as Graham's (around the
time when Graham's wife was diagnosed as terminally ill).

Early in our first conversation I asked Graham about his use of the term
'absence', it being a specific term used in epilepsy:

> G: -and I've, I often get these little, I think you call –well, they say it's
> absences, I'm not quite sure.
> VF: Do they say - is that your word, or their word?
> G: It's my word.
> 12–127 (1)

Graham takes ownership for the terms he uses being comfortable with its use
wherever it arose from. However, he appeared to be conflating both their
experiences saying, 'That, I'm using these words because me son goes through
between seizures and absences, they're called absences.' G:182 - 183 (1) adding
to this later, 'He goes through that when he has his little flutters like, goes off in
little world.' G:191 (1).

Thus Graham's lexicon for his own and his son's experiences mirrored each
other, were conflated early on, often appearing in the same paragraph and often
in a combination of first and second person, 'That's what the doctors, Mr M***,
he's under Mr M*** you see, and em, going back to that one, on this morning, it
happened, this ... absence we'll call it, and it took over me, of having a fit'.
G:211-213 (1).

He did however, did feel the need to document his own experiences with his
own personal information in order to differentiate from his son's experiences:

> G: I've got to put it down on paper you see,
> VF: Hmm, hmm.
> G: -with me date of birth, initials.
> VF: Yeah just to make sure.
> 25-259 (1)

His son however, had apparently experienced one seizure which was very unlike
those Graham experienced, sustaining some physical injury. Oddly, Graham
put more emphasis on the cleaning up operation he had to undertake, rather

than attending to his son's needs, appearing to be distancing himself from even his son's physical experiences:

> 'Like one night he, er, was upstairs on the computer, and all we heard was this bang, he hit the head, he hit the table with his head – cut his nose open and blood all over the place, so I had to strip the whole computer down and blood was inside the computer, had to clean all that down.' G:1340-1350 (1)

2.3 Contradictions - awareness, unawareness and gaps in experience.

Graham described a second experience in which his absence developed into something which he could no longer control and which propelled him into a fit. His lack of agency over this force lasted until he saw the inside of the ambulance his wife had called for and responsibility for his care was taken on by medical staff:

> G: This ... absence we'll call it, and it took over me, of having a fit.
> VF: Took over you?
> G: Have a fit, I didn't realise what was happening till I was getting transported into the er, ambulance outside, I don't remember the ambulance people coming to me -
> VF: Mmm.
> G: -er, even wheeling me, getting me up into a wheelchair and taking me out, till I was, basically inside the ambulance so there was a bit of er, gap there you see. And er, all I was saying was to me wife with me, er 'what's happening' or 'what are we doing here', and I kept repeating meself, and I was sent down, well, after I had been in the A and E for a bit, in Royal Infirmary, I was put into the acute assessment.
> 212-227 (1)

Graham talks of contradictory sensations, of looking straight ahead or, looking around, of being taken over by someone, not 'it' in this case, 'Yeah sort of like, someone just, just blacks me out in a way.' G:132 (1). He then appears to take control, being able to 'freeze' (it is not clear whether this is physically or mentally) himself in this state, whilst at the same time being able to discern internal sensations and the voices of other people:

G: I can see everything but I can't, I've got to concentrate, look
      straight ahead or, sort of look around and a slight buzzing sound
      in me ears, I still hear people talking.
VF: Yeah.
G: I still hear noises around, but I'm like, erm,
VF: You're just?
G: -frozen!
VF: Yeah frozen, I was going to say 'frozen'.
G: Frozen, cos you wanna, sort of like try and fight this, em side effect
      I call it, is it 'absence', I'm not quite sure?
135-151 (1)

This 'freezing' of his communication channels, depicts the embodied simulation
of a metaphoric concept. This illustrates Graham's desire to maintain the state
he finds himself in, and in doing to distancing himself from communication (the
side effects) with others.

However, he also offloads this responsibility by personifying the 'side effect' or
'absence' as trying to communicate something to him. When he talks of 'it'
going away, it is not clear what ' it' is, that is, then in direct contradiction to this,
Graham considers that if he gains control over 'it', he will be relieved of his
experiences:

G: And you sort of sit there, sit there sighing holding your breath, sort
      of like going, choking a bit, and your eyes just focus into
      something, and yer, you get a buzzing sound you get like a
      throbbing like it's trying to tell you something.
VF: Do you think you're trying to stop it going any further?
G: Yeah, I think that's what, I mean by freezing, you concentrate on
      something, and you think, try and put your mind into gear of, like
      freezing it, it probably, go away, you know what I mean?
965-974 (1)

Graham extends the power of 'it' to having the power to close his awareness
down to a sudden and complete blackness, conceptualises this as an electric
light being switched off. He does not appear to have any idea as to how long
these gaps are:

G: I don't know, I just, me light goes out.
VF   Your light goes out?
G: Yeah, I just don't remember it, you see.
VF   Mmm.
G: Until it's [pause] afterwards.
VF   But you don't remember then, or you're just there again, you're back again.
G: No, I'm sort of, trying to think, what on earth, what the Hell's happened, what on earth's happened, and how long it had been, I don't know, I don't know anything about that, until my wife explains to us, you know, to the ambulance people, or the people at A and E what I was actually like.

1024-1043 (1)

Superordinate theme 3. Multiple beginnings as a process of understanding

As well as using metaphor to illustrate his current concerns, Graham used this device for an understanding of the pre cursors to his physical experiences and that these may be the causes of them. The metaphors that Graham applied to his experiences, that of the subordinate themes of, concepts of war - encompassing fear and fighting, and those of trajectories and journeys, helped to illustrate the super ordinate theme of, 'Multiple beginnings as a process of understanding'.

Graham began to talk to me as we were travelling to the interview, saying he is getting nowhere with 'it'. What he meant by 'it' was not clear at this point, because although Graham had told me he had had fits, I had assumed that they were of fairly recent occurrence, given that he had just had his first appointment with the neurology clinic. He wanted something done about 'it', had not seen any progress, and had been trying to tell the doctors about 'it' for years being confused about what was happening to him:

'I don't really know, erm, what it entails. 'I'm [pause] walking around, em, going round in circles getting nowhere, cos I'm getting no results cos I don't know what I'm dealing with here, you know what I mean?' G:881-883 (1).

From the start Graham linked his car accident 38 years ago and his current physical experiences although, on the other hand, he was equally certain about the precise beginnings, of a novel experience, 'fits' and one which demanded his attention:

> G: Yeah, that's the first fit I ever had.
> VF: And you went to the Acute Ward?
> G: The assessment, yes, cos it's the first fit I've ever had.
> VF: Right.
> 75-81 (1)

However, far from being a new experience, Graham contradicted himself immediately, acknowledging that he was equally sure that 'these' had followed on from his car accident, 'Yeah, but they told me I've had bad head injuries.' G:114 (1):

> 'I often get these little, I think call – well they say its absences.' G: 122-123 (1). 'From '69, yeah. I've been to doctors, to moan and groan about me 'aving headaches, and I don't know whether it's migraines or what, and they said to me, they can't give me no prescriptions because it's like a headache, trying to explain to him what I'm going through, and they just seem to [pause] shrug their shoulders.' G:163-170 (1).

After I had gathered information about Graham's neurological history as the interview progressed, he maintained that he had been given an EEG some years before and had been told of some physical brain damage. 'Maybe that's when -I remember him saying, I've er, got a couple of dark patches, dark patches from me head injuries.' G:759-760 (1). He maintained however, that this previous visit was not about his present 'fit' experiences and he related this to the consequences of sustaining substantial head injuries:

> G: Is it a -? I dunno, there's sommat there due to me car accident I
>   was a passenger in.
> VF: Yeah
> G: Bad injuries
> 337–341(1)

> G: Years before, because I've had, erm, I saw Mr M*** years ago.
> VF: Oh, did you? You've already seen him then, years ago?
> G: Not on this fit business.
> 733-737 (1)

In trying to unravel his experiences, which appeared different but also the same, Graham was pinpointing when things had began to be more apparent and, thus more problematic to him. Medical staff hinted that his experiences could be down to stress:

> 'Going back to the first one. When I mentioned it to this doctor, I can't, don't know who it was, he said maybe it's what me son and me daughter, I was told by some doctor, I think it was, it could be due to the stress and the strain.' G:315-317 (1)

The headaches/absences had already been conflated, but which Graham perceives of as leading up to his current experiences and equating with this personal stress:

> G: No, no, these little absences have led up to these.
> VF: Mmm, you think they've led up to them?
> G: Yeah, I'm sure they have yeah. The spitting image all the time, of these absences, and it's that's having fits.
> 418-423 (1)

> G: These absences will spark things out and about - in between two to four a year. Maybe three a year,
> VF: Hmm.
> G: Two or three, it all depends on what's going on I think, at the moment.
> 358-364 (1)

Following the occurrence of a second fit, approximately a month after the first, this acted as an impetus and propelled Graham into action in obtaining some medical attention to these, having previously left A & E with an inconclusive diagnosis, and feeling dismissed by the hospital after his second experience:

> 'I mentioned about it, and they were sort of like I mentioned to them could it be stress and strain again, and they just like shrugged their

shoulders, they was a bit, shall we say a bit blunt really this time.'
G:702-704 (1).

Graham then began his quest to find out what was happening to him being
genuinely worried about coping with his family, a main worry appearing to be
that his 'new' experiences would not be manageable and that they could increase
in magnitude causing further physical damage:

> 'You see, I've always thought, I'm not, er erm, how can I put it, I'm not a
> medicine man. I don't know nothing about the human body as doctors
> know it as, but er, I always thought these were probably like thinking
> they could be causing another stroke again, you know could it lead up to
> this or what?' G:439-442 (1).

Graham clearly needed support of some kind, 'what's exactly going on you
know, is there anything I could, anybody I could talk to, put me in gear, please, I
want to know.' G:719 (1).

3.1 Concepts of war, fear and fighting.

I observed that my presence at this point in Graham's life appeared to give him
the opportunity to formulate a battle plan against his experiences. Graham's
allusions to fighting his experiences suggest they are troublesome and a threat
to him and he takes up the position of mounting this fight, cos you wanna, sort
of like try and fight this, em side effect I call it, is it 'absence', I'm not quite sure.'
G:122-123 (1). His metaphoric use of weaponry indicates concepts of fighting
his experiences, 'now this has come up, put it forward let's go guns at the ready.'
G:331 (1). Within this, some element of fear as Graham's experiences threaten
his ability to cope with what fate has dealt him, 'these fits I'm having, the second
fit I've had now, and I'm getting a bit scared now because I've got a wife who's
badly, a son who's badly' G:264-266 (1).

His perceptions that something other than himself propels them, results in him
feeling out of control of his experiences, 'this absence we'll call it, and it took

over me, of having a fit.' G:212-213 (1) and he seeks an understanding of what was happening to him, using the metaphor of a constructing a picture of the workings of his brain, before this could commence:

3.2 Concepts of journeying

Fuelled by the fear he may not be able to cope, and a second seizure experience occurring moves Graham towards using further metaphoric concepts of travelling or journeying along a route which he hoped will lead him towards some understanding. Graham appeared to me to be both a vehicle which needs redirecting, and a passenger who needs to know his destination in this journey. Graham reifies the EEG in this respect, i.e., again this is a metaphor itself, in that it will give everyone a 'picture' of what is going on in his brain even though Graham himself would not be able to interpret this:

> G: These fits I'm having, the second fit I've had now, and I'm getting a bit scared now because I've got a wife who's badly, a son who's badly, and I want to put on the rails? You know what I mean, I want to go to the doctors and see about this AEG.
> VF: EEG, yeah.
> G: EEG, sorry. Again, I'm still waiting for that to come up, so I said, 'Any chance of you putting the wheels in motion for us?' - which he 'as done.
> 264-272 (1)

Graham adds in a physical effect of this fear, what we all know as 'goose bumps':

> 'Cos it's scaring me, it really has put me hairs up. Do not want it to happen again, you know, I'm scared as I said about the family, and me wife can't cope.' G: 581-583 (1)

The fact that Graham had no physical effects of his experiences, such as sustained injury may have helped him to distance from them. The metaphoric concepts he uses in order to gain some understanding of what is happening to him, be it organic or otherwise depict his mind as having the potential to fragment from a whole into parts. Graham also applies this metaphor to his

son's coping strategies and with whom he often conflates his own experiences
with:

> G: He's had fits, he's confused like we all are, his, your mind just goes
> like an omelette.
> VF: Like an omelette?
> G: Yeah, mushy. You think, well, why? If? What? There's that many
> questions in your mind.
> 1375-1381 (1)

Superordinate theme 4. Distancing

4.1 Second person narrative

There has been a recent dialogue within the IPA group relating to how
significant it is when someone utilises the second person narrative in describing
their experiences. The use of this linguistic strategy brings into question
whether Graham is attempting an emotional distancing from experiences [107].
and/or, using it to make it easier to explain how another person would
experience similar things [108]. The discussion was thus around whether they use
this strategy consistently. Graham uses mainly the second person narrative in
his interview in relation to his physical experiences, although this does shift.
Some of the quotes above pertain to this theme (for example, 1375–1381).
Graham states, 'you sort of like sit there, and you put your hand up and say,
whoa, whoa, whoa, you just.' G:934 (1)

> G: I think you call em absency things, I think you call em, where you
> have your little flutters, little, well your ears start buzzing, it
> seems, it can't really-
> VF Your ears start buzzing?
> G: Yeah, you can't really take in what people are talking to you about.
> 100-106 (1)

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[107] ipanalysis@yahoogroups.com on behalf of [P.Flowers@gcal.ac.uk] 09 July 2007. Accessed
09 July 2007.
[108] corbettmandy@hotmail.com] ipanalysis@yahoogroups.com 09 July 2007. Accessed 09 July
2007.

Graham did not use the second person narrative to describe other aspects of his life, and, in fact actually shifts towards the very end of his interview to first person narrative when reiterating his loss of awareness and loss of memory in his experiences, 'I don't know, I just, me light goes out. Yeah, I just don't remember it, you see'. G:1024–1028 (1). This late shift suggests that he was coming to accept that something was happening which was internal to him.

Comments of Graham's use of metaphor

Graham's use of metaphor relating to his process of understanding and physical experiences was profuse, coherent and persuasive. The concepts behind his metaphors appeared to be around what to do *about* his various experiences, rather than being used to enhance phenomenological descriptions of them. Although, Grahams also alludes to the seizure taking over him, he also appears to have made a decision to understand and overcome them.

Coda

When I visited Graham at his home, some 18 months later, compared to the first time I saw him he was calm and coherent, and talked at length about his wife's death, funeral and how the family were adapting illustrating a grieving process taking place. He passed off what he now termed, for the first time in relation to himself, 'the epilepsy' which had been replaced by another new symptom, high blood pressure, for which he was being monitored. He maintained vestiges of his previous experiences were still apparent but the 'flutters' were now simply occasional non specific feelings of dizziness:

> VF: How are you then, because you were having a sort of few problems physically, before weren't you, seizures and things?
> G: Ooh the epilepsy oh yeah,
> VF: How's that going now?
> G: Well I have high blood pressure now I'm on blood pressure tablets
> VF: But are you still having any seizures?
> G: Touch wood, no
> VF: No, did they stop then?

> G: Well, I'm not saying that but, keep (ing myself?) on a level, you
>   know what I mean? Keep myself, you know, alright. Have these
>   sort of like, little sort of like little flutters now and then but
> VF: What's a flutter then?
> G: Well its sort of like em, you don't feel right.
> VF: How don't you feel right?
> G: Well you feel a bit like, dizzy
> VF: Yeah, so you feel dizzy now and again?
> 37-44 (2)

Graham continues to attend the neurology clinic and to take his AED medication, and he told me that doctors were attempting to ascertain what his true diagnosis might be. Simultaneously, Graham himself appears to be distancing himself from them, dismissing a recent neurology appointment as almost a burden to take time out to attend:

> 'Oh, can't remember what she said now, this was HRI, kept on asking me
> am I having these dizzy spells, what time of day, how many times a day
> how many times a week [indistinct] your mind's too busy on other things
> really at the moment, to make... questions, after questions after
> questions you know. I was in and out you know'. G:156-159 (2)

His new symptom, one of high blood pressure is one which he has put into the hands of medics while he continued with his caring role, one that he is now more at home with. From having symptoms and experiences which were difficult to find the language for, and to comprehend, and with no apparent organic cause, monitoring his blood pressure is measurable by the medical profession, he does not have to engage with this symptom and did not take on the responsibility of understanding this as he had attempted to do with his seizure experiences.

Graham's seizures appeared to have stopped by the time I saw him again, which he put down to the lessening of the stress of caring for his wife:

> 'Well me wife's gone, do you know what I mean? It's all the tension and
> stress of what's going to be round the corner cos I was.' G:129-130 (2),
> acknowledging that things,

'has slowed down a lot now, what's happened, s'appened, I gotta think of the future now, gotta think forward'. G: 275-276 (2).

Drawing on cognitive theories of metaphor helped me understand Graham better and the way in which he formulated his pressures in a way that made sense to him. He continued to make use of metaphoric language to help him explain how things had shifted, this time not for physical experiences but for his day to day life and representing being grounded, in control and directional:

'it's just a matter of having to get your feet on the ground and go forward cos losing your wife, big thing innit?' G: 6-7 (2)

Graham had expressed concern to me more than once that he was not describing his experiences well enough to doctors, and put this forward as a reason why no help had been offered to him relating to his previous experiences:

'You can't really explain to anybody, I think that's why, when I've been to doctors complaining about, having headaches, and these little things, they haven't done, I sound a bit grotty that. I don't think they know how to handle it, I don't think, cos maybe I'm not giving them enough descriptions what's actually... I'm trying me best to explain to em.' G: 850-854 (1)

Sometimes however, an everyday shared language cannot fully describe what a person is experiencing because it may be difficult for an individual to express 'the essentially unique and private qualities of inner experience' (van Manen 1998)(pxiii). Graham's life was in transition and his own, individual personal use of language did aid in facilitating his understandings and his intuitive use of metaphor helped to formulate and illustrate his fears and concerns.

IPA as an approach does not simply rely on the text produced by an interview for an interpretation. Moving beyond the text and exploring Graham's use of metaphor - and thus his cognitions and understandings shifted the interpretation towards an understanding of how he made sense of his life. Nonetheless, Graham's comments about difficulties in communicating his experiences to a doctor add support to the idea of developing a seizure discourse

both lay and professional people could use which could be beneficial in clarifying individual seizure experiences.

The nature of IPA and its underpinnings are such that the researcher's previous understandings can inevitably colour an interpretation (Landridge 2007). Graham's first interview was extremely difficult to follow at the time and the 'peculiar conversational behaviour' (of people with NES), a phrase that had been coined in the context of the Bethel work (Surmann 2002; Schoendienst, Surmann et al. 2005), resonated with me the moment I met him. He had certainly had more than his fair share of adverse events, which can act as a catalyst for the onset of dissociative seizures (Mellors 2005).

Graham had undergone a change in his biography, he had taken on a new role for which he was unprepared and ill equipped emotionally and, although he purported he preferred to act alone, Graham appeared to be searching for some support in terms of someone to talk to, to put some coping strategies in place and 'sort out' his seizure experiences.

His beliefs about his seizures went back to the effects of a car accident some 38 years before in which he sustained head injuries, the side effects of which had become more apparent and which he used as a vehicle to gather medical support, attention and help as a 'new' symptom, and for which he demanded help with. He also feared for his future coping and that his current stress could lead up to another stroke.

Throughout the interviews, Graham had deliberated as to what the root of his experiences were and, in the process of talking to me, he appeared to accept that his previous, 'stresses and strains' had contributed to these, 'Well me wife's gone, do you know what I mean?' G:129 (2). He had reached some understanding of what had happened to him, was eager to shelve his seizure experiences on a permanent basis and move onto more pragmatic concerns.

Addendum: Information obtained from the Consultant (A.M.) after the completion of the research.

Graham's diagnosis of focal onset epilepsy with secondary generalisation somewhat surprised me. His MRI scan showed an old area of damage in the left temporal lobe which was interpreted as being vascular or trauma. Although he talked to me about 'experiences' since his RTA, he did not appear to have been receiving medication for these until he presented in neurology (and when I first met him) as these were passed off as headaches. That Graham talked so much about the circumstances surrounding his experiences rather than how they actually felt to him, could have acted as a 'red herring' to me as his current situation appeared to override his own personal situation as he struggled to grapple with acute stress.

5.5 The doctors are quite baffled, you know, to why I'm have em *now*.

Mini biography

Mary (M), a woman of 31 with two children (a girl 13 years old, whom she had had at 18 years old and a three year old boy) informed me within the first seventeen lines of her interview, about the major concerns in her life. She cited a flurry of seizures which had occurred and explained that neither she nor the doctors could understand why she was having seizures *now*. She described at length her memories of, and feelings about, her brother's unprovoked, brutal murder just over four years previously and her subsequent, ongoing depression, her constant pre-occupation with his death and her strategies for distancing herself from this emotional trauma.

The trajectory of our conversation continually moved between her and her mother's illness perceptions and Mary's concern with her brother's murder. Mary asked her mother (Mum) to join us later in the interview and she offered me more information about the semiology of Mary's seizures, her behaviour weeks prior to their onset and pre and post ictal behaviours. Her father and sister were both present in the house but did not participate in the interview.

Although the interview reached a point whereby I nearly drew it to a close, (line 1335). However, Mary and her mother continued talking for a significant length of time during which Mary and her mother made a significant disclosure about Mary's illicit drug use at line 1632, which offered more food for thought about the nature and roots of her experiences. I only had the opportunity to meet Mary once as she was unavailable a second time having since been taken into rehabilitation for drug and alcohol abuse. However, having talked to her mother twice on the telephone and to her neurologist via e mail, Mary's

interpretation incorporates this later information. Three superordinate themes emerged from Mary's interview.

Table 13

Superordinate and subordinate themes

Superordinate themes	1 Secondary social gains from seizures	2 It's like a two: it's like split in half	3 Illness perceptions/tracking conceptual connections
Subordinate themes	1.1 Seizures as dramas	2.1 **Distancing** 2.11 from seizures and injuries 2.12 from self 2.13 from emotional trauma	3.1 Causes 3.2 Trauma 3.3 Cannabis connection

Superordinate theme 1. Secondary social gains from seizures

1.1 Seizures as dramas

Mary was comfortable talking about her seizures, indeed they took up a substantial amount of interview time. She had a clear picture in her mind of the chronology of them, this taking up much of the word count about her seizures (see table 15, p 318). She described what she remembers as happening before and after each of them, constructing for herself a picture of her seizure behaviour from witness descriptions, particularly her mother's. They described an earlier experience a few months prior to the flurry of seizures but this was not recognised as a seizure at the time, 'we didn't think anything about fits.' M:197. Three later experiences identified as seizures occurred within a period of a month, all taking place when her family was present (her parents moving into her house following the second seizure). Two of these seizures resulted in emergency services being called and Mary being kept in hospital for tests the second time, after which she was put onto AEDs. Mary was up to her prescribed

maximum dose three weeks before we met and had not experienced any more seizures since.

Each of these seizures was documented, in writing, by Mary's mother, including the initial one which they decided, in retrospect, may have been one too. Records of these were considered important, 'Don't lose all o' them. Because you need all of them, don't yer?' Mum:1224, and are described in box 10.

Box 10

Details of Mary's seizures

'Seizure' one	Seizure two
Not witnessed by anyone but Mary thinks she fell and passed out getting out of a bath, sustaining a painful head bang and bruise. Her family were trying to gain access to the house but could not. Her son was crying at the front door saying he could not wake his mummy up. Mary did not understand her family's concern when she let them in. Her mother reported Mary's eyes as glaring,	All the family were present, including her parents, sister and brother in law. Mary was making a cup of tea in the kitchen, her father was there and suddenly there was a sound of crashing pots. She fell to the floor, banged her head on a cupboard, and scalded her left breast. Her mother witnessed this as lasting five minutes saying Mary was, stiff, foaming from her mouth, going blue, 'came round' and 'went off' again. She was convulsing, making funny noises, her eyes were rolling and she was yelling on the floor. Mary does not remember 'coming round'. An ambulance was called. Her mother said she was confused for around half an hour afterwards.
Seizure three	**Seizure four**
Mary awoke at 4 am, her parents were in the house with her, her father sleeping downstairs. She made a drink, had a cigarette, could not sleep so decided to complete a tax form. Her father then heard a crash, Mary was discovered convulsing and making strange sounds. She sustained a hurt shoulder, damaged the side of her face, resulting in a black eye. She does not remember 'coming round' and found herself on the settee with her mother, father and the ambulance men around her.	Prior to this seizure, Mary had mentioned having a funny taste in her mouth in the morning and a headache the evening before. After making a meal, Mary sat at the table with her family and ended up on the floor. She experienced urinary incontinence, bit the side of her tongue and neighbours were called in. When she 'came round' she remembered nothing.

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

Mary, presenting in A & E, appearing to medical staff from witness descriptions, to have experienced tonic clonic seizures:

> M: Well, yeah, he did say to me, "You're epileptic," you know, when I will start you on Tegretol.
> Mum: When I, when I was at the hospital, one of, one of the doctors said, it, it's er, erm, well it definitely, sounds, definitely sounds like epilepsy.
> 1678–1681

The issues about patients being 'diagnosed' in A & E as having epilepsy, and being open to what could be potentially, dangerous and unnecessary diagnostic tests such as emergency intubation and parenteral medications (LaFrance, Gates et al. 2008) and that this diagnosis could remain long term, was one recognised by the local neurologists:

> 'If you wouldn't mind just giving me three lines, I am just curious. It's too often I mean we take the diagnosis as being made. If they've come into hospital in A & E they've been seizures witnessed blah good history from family, you will ask the person again what they know, but you - delve, I don't delve'. A.M., (591–595) [109]

Mary's seizures involved both significant physical injury and also 'social gains' (Reuber 2008i)(p166). Her personal experiences of her seizures are very different to those who witnessed them. She initially equates them with being completely unconscious until she 'comes round' again, 'I totally go out when I have em.' M:94. Mary initially appeared to have nothing to contribute to descriptions of what happens to her when she is 'out', repeating what others have told her about her behaviour during these periods of unawareness:

> 'They say I was, convulsing, and er, you know, erm making funny noises, erm, I think me eyes was rolling and stuff like that, but I was yelling on the floor, like convulsing and stuff like that, me Mum obviously will be able to describe it to you, better, er, so and when I came round, I don't even remember coming round.' M: 123–127

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[109] Please see thesis appendices, document C.

However, she began later to 'add in' some 'memories' of what happened:

> M: Erm, don't really remember coming round from, that one. Well, I don't anyway. Obviously, erm, an ambulance was called. I mean I feel a bit thingy because I can't really tell you nowt about afterwards, or ...
>
> VF: Mmm.
>
> M: ... and the ambulance an' that. I do remember –no I do remember the ambulance men coming in here and I just –the next thing I remember is being sat on the settee, looking up, and the ambulance men was there, and like me Mum was there, me Dad was there.
>
> 239–247

She also had little to contribute in terms of her own personal feelings and emotions about her seizures, although as the interview progressed she began to formulate these a little further, 'it's like it's not happening to me.' M:1330, ' I can't associate meself with it.' M:1385, 'I feel like I'm on the outside looking in ... If you know what I mean.' M: 1441, and 'It feels like it's not me.' M:1443.

In speculative mode, people with NES often equate their seizure with complete unconsciousness. They know a seizure has occurred and can offer much trivial information about the setting and context in which it took place. The seizure, itself, however, is only described cursorily (Furchner 2002). Moreover, it has been suggested that seizures occurring in front of an audience could also be a feature of psychogenic seizures (Benbadis 2005) as could a flurry of seizures leading to emergency admissions and hospital stays (Alsaadi and Marquez 2005).

Mary's seizures resulted in attracting attention from neighbours who were called in to support and accompany the family to the hospital, paramedics arrive, her family moved into her house in order to take care of her, her mother sleeping with Mary. It was not clear why her parents had found it necessary to move into the house and to go so far as her mother sleeping with her, her father

sleeping downstairs on the sofa. Mary appeared happy to be accompanied in all areas of her life, delegating responsibility for her own personal safety:

> M: I haven't been on me own, since the second fit.
> VF: Yeah.
> M: -someone's been with me all the time. When we go out shopping, erm, me Dad's with me, he takes me all the time.
> VF: Mmm.
> M: I've never been on me own.
> 353 – 359
>
> M: But I'm quite happy to, just to go along with everything, everyday.
> 381

This anxiousness of relatives is often a major factor in people with NES and their over protectiveness can lead to a restriction in their activities (Bodde, Brooks et al. 2009). Although the other family members had all experienced health problems as a consequence of the murder, all having had periods of receiving medical attention, having been effected emotionally, 'me Mum, and me sister, and me Dad, they're all a bag of nerves about it, aren't yer?' M:966, it was Mary's seizures which were a main focus of attention for the family when I met her:

> M: Erm, obviously since that happened to me brother, we've all been, you know, we've been in a right state, each one at different times.
> VF: Yeah.
> M: Me sister's on anxiety tablets and stuff like that now, but she, me sister is, really is a bag of nerves now cos she's frightened of what's happening to me, she's frightened of losing me, sort of thing, erm, so it's like them –they're really suffering, but I'm *not*.
> VF: Mmm.
> M: I'm not really suffering because I don't, I don't see any of it.
> 299-307

Mary had assumed a 'sick role' in her family and friends, one of a number of social gains that some people with NES can adopt (Reuber 2008i). Her mother and father had duly taken on the role of carers, her mother, initially finding the seizures difficult to cope with had, 'learnt to handle it a bit, better.' M:971.

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

Superordinate theme 2. 'It's like a two, you understand what I mean? It's like a two: it's like split in half.' M:481

Emotionally, Mary perceives herself as being splits herself into two. She is constantly pre occupied thinking of her brother whilst at the same time, conversing with others on a day to day level, 'it's *there*, but I'm chatting away to people but I'm laughing, and things like that' M: 485-486. I'm re-living it all the time when I'm talking to people but I'm smiling' M:477-478. This allows her to distance herself from the physicality of the seizures and from the trauma of her brother's attack.

2.11 Distancing from seizures and injuries

The gaps in knowledge of her experiences allow Mary to dissociate herself from seizures, seeing them as a single 'thing' in her life. 'I can't associate meself with it.' M:1385, 'I don't have any knowledge that it's coming.' M:1448, leaving others to concern themselves on her behalf. I attempted to explore how this felt to Mary:

> VF: No. So when you said, you didn't think it was happening to you, it feels as though it's not happening to you, how does that feel? What do you mean by that?
> 1368–1369

> M: But it's not really, hitting home that it's me.'
> VF: Yeah.
> M: Because, and I think it's down to because I don't see what's going on, and I don't, you know,
> VF: You haven't got that in, in your brain, in your head.
> M: I haven't got that in me head.
> VF: Like other things, yeah.
> M: Like other things, and, so I can't really, I can't associate meself with it.
> VF: Right.
> 1378-1386

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

Expanding upon this later, Mary contradicts her previous comments about not remembering anything as she does allude to some level of awareness rather than complete unconsciousness:

> VF   Where do you feel as if you've been?
> M: [Long pause] I don't, I don't really, I, because I don't know what's gone on. I'm just sorta like, listening to what every, what, you know, what, like, like me Mam's saying, sort of thing, and I, I'm just sat there and then, and then it's sort, the reality sort of like hits me, oh yeah, I've had a fit ...
> VF: So you know, yeah.
> M: ... and it's sorta like, then I sorta like come round sort of thing, you know, it sort of like registers, er up, up there ...
> VF: Yeah.
> M: ... or, oh yeah, I've had a fit, then. So then, but [pause]
> Mum: Well, I mean it's all, it's like all new to her, you see, innit?
> M: That's what I *mean*. It's just all like a big question-mark. It's like, I can't [long pause] I feel like I'm on the outside looking in.
> VF: Yeah.
> M: If you know what I mean. It feels like it's not me.
> VF: You couldn't draw it for me?
> M: No.
> 1429-1446

Even though she sustains significant physical injury from her seizures, Mary still manages to dissociate from them, 'I'm not really suffering because I don't, I don't see any of it'. M:307. She mentions background general pain, 'I have a lot of pain here, but erm, it's, that's the only thing, that's affected me, I'm not frightened of it, at all. I'm not anxious about it.' M:962-963, but does not describe to me, what would be quite painful, physical injuries she has sustained during seizures:

> Mum: Erm, like er, she bites her tongue.
> VF: Oh, does she?
> Mum: More or less each –
> M: Oh yes, sorry, I forgot to tell you about that.
> VF: Because that would leave –hurt you, wouldn't it?
> M: Oh, I made a right mess in me in, the last one I had.
> VF: Really? On your tongue?
> M: All on the side of me mouth, and all the side of me tongue.

> VF: Oh, it really hurts that, doesn't it?
> M: Yeah, it was terrible.
> 762–771

On the one occasion Mary experienced unpleasant internal physical gastric sensations, this resulted in a forcing her awareness of her experiences and engendered a fear of them:

> 'Yeah, I went this time. Erm, this time, I was really did feel ill, after, you know, this third one, when I got in the ambulance. I wanted to be sick. And I was really violently being sick, erm, and I went, so then I was getting quite distressed, I was thinking, you know, I was really frightened then, I was thinking, what, what's happening to me sort of thing.' M:264-268

2.12   Distancing from emotional trauma

> M: ...four and a half years ago me brother was murdered ...
> VF: Oh Gosh!
> M: ... he was brutally murdered
> 18–20

'But, it still feels like yesterday.' M:435

Mary brought up the subject of her brother's murder early in our conversation. Although this had occurred nearly five years previously, she was still very affected by it. Some authors argue that the thoughts and feelings of people who have had a traumatic experience are disintegrated, and memories of the trauma may be in the form of, amongst others, 'obsessional ruminations' (Smyth, True et al. 2001)(p162).

The room we were in housed a plethora of reminders of Mary's brother, the walls being covered in his photographs and Mary having one of these on her mobile telephone. She spoke of his injuries from a violent, unprovoked attack which left her brother unrecognisable, and although it was not clear whether Mary had actually seen her brother's injuries, she continued to experience

'visual flashbacks of disturbing memories' (Reuber 2008i)(p154), whether real or imagined which were continually in her mind.

> 'Because I'm on medication, of course. Because I'm on medication, erm,that's keeping me at a level and I'm coping, but, is it coming out? Because it's that, you know, it's that vivid, and it's that severe, and I know it's that severe what happened to him.' M:460-462

> 'It's erm, it's that, as I say, it's that, I can't, I can't *bear* it, what happened to him, I can't, I can't, just can't bear it, and I think that, that, me Mam thinks that because of the trauma, of what happened to him, that I'm re-living it all of the time. I'm re-living it all the time when I'm talking to people but I'm smiling'.
> M: 474-478

2.13 Distancing from self

In addition to distancing herself from the physicality of her seizures, Mary also appears to be distancing herself from memories of what happened to her brother. She manages this in two ways, consciously - by managing to look at her brother's pictures feeling, and then withdrawing from, the emotions they evoke:

> M: Terrible. It's like, now when I look up there, when I see him there, it's like [sharp intake of breath] –I go like that.
> VF: Mmm.
> M: But then summat just stops there, it's like, it's like ...
> VF: Shuts it off.
> M: Yeah, I, I have trained meself to stop it or I'll just break down.
> VF: Mmm.
> M: But it's, it's emotion all the time, it's there, and I'm suppressing it, I'm stopping it.
> 547–555

Mary also considers her prescribed anti-depressant medication is suppressing these emotions and that these would be far more intense without this:

M: But I'm not feeling it, to a point I'm not feeling really, really, I can't, it's hard to explain, not feeling really, really, bad about it, in, the tablets are doing summat for me,

VF: Mmm.

M: ... you know, they're keeping me going, sort of thing.

VF: Is that a good thing then?

M: Yeah, well yeah, it is, because if [long pause], I'd just be a mess. I would, I'd just be a mess. I know that I would be.

465-472

I asked her again later if the seizures acted as a release for any emotion she could not control:

VF: You think you are?

M: I think I'm stopping it, so I think that's maybe how it's coming out, like that.

VF: Because you know when you said you didn't feel bad about the seizures, you didn't feel bad, maybe, I wonder why that is then? 'Cos you, maybe it is coming out, and it's been, sort of, a relief, but, I don't know, is it a relief?

M: I don't, I, -no, I,

VF: You don't feel any different?

M: No, no.

VF: Right.

M: I still feel the same. That's what I mean, I don't feel any different, I can't ...

556-566

Superordinate theme 3

Illness perceptions

M: Yeah, but obviously I want to know [long pause]. I suppose, a-after today, I'll probably, start thinking to meself, more, because we've talked about it.

VF: Yeah.

M: Am I, am I having em because of trauma?

1238-1241

Illness representation models are rooted in attribution theory, some models reflecting the subjective experiences of illness and people's consideration of

factors such as; what caused their condition, how much it is controllable by self, how serious their condition is, what the consequences of it are, how much they are personally responsible for it, and if it will alter over time Leventhall et al, (1992) in (Green, Payne et al. 2004).

A main feature of these models of appraisal are the temporal aspects, which include looking back at the possible causes of the condition, examining the condition in terms of its label, symptoms and how severe it is, and looking forwards in terms of the time line of the condition and its consequences (Marks, Murray et al. 2000).

However, the traditional social cognitive approach to studying illness perceptions and beliefs tends to do this outside the context in which these are expressed. In the context of our interview this is a case in point here. The story Mary told to me, to the hospital, to her family might be three different stories depending on what she wishes to tell (Marks, Murray et al. 2000).

3.1 Causes

Mary's and her mother's beliefs about the causes of her seizures were voiced throughout the interview, rather than collected in a way which gave me narrow, packaged, cognitive representations that fitted into an existing model (Marks, Murray et al. 2000). IPA, having an interest in cognition, can make use of the social cognitive models of illness representations, adapting them in the context of an in-depth interview (Green, Payne et al. 2004).

3.2 Trauma

Mary suggested to me early in her interview that the seizures may be stress related, the root being her brother's murder. It was not clear whether the neuroloigsts had been told about this:

M: The doctors are quite baffled, you know, to why I'm have 'me now,
15

M: and erm, me Mum seems to think that, it's the stress of every –the stress of it all. Me Mum seems to think that's what's triggering these off. Because I have erm, constantly in me mind, most of the time.
22-24

However, when Mary later put forward their, apparently joint, hypothesis as to the causes of her seizures, 'But, but you did say, Mum, didn't yer, that erm, I've explained to Val and that, about our Jeff, erm, you said, that you think it, might be down to trauma, and stress, didn't yer?' M: 1100-1102. However, mum had already articulated that she thought this may be a contributory factor only:

VF: Yeah. What do you think to it all, then?
Mum: Well,
VF: What do you put it down to?
Mum: Well, I don't, I don't know really, to be honest, I can't,
VF: Mmm.
Mum: Erm, mind, it might be stress, you know, it could be,
VF: Yes.
Mum: Some, some of it,
VF: Yeah.
Mum: -some, some of it to do with stress.
1053–1062

Mum: I mean that could be some of to do with it, erm.
VF: But you don't think that's the whole thing?
Mum: You don't, you know, you don't, you don't, who knows? You don't know to be honest, do you?
1111–1114

Mary and her mother had several ideas about the causes of her seizures ranging from 'biological' hormonal explanations to it being epilepsy after all. Mary herself requested information about her brain function from a radiographer, her mother suggesting immediately this alternative 'cause':

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

M: Oh, 'I said, 'can't you tell me?' Because I was, maybe, yeah, sorry I was, probably worried about that.

VF: What, that there was something there?

M: That there was something there. I was frightened. Erm, and she said, 'No, it's fine.' That's all she said. She just said, 'No, it's fine.' sort of thing. She sort of like mumbled it, sort of thing, she didn't, you know ...

VF: Yeah.

M: ... because she's not supposed to say to me ...

VF: No. It's got to be the doctor that delivers it, I suppose.

M: Yeah. So she just said, "No, it's fine. There's, there int nothing there." So, there's noth, so there int, you know, there's nowt going on up there, what would you say, erm, wi' me brain. say, erm, wi' me brain.

VF: Yeah.

M: There's no, there's no, erm, trouble,
        Mum: You can just have a chemical imbalance, can't you, sometimes? That causes em dunt it?

1146-1161

I put to Mary the idea of her seizures being psychological and she preferred this explanation rather than an organic cause:

VF: I mean if they were psychological, would that bother you? (Long pause). If they were, I mean, it's not, not rooted in the brain?

M: If it, erm, no, I'd be more bothered, I'd be more bothered, if, if it was, med, you know, if it was med, if it was in me, if it was medical, in me brain ...

VF: Yeah.

M: ... I'd be more bothered.

VF: Mmm, mmm.

M: If it was, if it was down to trauma, to do with me brother, then, I think, [long pause] I wouldn't be relieved, but ...

VF: Mmm.

M: ... I'd be, it would answer, you know, it would answer it for me sort of thing.

1309-1319

Mum, in an effort to resolve what was happening to her daughter, later considers the 'diagnosis' of epilepsy Mary has been given and links this with appropriate 'medical' physical and psychic symptoms she knew of:

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

Mum: What happened was, that last one on the 2nd of July, erm, she'd got up, and she's, 'Oh, I've got a bit of a funny, funny taste in me mouth.'
VF: Mmm.
Mum: And then she went, "Mind you, that might be just like the taste of me breath." With just getting up, which sometimes that happens, doesn't it, with people?
VF: Yeah.
Mum: And then she never mentioned it anymore ...
VF: Yeah.
Mum: ... that day.
VF: Mmm.
Mum: And then that's when she had the fit at the tea-time.
VF: Mmm.
   Mum: But the night before, she had actually said she had headache as well.
VF: Right.
Mum: So, whether them's the warnings ...
VF: You think that? Yeah
   Mum: 'Cos, I think they said at hospital like, that you can get a funny taste in your mouth –
1454–1472

Mum: Like, going like into, you know, a daydream glaring like that, erm, when you ask her a question she's not even hearing you. Erm, well she does it now.
862-863

Mum: You know, some people with epilepsy, they have them ones where they're go into a like er, they just like, look up, don't they?
VF: The sort of absencey ones where you just like, shut off for a few minutes?
Mum: Yeah, they're like looking up like this ...
VF: Yeah, and it's not –
Mum: ... and you can't get no response from them.
1687-1692

Thus the illness representations of Mary and her Mother appeared to diverge. Mary steadfastly remained with her view of her seizures being trauma related; her mother was not convinced and shifted from this reason to it being epilepsy to biological explanations of hormonal imbalances.

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

Tracking conceptual connections

3.3 Cannabis connection

Mary's mother volunteered some information which gave me food for thought about Mary's seizures and her mental state. Mary's mother disclosed Mary's, prior illicit previous drug and that she had been a heavy cannabis smoker over a number of years (13) but that she had stopped this relatively recently. That would be some months before the interview took place. That Mary's mother brought this up at all, and Mary not challenging this disclosure, is significant in terms of whether they were considering this as a possible cause. Mary's mother denying the possibility and Mary saying she disclosed this to her epilepsy nurse received advice from her:

> Mum: You've been a smoker, though, haven't you?
> VF: Ooh. (Laughs).
> Mum: Which you have.
> M: Oh, God, I've erm, [long pause] marijuana.
> VF: Oh, really?
> Mum: She's smoked cannabis, yeah.
> M: Not now I don't.
> VF: No. I think a lot of people have though, haven't they? Do you mean a lot, smoking it a lot?
> M: Yeah. For quite a few years.
> Mum: But on and off, it weren't constant. It was on and off.
> M: On and off, but, erm, I've asked, I've asked about that, and, and they've said, I asked the Epileptic Nurse at Hull Royal.
> VF: Yeah.
> M: I've asked her about it, and she said, there's no real connection of, of that *causing* em, but, but you *cannot* do it while you're epileptic, sort of thing, which I, which I stopped last, a good few months ago, I didn't, last year time, didn't I, I stopped.
> VF: Mmm.
> Mum: Mmm.
> M: Erm, but I did do that for quite a few years on and off, but I, I don't do ...
> Mum: No! I don't think it's to do with that, I don't think it's to do with that, I really don't.
> VF: Is it the last few years you did that, then?

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

      M: Well, 13 years, didn't I? On and off.
      VF: Mmm.
      M: A lot. I did do it a lot.
      VF: Yeah.
      Mum: From being young.
      VF: Yeah.
      M: Erm, but as I say, I've been stopped, good few months, last year time, now, and not looked back.
      Mum: Have you met a lot of people then with epilepsy? You will do, won't you?
      1633-1665

A later e mail communication from the neurologist had no record of Mary smoking cannabis even though she told me she had informed them. In terms of psychostimulants and epilepsy, marijuana is the one substance that will *not* induce seizures in healthy people. It has been found that cannabis products are indicated in the treatment of epilepsy. A cannaboid called, D-9 - THC, has been found to be, 'associated with serotonin-mediated anticonvulsant action.' (Zagnoni and Albano 2002)(p30). This German survey showed that epilepsy was among the most frequently mentioned indications in terms of using cannabis medically, and that marijuana use was a protective factor for new onset seizures (ibid).

One study found that people with NES tend to use narcotics and benzodiazepines (Hantke, Doherty et al. 2007). Mary's ceasing to smoke cannabis could be significant, given that she began experiencing seizures soon after she stopped smoking. The question arose in my mind that she may have had epilepsy all along, but having smoked cannabis since the age of 18, it could have suppressed seizure occurrence. Her mother had also mentioned a period where Mary was 'daydreaming' for a period of months before her seizures began:

      Mum: I'll tell you what she does do a lot of though, and she's done it for a long time actually, before these seizures, is daydream a lot.
      VF: Yeah, you said that though, didn't you?

Mum: She does it a lot, you know, you might ask her a question, and she'd be, miles away.

VF: Before the seizures? How long before?

Mum: Cos, you know, 'cos I used to say to her, "I ca –are you there?" You know, sort of thing. Not knowing what's …

VF: Yes, yeah. So a long time before, then?

Mum: I would say, a good bit.

VF: A few years?

Mum: No, not years, I wouldn't say years, no.

VF: Oh, months, right.

Mum: Quite a while before though,

VF: Mmm. Months?

Mum: Like, going like into, you know, a daydream glaring like that, erm, when you asked her a question she's not even hearing you. Erm, well she does it now.

847-864

I contacted her neurologist later about the cannabis issue and these are his comments, interestingly he was unaware of Mary's drug use:

Mon 12/01/2009 19:27

Hello Val

I have just looked through this woman's notes. She missed last 4 appointments, the last of which was scheduled for 31 July 08. She would have been discharged after this. We last saw her in clinic on 23.08.07. At that visit she was taking Carbamazepine and reported improvement in seizures. I note you say she is in rehab – this would raise the question whether previous seizures were related, although she denied substance abuse when she came to us.

A.M.,

When I asked him to clarify how withdrawing from substance abuse, and her traumatic situation regarding her brother, could affect Mary, he replied:

Fri 16/01/2009 18:16

Hi Val

In general, it is usually <u>withdrawal</u> of CNS depressants e.g. benzodiazepines, alcohol, cannabis that triggers seizures. CNS stimulants

> cause direct irritation of the brain – direct cause of seizures. It is
> debatable whether stress itself causes seizures or whether it relates to
> sleep deprivation associated

> A.M.,

Coda

Mary was not available for a second interview. I telephoned her home and
talked to her mother on two occasions. She informed me that Mary was in
rehabilitation for drug and alcohol problems and had been there for the past 14
weeks. She was being assessed for bipolar disorder and manic depression after
years of mental health problems. Her mother maintained that she still had
'trance' like seizures, when she had headaches or if she is overtired she could
have a seizure. One such episode consisted of her arm going funny and one side
of her mouth lifted up. She has a very bad memory and was still on her AEDs,
although these were also being monitored by the rehabilitation unit. However,
given that she had not seen Mary in 14 weeks, it is not clear what time period
she was referring to. Even though her mother did suggest that it may be
possible that Mary would talk to me on the telephone, by special arrangement,
from the clinic, this did not happen.

The comments from Mary's neurologist about her disclosure of illicit drug use is
interesting in terms of how my interview with her had altered his perceptions of
her [110] 'case' giving him another view of it. He summed up the situation, from
his point of view, when a new patient arrives from A & E, with their diagnosis
already in place, and the constraints, in terms of time to gather personal
information about patients, the clinics are under:

> 'So like with these, I would like to know about the details, I will get the
> names from you again but, erm it's often people are going to deny the
> cannabis and er, some people, speak about, you know, it started when my

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[110] That is, of the other participants.

> brother was murdered but often you don't get that but the referral from A
> & E, 'this person came in and had definite tonic clonic seizures, they bit
> their tongue and so on' and you get on with it. And we don't go through
> the process of saying, well, are there any recent bereavements, any social
> things, 'cos we may have ten people waiting outside. And you know,
> maybe, even what might be straightforward might be not be so
> straightforward and that's why I am very curious to pull out the notes on
> these'. A.M., (29–38) [111]

Despite only meeting Mary once, far from leaving Mary's interpretation incomplete, follow up conversations and contacts helped me put the pieces of her puzzle together to expand the interpretation from one, single interview moment, to a deeper one which took into account contextual factors. It is possible in IPA to couple the initial interpretation with 'questioning hermeneutics' (Smith 2008). Discovering her history of substance abuse, and her subsequent mental health issues all offered more clues with which to deepen the interpretation.

Basing some of Mary's interpretation around the illness representations of herself and her mother illustrated their conflicting views of the causes of her seizures, Mary almost always believing that the trauma of her brother's murder was at the root of them, (apart from one time when a brain scan could have shown otherwise) her mother vacillating between this and a diagnosis of epilepsy, searching for clues in her daughter's behaviour to support this. For Mary's mother a diagnosis of epilepsy may have been preferable to the scenario that followed. Mary did gain help for problems other than the seizures which became peripheral although her mother told me that they were being addressed at the rehabilitation clinic.

Mary had always preferred an explanation of non organic seizures and her approach to them may impact on her adherence to seeking help and treatment for them (Plug, Sharrack et al. 2009). With her strategies of distancing – from

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[111] Please see thesis appendices, document C

Chapter 5.5. Mary: The doctors are quite baffled, you know, to why I'm have 'em *now*.

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herself, from her seizures, from her emotional trauma and eventually from her domestic responsibilities (Mary hardly mentioned her two children in her interview one of whom was present in the house when I saw her), Mary gave herself a cushion against her stress. Whilst still allowing herself to be visible within the family and gain attention from them and others with the physical manifestation of the seizures, she also succeeded in hiding from her neurologist, her problems of drug and alcohol abuse.

5.6 Diamond Cutting: Poetic interpretations of seizures.

There is magic within the method of qualitative data analysis. (Hunter, Lusardi et al. 2002)(p388).

Evocative interpretations are ingredients of the complex features of lived experiences. Merleau-Ponty (1945/1962) in Öhlen, (2003).

Phenomenological research generally, aims to 'evoke understandings through language that in a curious way seem to be non-cognitive' (van Manen 1998)(pxviii). The poetic interpretations here aim to represent people's experiences in short, 'elementary' forms (Landridge 2007)(p161), which reveal events in ways which are easy to engage with and understand.

Qualitative researchers can exploit the possibilities of various ways of representing their findings (Sparkes 1999) which can allow for readers to see the world in a different way to that already represented by traditional researchers Tierney (1993), in Sparkes, (1995). Medical sociology points out the potential of using novel methods of collecting and interpreting data other than just a research interview and that there is 'uncharted terrain' and there are, 'missing voices' within this literature (Lawton 2003)(p25), valuable in their own right (Scrambler and Hopkins 1990)(p1190).

How we represent our participants' words is important, both for them and for other readers of our research endeavours and has been the subject of ongoing debate (Glesne 1997). Writing up research is a process in itself - one not only has to learn to write (van Manen 2006) but experimenting with different methods can enhance findings and, potentially, make findings more accessible to a wider audience (Richardson 1998). These can be presented in such diverse forms of performance science, as screenplays, artwork, dance (Bagley and Cancienne 2001) metaphor, quilt making, plays and pastiche, (Hunter, Lusardi et al. 2002) 'writing with light' (using photography) (Szto, Furman et al. 2005)

(p140), all subsumed under the term expressive and creative arts research, which is grounded 'in the empirical world' (Szto, Furman et al. 2005)(p138). Presenting findings in different modes and foci may allow 'previously unseen aspects of the objects of our interest' to emerge (Blumenfeld 1995)(p400).

This chapter describes another method of presenting findings, which involves poeticising participants' words into constructs which combine their words with a placing of these by the researcher (Glesne 1997). The terms uses for this are 'poetic interpretation' [112] and the idea for doing this began in an exploratory study in which the words and phrases of participants were often poetic and evocative lending themselves to being presented in this way (Featherstone 2004). Also, because this present study is also exploratory and it was important to capture any other form of representation which may elucidate further the seizure experience.

Poetic representations can depict core themes, narratives relevant to these themes, using evocative language in a very economical way, educating through the power of language (Poindexter 2002). Re-presenting findings in this way is just one prism of many in a crystal which, potentially, offers many different views of the same phenomena (Denzin and Lincoln 1998). Such representations have the potential to illustrate 'truth' if they impact on the reader and give a real sense of the phenomenon in question (Richardson 2000).

The emergence of poetry as a form of representing research findings

Poetic representations (Richardson 1994) emerged from postmodern ethnography representing, 'an important turn for both theory and research on social science writing' (Richardson 1992)(p132), and were welcomed, in

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[112] Interpretation meaning here moving words and phrases around and placing them to emphasise meanings, rather than interpretation in the sense of interpreting those words and phrases, which is a different endeavour. Szto, P., R. Furman, et al. (2005). "Poetry and Photography: An Exploration into Expressive/Creative Qualitative Research." Qualitative Social Work 4(2): 135 - 156.

particular, by interpretivists. Other terms and methods used for this form of representation include approximated poetry and poetic transcription, which shapes the concentrated language of an individual into a version of the 'truth' (Glesne 1997), generating poetry from research interviews, (Poindexter 2002) poetic condensation of narratives (Öhlen 2003) and, using an original poem as 'data', coding this, then compressing the emergent themes into formal poetic structures which highlight different aspects of the findings and focus increasingly closer to them with minimal words (Furman 2006).

All essentially involve the researcher in bringing out the depth of experiences in various creative ways whilst attempting to illustrate as clearly as possible how they did so - although this is not an easy task - relying as it does on the instincts and hunches of a researcher, it is difficult to explain and replicate (Poindexter 2002).

Diamond cutting

'Diamond cutting' refers to the carving and chipping away in the transcript of material other than that which contains the kernel of the phenomenon (Poindexter 2002)(p709).[113] Some authors use formal poetic structures such as Tanka or Pantoum [114] in order to capture central concepts (Furman 2006). Others use the collective words of participants to form a story from the memories of a group of people, which also uses central phrases and images from the memories. Common to all however, is that they are all based on empirical

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[113] This close reading of the transcript brings into the arena issues as to how we should transcribe our conversations in the first place, whether we record all emphasis, pauses, hesitations, tones of voice etc. in order to capture all of these nuances Poindexter, C. C. (2002). "Research as Poetry: A Couple Experiences HIV." Qualitative Inquiry 8(6): 707 - 714.

[114] Tanka is Japan's oldest poetry form. Traditionally a tanka has five lines with 5-7-5-7-7 syllables. In English some count syllables and some just have short-long-short-long-long lines. If you know haiku, you know half of a tanka. Unlike haiku, tanka encourage feelings and emotions.
The pantoum is a form of poetry similar to a villanelle. It is composed of a series of quatrains; the second and fourth lines of each stanza are repeated as the first and third lines of the next. This pattern continues for any number of stanzas, except for the final stanza, which differs in the repeating pattern.

data, use the images the participants' produce and are, therefore, easy to 'consume' (Furman 2006)

Compressing participants' words then is the major tool in poetic interpretation (Szto, Furman et al. 2005). Poetry can be defined as including, 'compression, image and metaphor', 'the clarification and magnification of being, through words', or, 'the distillation of the essence of being, through language' Furman, (no date) in (Szto, Furman et al. 2005)(p146). It can be, 'metaphorically, generalizable' Stein, (2003:2004) in (Szto, Furman et al. 2005)(138), involve the lives of the researchers (which can help illustrate any effects this may have on the interpretation) and can, potentially, generate theory (Szto, Furman et al. 2005).

However it is done, poeticizing participants' voices remains a controversial undertaking, as there are no formal methods of evaluating it, be it scientifically or artistically (Poindexter 2002), and it is not agreed what the elements of a good interpretation are (Denzin 1998b), some people still demanding 'valid' explanations in the form of transcripts or recordings of the conversation in question (Richardson 1992)(p132).

Examples of other author's work with poetry

Glesne (1997) developed her own form of poetic transcription from generating themes in the transcripts, coding and sorting them, keeping participants' ways and rhythms of speaking. This succeeded in conveying a real sense of Puerto Rican political and social history as she wove the story of her participant's life and work into what she termed 'approximated poetry'. Again this sweeps away research conventions in an attempt to combine both scientific and literary endeavours and, undertaking poetic transcription in this way, she argues, makes the process of analysis even more transparent (Glesne 1997).

Chapter 5.6. Diamond Cutting: Poetic interpretations of seizures.

Killick (1997) talking to people with Alzheimers over a period of 10 years, poeticised several aspects of how people lived with this condition. They spoke of their confusion and panic, what it meant to live in a nursing home, family relationships and other subjects, using emotional, metaphoric and sensual language whilst doing this. These poems showed that people still maintained some of their humanness, resilience, wit, insight, humour and creativity, mitigating against the myth that people with Alzheimers lose such personality traits, Benson (1997) in (Killick 1997).

The spontaneity of their words also illustrated that these people were experiencing memories and insights and coming to terms with what life was like for them before and after the disease, saying, 'listen to me, I am still here' (Killick 2005). In some cases Kilick used the words exactly how they were spoken, the lines simply being rearranged on the page. 'I could write down what they said and what they were saying was extraordinarily interesting, and some of it was highly poetic. And I suddenly realised I was on to something rather special.' (Killick 2005).

One poet's words describing how she saw her dementia could not be presented in any other way:

> 'This is your forehead (gesturing with her thumb and forefinger to demonstrate a circle shape and indicating the top part), and it's like something hits it, smashes into it really hard, like a collision of planets and the hole goes into pieces, you lose a piece of the hole or you become many separate parts of the hole but not one planet, not one hole anymore.' A person with Alzheimers (Killick, 2005).

That the words of the poems belonged to the people themselves was made clear by one participant who was shown a poem Killick considered they had written together, 'Do you know I'm a poet too? (Killick) to which she replied, 'No you're not, you're my editor.' Second person with Alzheimers, (Killick, 2005).

As 'editors' of other people's words then, we write their stories (Vanderford, Jenks et al. 1997) and the responsibility is ours to represent these in ways which can aid understanding of the conditions they suffer from. One of Killick's 'poets' impressed this upon him, 'Anything you can tell people about how things are for me is important.' (Killick 2005).

Writing is affected by the mode in which we write, and some might claim that computers have transformed this process. Unlike speech, the words on the screen can be moved, deleted, copied and added to with ease, always looking professional and complete. As our poems evolve on the screen, they invite us to engage, edit, alter and revise them, until we are satisfied with the finished product (van Manen and Adams 2009) the form and content of which will inform the reader and capture their interest (Sandelowski 1998).

Simple devices such as repetition (Öhlen 2003) word reduction, maintaining the rhythms of people's speech and repeating words and phrases, can be an integral part of the new poetic configuration (Richardson 2000). Taking excerpts from different parts of the conversations can also be appropriate, as in the interpretations undertaken for this study.

The rationale for constructing poems from the accounts of two of the participants in this study was that their words and phrases particularly lent themselves to being poeticised, and because a booklet about seizures was being considered for production. This would contain contributions from participants' interpretations along with a clinical commentary. It was hoped that participants would be a part of this production and poems which give a vivid picture of some seizure experiences could be included in it.

A poetic interpretation, therefore, from a part of their interview transcript was shown to Vince and posted to Dave. Having already 'worked' in that they had already talked to the researcher at length previously (Miczo 2003), this method did not overload them, offering them a glimpse of their individual

interpretations in an accessible form. It acted as a form of verification of the interpretation of their words, giving them the opportunity to confirm or deny that some aspects of their experiences has been captured (Szto, Furman et al. 2005), albeit from a fraction of the whole interview conversation.

Care was taken not to move the words far beyond their original places in texts (Glesne, 1997, in Öhlen, 2003). This can 'become a description too far from the narrated experiences of the participant' (Öhlen 2003)(p559), and the narratives needed to speak for themselves. However, 'in thoughtful phenomenological texts, the distinction between narrative and poetic is hard to draw.' (van Manen (1997)(p368) in (Öhlen 2003)(p558).

Validation of my interpretations

The poetic interpretations here are another layer of interpretation of people's seizure experiences. IPA, notwithstanding its intense focus on the person, still adheres to a (traditional) focus on themes arising in a person's conversation. These poems provide an addition to the conventional presentation of an interpretation.

Requesting comments from two of my participants about poems constructed was considered justified because the task was small and manageable for them. After being shown his poetic interpretation, Vince confirmed that his illustrated how he had felt, and neither Vince nor Dave wanted to adjust anything in their poems.

The poetic interpretations below are representations of aspects of two participants' experiences in their own words. The sections of transcripts they were taken from are at the end of this chapter, so that how they were constructed can be shown. Simply moving the words around, or making them stand out, can make ordinary words (and sometimes not so ordinary) more emotive and meaningful, resulting in capturing the essences of people's

experiences, often being more effective than offering selections of quotes to illustrate points or themes but serving the same purpose (Richardson 1998).

The poetic interpretations

The poetic interpretations here are a compression of participants' own words, [115] whilst remaining faithful to the original words, i.e., they are based on empirical findings and do not adhere to any formal poetic structure being, 'quasipoetic' (Furman 2006)(p560). The original rhythm of participants' speech is kept rather than risk the effects of forcing their words into a prescribed format which could result in subtly changing the meaning (ibid). These interpretations are more than the parts of the whole, not simply a combination of the participant's words and the researcher's interpretation, rather they represent the findings in a 'third voice', being a fundamental shift away from traditionally accepted methods of presenting findings (Glesne 1997).

In phenomenology, 'one does not write primarily for being understood; one writes for having understood being'. (van Manen 2006)(p721).

Three poetic interpretations
Vince

Vince's poem is about his perceptions of his first seizures experiences, his awareness and consciousness, his bodily sensations and realisation and acceptance that he had epilepsy. His poem is taken mainly from the beginning of the first conversation, incorporating elements of the written description he had written prior to this, with one line from his wife's words making up the penultimate line of the poem. Any words the researcher spoke were not included but they can be seen in the original transcript sections at the end of

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[115] I have included at the end of this chapter, the parts of the transcripts these poems were taken from in order to offer an 'audit' of how these poems were constructed.

this chapter. After the poem was constructed, it was taken back to Vince at the second interview and he endorsed the efforts as epitomising his experiences at that point, 'that is exactly it yeah, the second verse actually depicts the reality of the total' V:387 (2)

This poem only existed for Vince at one point in time. At the time of the second interview Vince's experiences had reduced into one of simply experiencing a very bad headache, and he had almost lost the insights he had spoken of earlier. Reading through the poem with him again and asking if it still stood as his experience now, Vince replied, 'I don't really notice it' V:48(2) '*I* don't feel it' V:137 (2). The experience had becomes a headache he feels for around half an hour and he waits for this to go before he can relax once more. He is not aware of anything else.

Vince also commented on the repeated lines in the poem which describe his becoming epileptic and agreed that, at the point of the first interview he was coming to terms with this but at the second interview he said, 'I have to accept it because it's real.' V:514 (2)

"Going funny"

Drawn away the company I was talking to;
this feeling of being with, but totally apart from.
I was there but, indeed, I wasn't.
I seemed to be totally removed.
I have become epileptic.

When I came back I knew I'd been;
it almost felt as I'd had been somewhere else.
I hadn't been *there*, but when I came back
I realised that I hadn't left.
I had become epileptic.

As I pulled away, I seemed to be suspended,
I could see the people I was talking to, but
The *contact* seemed to be broken;
I seemed to have been taken away.
I had become epileptic.

The contact I was making, even though I could still see,
the contact with them was no longer there.
I was *trying* to speak but it was mumbo jumbo.
The contact had been broken.
I had become epileptic.

Because I failed to realise just what was actually going on.
And I couldn't understand the reality of why.
He isn't there, he's gone.

He has become epileptic.

In the second conversation, Vince reconceptualised his experiences into one in which a person not experiencing seizure could relate to and understand using everyday examples of things we may all have experienced:

> 'Yeah, I remember all that - but that was the weird thing about it I could see, I could see, feel, but not totally understand. Becoming, you know getting on the train or a tube in London and going towards somewhere but going the wrong way' V: 542–544 (2). 'But getting on the tube, you're suddenly thinking, I'm going the wrong bloody way, get the tube back. But how often would you actually get on and get a tube back, how often would you actually think like that?' V: 546-548

> When that happens, it's like a loss or it's like - you come out, you go to get in your car, another car, there's another car, the exact same car, put your key in, you wonder why you can't open it.' V:561–563 (2)

A poem constructed from these words would be very different to what is shown above. Although they give the reader an idea of what being Vince would be like, they are not a description of a phenomenological experience.

Dave

Both of Dave's poems illustrate behaviours he cannot control and that he is not aware of whilst they are happening, but which he is in the process of accepting as being part of his life. The surprise he first felt about these experiences is clearly depicted in the first poem, as he realises that he is undertaking complex tasks whilst not being aware of this. The drawing, one in a series included in his individual interpretation, illustrates the third stanza of the poem.

Dave depicted two stories in his poems which were similar. The first illustrated that he could still respond to danger in his environment notwithstanding him saying he remembered nothing. He had planned what he was going to buy on a shopping trip and found himself in the middle of a road, in front of an oncoming lorry before he 'came to' in the nick of time (the climax of his story) and ran to safety, the aforementioned shopping having been bought unknowingly in his hands.

Some of Dave's language in the poem, 'pressing down', 'pulling down', 'everybody's screaming at you' and, ' stopped right bang smack', resemble what Menz et al (2005) term, 'metaphorical predications'. Metaphorical predicates in general, help express the qualities of things and experience (Tye 2003) and can be useful for patients in describing something. The use of words such as ' sharp', 'stabbing', 'pointed', 'pinched', 'lightening', 'cutting', 'dull', 'burning', 'searing', 'gnawing', 'convulsive', 'tickling', 'prickling', 'electric' and 'pressing down', could be valuable linguistic resources for people as they add depth to the

meanings of experiences (Menz, Lalouschek et al. 2005) without a person having to formulate more complex metaphors.

Dave uses metaphoric predications in relation to the drawing below, and to describe depicted auditory, 'modality-specific sensations' (Johanson, Valli et al. 2008)(p175) of people in a crowd shouting, their voices hitting the top of his head. He alludes to a period of 'partial absorption', whereby he is aware of what is going on around him even though his attention is directed inwards (ibid). Dave says he is not conscious but half awake and half asleep, i.e., as he puts it, he is in autopilot.

These experiences point to Dave being able to perceive what is going on around him - after all he takes avoiding action and is not killed by the oncoming lorry. However, he does not consciously perceive, or this is how he reports his mental state to be. That perception can exist without awareness is an ongoing debate between sceptics and believers [116] (Simons, Hannula et al. 2007), and we cannot expose Dave to experiments in which we test his awareness (or not) of lorries thundering towards him. Subjectively, Dave says he is in automatic pilot, and he is accurate in this, his perceptual system perceived the lorry and directed him to safety. The subjective experience of Dave and others like him are worthy of study in their own right (Simons, Hannula et al. 2007) in terms of their levels of consciousness.

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[116] The implications being, for neuropsychologists, that if implicit perception of a stimulus can take place then this also implies that 'selective attention is not necessary for semantic processing'. p208. Simons, D. J., D. E. Hannula, et al. (2007). Behavioural, Neuroimaging, and Neuropsychological Approaches to Implicit Perception. The Cambridge Handbook of Consciousness. New York, CUP, P. D. Zelazo, M. Moscovitch and E. Thompson.

Dave. Poem one. "Being in Autopilot"

But er another worrying thing is the black outs.
Yeah, it may not be a fit but - me brain just seems to turn off and I can walk around.

Not know where I am.
Not know where I've been.
Not know what I've done.

I started to feel rough like something's pressing down, pulling down my head or whatever.
It's like being in a football crowd and everybody's screaming at you for attention but you're not able to respond to any of them.
It's basically em, how can I put it? Em, half awake, half asleep
and this part - that's where the scream's coming from.

I knew I wanted a couple of onions and a bag of potatoes.

The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me.

Unfortunately, I'd stopped right bang smack in the middle of Beverley Road looking at this lorry coming towards me.

I don't know.
I just came to.

I can move like a rocket when I want to!

Ah, but this is a weird one - carrying a bag of potatoes, yeah.

Autopilot.
I'm in auto pilot.
I'm in auto pilot.

The second poem was constructed from Dave's second interview conversation, in which the novelty of his experiences has shifted to one of frustration that these things happen, to accepting that he can do nothing about them. Dave is short of money and buying five coconuts is not something he would wish to spend his limited resources on. When he replied by letter after being sent these interpretations, he added to his validation of them. They appeared to mirror events in his childhood when he was around eight years old, in that he does not remember some of his behaviours, 'apparently I had a dazed look in me face tried getting into me grandparents gas cupboard and had a good chat with no-one in particular - of which I have no memory!' (Dave, personal written communication 28/1/09).

The coconut day

How can I put it, er the coconut day. The coconut day, yes.

When I have my little er daydreams where things, where I'm walking, or whatever where.
When I went out for some food, well I went out for milk, something to eat.

I noticed the day previous, I noticed you know.
I noticed the day previous - coconuts 60p right?

I went out with three quid, walking down the street and I had me rucksack on.
Anyway, I gets home, thought never occurred to me.
I gets home, and guess what's in me rucksack.

Five bloody coconuts
Five bloody coconuts
Five bloody coconuts

It still bugs me now,

How on earth do you walk into a shop to buy five coconuts. How do you do it!

Well, I mean er, obviously I do .....

Last word

"What is most true is poetic. What is most true is naked life. I apply myself to 'seeing' the world nude." Cixious, (1997) in (van Manen 2006)

Vince and Dave engaged with their experiences in a way in which Mary and Graham did not, their experiences being based mainly on what other people had told them. For example, Mary's mother's was the only descriptions of Mary's experiences:

> Been the same ones, each time, it's the same
> She goes all blue, her face goes absolutely blue
> But she's like, you know like as if she's choking
> And she's like making that noise, you know.
>
> Yeah, and she's you know, the arms and that –
> She bites her tongue, and her eyes like go up, could go up into her head–
> er, foams, you know from her mouth
> Her eyes sort of go, and she'll be like, like, like cho, more or less like choking, sort of thing, you know, erm,
> But that's what it, it goes on from five minutes, a good five minutes, each time it has.
> Her eyes was like glaring and she didn't know where she was.
>
> When she first, comes, sort of comes out of it, she's real confused for –
> a good half hour, you know, a good half hour, you know.

Mary's personal experience of her seizures amounted to just a few words,

> 'It's just all like a big question-mark. I feel like I'm on the outside looking in. It feels like it's not me.' Mary:1440-1444.

Although the last two lines give some idea of Mary's personal experiences, this is all there is of her personal voice, whereas the ones given by Dave and Vince illustrated how deeply they personally remembered their experiences and, because of this deep engagement with these experiences, their words and phrases translated readily into poetic evocations of this.

Vince's are particularly valuable, because they are 'moments' in his remembered experiences at one point in time. Another phenomenological 'moment' and his poem as it stands above would not have existed as the same expression of his experiences, given the alterations in his perceptions of these. Dave acknowledged his two poems as remaining more stable as experiences, although the language in the second one, taken from his second interview, shifts in tone as these experiences became a more accepted, but frustrating, part of his life which he increasingly wanted to dissociate from.

Poems have been used to understand clinical practice. An analysis of poems collected from American midwives' lived experiences, explored their ways of knowing about their own practice. They illustrated three ways of knowing that guided the care they gave, their own individual beliefs and self knowledge, their knowledge grounded in their everyday experiences of childbirth as well as objective 'text book' knowledge. These poems championed 'multiple ways of knowing' and that intuitive, experiential and contextual knowledge can offer holistic care for women and there are more than one ways of 'knowing'. A proposed anthology of poetry by midwives could offer midwifery students a 'new' look at their art (Hunter in press).

These poetic interpretations are just one form of phenomenological interpretation and extend the boundaries of IPA as it stands today. They offer some additional understanding of the data collected (Weintraub 2002) and new ways of 'knowing' about seizure experiences. Even the poem derived from the words of Mary's mother is a way of knowing, that is, it offers one witnessed description of her daughters' behaviours.

Audit trail - Poem one. Vince's original words

Emboldened text is that used in the poem.

<u>Part of Vince's written description of his experiences</u>

At first these feelings were difficult to understand and even harder to explain. You see I felt that I was **drawn away the company I was** with and **talking to; there was this feeling of being with, but totally apart from.** It seemed to me to be quite inexplicable! You see **I was there but, indeed, I wasn't.** Even now I find it hard to explain the reality of what was going on; it is still confusing to me. The feelings of these moments are in fact quite altruistic to me and yet, like cubism, not really understood.

Conversation, lines 25-43. (1)

V: Ok well basically it started off - I was having these 'situations' and they started last year – where I was talking to. talking to people and **I seemed to be totally removed** and well, Eileen'll be able to tell you much better, how my voice went -. How did my voice go Eileen?
WF: Well, **just went funny** - couldn't understand him
VF: Couldn't understand him? Incoherent sort of – you couldn't understand the words?
V: and basically that is, is what happened and – **when I came back I knew I'd been, it almost felt as if I'd been somewhere else. I hadn't been there, but when I came back I realised I hadn't left.** So I didn't, I didn't comprehend it at all, so I saw Dr Davies (GP) about it and Dr Davies got in touch with Dr Ming (Neurology specialist). And Dr Ming put me through these tests and found there that er, there was something going on up here in the brain and that I, **I had become epileptic** and that's about, the whole thing. I can't really describe it any better, other than the fact that I. **As I pulled away, I seemed to be suspended** – I was slightly moving away from – and that I can't comprehend at all.

Conversation lines 80-113 (1)

V: yes that's what it felt like as if I was lifted away.. **I could *see* the people I was talking to,** ... **but** as the .... em what's the word? – **the contact seemed to be broken** and that's one of the points that erm, I *don't* understand – it didn't seem to make an awful lot of sense.
VF: Did the, the fact that you broke contact with somebody – that didn't make sense to you?
V: What – was the fact that **I seemed to have been taken away** -and **the contact I was making - even though I could still see**
VF: You could still see them?
V: yeah ...but **the contact with them was no longer there.**
VF: By contact you mean you couldn't speak to them.

V: I mean **I was *trying* to speak but** as Eileen's just told you, **it was mumbo jumbo.**
VF: Mmmm
V: and **the contact had been broken because I failed to realise just what was actually going on.**
VF: You failed to realise
V: Yeah
VF: That you were – because you said that you had been lifted – felt as though you had been lifted away.
V: **And I couldn't understand the reality of why** – you know. what it meant.

Line 551 (1)

Wife: **He isn't there, He's gone**

Audit trail. Poem two. Dave's original words.

Emboldened text is that used in the poem.

Conversation lines 183-260 (1)

D   well I told you, it's on record with Dr **** **but er another worrying thing is the** <u>black outs</u> .

VF   on top of the fits?

D   **yeah, it may not be a fit but** pause, **me brain just seems to turn off and I can walk around, and not know know where I am where I've been, what I've done,**

VF   right

D   for example, em the worse one I'd been to me doctors, on Alexander Road, picked up a prescription, er went to Boots, got me prescription and **I knew I wanted a couple of onions and a bag of potatoes.** So I thought, I'll go down Newland Ave, into a veg shop get the onions and potatoes. So I went to the er veg shop near er Nag's 'ead, looked at the price of potatoes and thought, well I'm not buying 'em here. I got a couple of onions, and I thought well, I may as well go to Aldis, or Netto's

VF   yeah

D   so I though I know where I wanna go, down at bottom of Newland, round the bend, cross into Pearson Park, through Pearson Park, well back of Aldis Park street or was it Cave Street? Aldis, get the potatoes and back home again. 'Cos I live just off Sculcoates. I could remember er getting up to about er Princes Ave, **I started to feel rough**

VF   how does rough feel like?

D   **Rough, er, like something's pressing down, pulling down my head or whatever.** And, I can just remember **it's like being in a football crowd and everybody's screaming at you for attention**

VF   right

D   **and you're not able ter ...**

VF   respond?

D   **respond to any of 'em.**

VF   but they weren't - nobody was screaming at you

D   no, no, course not, no and I said I can remember just getting to Pearson Park, **and the next thing I remember is being stood on the middle of Beverley Road, looking at a lorry coming towards me.**

VF   oh gosh

D   **ah but this is a weird one, carrying - a bag of potatoes**

VF   oh my goodness, you must have done all that unconsciously then

D   **yeah.** So I'd ran through it in me 'ead, what I was gonna do,

VF   yeah

D   so I've gone onto automatic and actually done it

VF   yeah

D   but **unfortunately, I'd stopped right bang smack in the middle of Beverley road looking at this lorry coming towards me**

VF   did you stop there because you, why did you stop in the middle of the road do you think?
D   I don't know, I just came to
VF   ah you came to, that's what I mean that's where you came too then
D   yeah,
VF   and you didn't get killed obviously!
D   laugh, **I can move like a rocket when I want to!**

Conversation lines 650-693 (1)

D   what it feels like .... in my brains.
VF   explain that then
D   that's a crowd,
VF   I see, right, that's a crowd of people, demanding attention,   yeah, right and you're you, there, right are you sort of conscious then then?
D   nnn, no

VF   but you still remember that?
D   yeah
VF   right, ok, right?
GD   It's basically em, pause, how can I put it? Em, half awake, half asleep, semi conscious and this part,
VF   the front of your head?
D   yeah, and **that's where the scream's coming from.**
VF   right, and then what happens?
D   mm,
VF   you can turn over if you like
D   just a minute, I'm just gonna,
VF   oh is that the potato business?
D   **autopilot**
VF   but you, so somewhere in there, you've bought the potatoes? And come round again
VF   because you make cups of tea and put the telly on
D   **I'm in auto pilot**

Audit trail. Poem three. Dave's original words

Conversation lines 84-103 (2)

D: When I have my little er day dreams where things where I'm walking or whatever where things er **How can I put it, the coconut day.**

V: The coconut day

D: **The coconut day, yes. When I went out for some food, well I went out for erm milk em, something to eat,** I was getting paid the next day, well I want some milk, I'll get some fish and chips or, a snack of something 'cos I get paid tomorrow. **I noticed the day previous, you know** on Newland Ave

V: Yeah

D: **I noticed the day previous - coconuts 60p right? I went out with three quid, walking down De Grey Street,** anyway walking back down Queens road **and I had me rucksack on. Anyway, I gets home, thought never occurred to me,** you know **I gets home, and guess what's in me rucksack, five bloody coconuts, five bloody coconuts, it still bugs me now, five bloody coconuts, loudly**

V   Right

D   **how on earth do you walk into a shop to buy five coconuts, loudly**

V: you've done this before though haven't you?

D: **I know but how do you do it (loudly)**

V: You do it I don't! laughing

D: **Well, I mean er, well obviously I do cos er, but** er, the

Audit trail. The words of Mary and her mum

Conversation lines 742 - 803

MUM: Erm. Shut the door, M****, please. Been the same ones, each time, or it's the same –
VF: The same pattern?
MUM: Yeah.
VF: So, what's the pattern then?
MUM: Yeah, so it's erm, well, it's like, she goes, **she goes all blue,**
VF: Yeah.
MUM: **her face goes absolutely blue,**
VF: Right.
MUM: -erm, and, she's like, they're hard to explain aren't they, **but she's like, you know like as if she's choking,**
VF: Yeah.
MUM: **and, she's like making that noise, you know, like er,** [makes choking noise].
VF: Yeah.
MUM: **Yeah, and she's –you know, the arms and that –**
VF: Right.
MUM: -are like this [demonstrates].
VF: This, right.
MUM: Erm, like er, **she bites her tongue.**
VF: Oh, does she?
MUM: More or less each –
M: Oh yes, sorry, I forgot to tell you about that.
VF: Because that would leave –hurt you, wouldn't it?
M: Oh, I made a right mess in me in, the last one I had.
VF: Really? On your tongue?
LM: All on the side of me mouth, and all the side of me tongue.
VF: Oh, it really hurts that, doesn't it?
M: Yeah, it was terrible.
MUM: **And her eyes like go up,**
VF: Yeah.
MUM: you know, **could go up into her head** [noises off] –er, **foams, you know from her mouth.**
VF: Yeah.
MUM: sort of thing, and, erm, **her eyes sort of go, and she'll be like, like, like cho- like so [demonstrates?], more or less like choking, sort of thing, you know, erm, but that's what it, it goes on from five minutes,** [noises off] **a good five minutes, each time it has**.
VF: Right.
MUM: Erm: And the, I've got it written down here, anyway. You see I've put down here, 'February – not witnessed'.
VF: That's the bathroom one?
MUM: Yeah. Now then, the first,

VF: Good job you were around, really, because you were around pretty soon after that, weren't you?
MUM: Yeah.
VF: Yeah.
MUM: Erm, as it happened that, this first one we witnessed we all happened to be here that day.
VF: Yeah.
MUM: Erm, that was the 9th of June, was the first –
VF: The sec-oh, I thought you said February?
MUM: No, yeah, that, the one in bathroom was –we didn't see that though.
VF: No. The 9th of June, yeah.
MUM: The only thing is, we came and she –we couldn't gain the access, you know what I mean,
VF: Yeah.
MUM: we did after 10 minutes.
VF: Yes, yeah.
MUM: and she'd come down and let us in, but she was like, **her eyes was like glaring and she didn't know where she was,**

Conversation lines 1425 -1428

MUM:Yeah. **When she first, comes, sort of comes out of it, she's real confused for –**
VF: Yeah.
MUM: **a good half hour, you know.**

Conversation lines 1440 - 1443

M: That's what I *mean*. It's just all like a big question-mark. It's like, I can't (long pause). **I feel like I'm on the outside looking in.**
VF: Yeah.
M: If you know what I mean. **It feels like it's not me**

5.7 A look across cases: Interpretations

The researcher took great care to stay with the four individual participants as long as possible to address what is the 'main currency for an IPA study' (Smith 2008)(p53), i.e., the detailed interpretations of meanings ascribed to particular experiences by individuals (van Manen 1998). However, individual analyses can be taken to a deeper level and the researcher began to 'parse' (Smith, Flowers et al. 2009)(p38), these more closely (ibid)(p73) and an interpretation across cases.

This chapter looks across cases for various attributes and was written before the neurologist supporting this study gave his considered diagnosis.

Table 14 below, illustrates superordinate and subordinate themes identified across cases, the overarching theme being the idiosyncratic experiences and perceptions of participants. These themes then contributed to suggestions for information for patients, a screening tool and towards ideas for clinical practice and further research (see chapter 6).

Overarching theme: Idiosyncratic experiences and perceptions

> 'So of course when you're told it is epileptic, your *understanding* of what epileptics are - and if mine's an epileptic, why is it so different?'
> Vince:583 - 584 (1)

Table 14

Superordinate and subordinate themes across cases

Superordinate theme	1 Seizure talk and terminology
Subordinate themes. 1.1 Metaphoric language **1.11 Metaphor** Graham: 'Getting into gear. On the right track.' **1.12 Metaphoric predications** Dave: 'The 'frazzle' type.' **1.13 Metaphoric approximations** Vince: 'It lifts you up and you almost feel as if you're floating ...'	
1.2 Elucidating levels of consciousness Vince: 'Yes, you float away and as you're floating you're looking - they seemed to have gone further away from you and - you're thinking - I can't really say whether the thinking is positive or negative.' Graham: 'Complete absolute, gap, out like a light.' **1.21 Elucidating contents of consciousness** Dave: 'I'm in a different dimension. Daisy dream world, everything's starting to slooow down.'	
Superordinate theme	**2 Coping**

Subordinate themes. 2.1 Distancing

2.11 from self

Mary: 'It feels like it's not me.'

2.12 from emotional trauma

Mary: 'But it's, it's emotion all the time, it's there, and I'm suppressing it, I'm stopping it.'

2.13 via use of second person narrative

Graham: I think you call em absency things, I think you call em, where you have your little flutters, little, well your ears start buzzing, it seems, it can't really-

Dave: 'And the first thing I noticed was a hand flying by me face, I thought that's strange and next thing I know another hand was flying by me face.

2.14 with medication

Dave: 'I want more: The Epilim's definitely helped.'

Superordinate theme	**3 Range and variety of perceptions**

Subordinate themes

3.1 Interpretations

Dave: 'There's the Dave locked inside that's always screaming to be let out. Please man - let me out.'

3.2 Beliefs

Dave: 'But one thing I have noticed, which I don't know whether it's true for epileptics, whatever I've got seems to run in an eight week cycle.'

Graham: 'But he can't pass it down to me, can he? I've got to pass it down to him?'

3.3 Causes

Graham: 'I was told by some doctor, I think it was, it could be due to the stress

Dave: 'It might have been me granddad's death actually, cos I was looking after my granddad and it would be about year and a half after he died that's when I

went - but, I was, I'd noticed and the strain.'

3.4 Understandings

Vince: 'And that's probably because my brain and, one part of the brain is being overruled by the other and that's the part of the brain which is damaged – it's actually been - during that period been stronger.'

Superordinate theme	4 Participants' reflections

Subordinate themes

4.1 Change

Dave: 'Yes, it seems to be getting worse and worse.'

4.2 Loss of insight

Vince: 'Well I don't seem to be getting affected the way I was.'

4.3 Transience

Dave: 'But definitely that one you can scratch out now.'

Graham: 'Well I have high blood pressure now, I'm on blood pressure tablets.'

4.4 Value of talking

Mary: 'Yeah, but obviously I want to know [long pause]. I suppose, a-after today, I'll probably, start thinking to meself, more, because we've talked about it.'

Graham: '... and have a chin wag you know, to have a talk of what's actually happened.'

4.5 Acceptance

Vince: '...which eventually I will have to have conquer and accept that it is - a part of my now reality. Takes a bit of doing.'

Superordinate theme	5 Etiological factors and health beliefs

Subordinate themes

5.1 Drug and alcohol abuse

Mum (of Mary): 'She's smoked cannabis, yeah.'

5.2 Secondary gain

Mary: 'Someone's been with me all the time. When we go out shopping, erm, me Dad's with me, he takes me all the time. '

5.3 Brain function

Graham: 'Is it a -? I dunno, there's sommat there due to me car accident I was a passenger in.'

5.4 Trauma

Mary: 'Am I, am I having em because of trauma?'

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1 Seizure talk and terminology

One of the aims of this thesis was to identify differences in the language used by people with NES and epilepsy. Being a prospective study design, the researcher was not aware of participants' diagnoses although being aware of certain verbal behaviour relating to differential diagnosis affected attributes of talk identified and noted. IPA casts a different light on the phenomenon of seizures and offers examples of individual experiences which were extremely variable (see table 15, below). The task was to identify any relations between these (Polanyi 1961).

A rough 'count' of the number of words participants used to talk directly about their seizures from the total interview word count and the way in which they described their experiences highlighted clear differences. For example, Vince never veered from the term epileptic and its variants. His descriptions were almost always about personal felt experiences, his wife describing when and where seizures took place and how he behaved.

Graham's rarely used the term 'epilepsy' preferring instead, 'fits' or 'absences' and in general conflated the terms into one and the same experience. Graham had already alluded in his interview to the term 'seizure' as being stigmatised by other people when he mentioned it to them and this perception may have

contributed to his continuous use of the terms 'fit' and 'absence'. Research has established that people with NES resist the use of the term 'seizure' (Reuber, Monzoni et al. 2009) as they actively avoid talking about them (Plug, Sharrack et al. 2010). Graham's disengagement with both epilepsy language and the seizures as events happening to him gave the researcher the awareness that this might have been a case of NES. Thus, there is the possibility that in addition to having epilepsy as diagnosed, Graham also had NES given that his seizures had all but disappeared following his wife's death.

Mary used the term 'seizure' predominantly notwithstanding her belief and hopes that these were not organically rooted. Whether this was in deference to her mother's preference for a diagnosis of epilepsy for her daughter was not clear. Although Mary's talk about her seizures took up the largest percentage of interview time across participants, her descriptions were informed by her mother. Mary had little to say about what seizures meant to her personally.

Dave's descriptions were his own in the main and he used the terms 'seizure' and 'fit' predominantly in his first interview, remaining with 'seizure' again predominantly in his second interview adding in terms relating to different epilepsies, specifically 'myoclonic'. Epilepsy specific terminology is preferred by people with this condition, possibly because they need to engage with their condition, its effects and treatment (Plug, Sharrack et al. 2010).

Table 15, below illustrates the total numbers of words and terms participants and others used to describe and talk about their experiences, and the nature of these.

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Table 15

Seizure talk and terminology

Total number of words describing/ talking about seizures	Vince	Graham	Mary	Dave
Interview 1	2626/10 397 (25%) Included; How they felt (2217) Descriptions from wife (409)	938/10935 (8.6%) Included: How they felt (609) Descriptions from wife (88) Descriptions of inhibiting strategies (89) Circumstances around them (152)	10124/15746 (64%) Included; How they felt (22) Descriptions from mum (2036) How they took place (5222) Their chronology (2866)	1698/6968 (24%) Included: How they felt (1377) Descriptions of inhibiting strategies (321)
Interview 2	790/6655 (12%)	332/4318 (7%)	No second interview	2834/6796 (45%) Descriptions of inhibiting strategies (214) Déjà vu (23) Descriptions from flat mate (211)
Terms used to describe experiences (number of times used) Interview 1	**Epileptic (14)** Epilepsy (6) Seizures (3) Epileptics (2) Epileptic fits (2) Situations (1)	**Fit (51)** **Absence (33)** Headaches (6) Frozen (5) Flutters (2) Buzzing (6) Epilepsy (1)	**Seizure (43)** **Fit (18)** Epilepsy (12)	**Seizure (16)** **Fit (17)** Epilepsy (8) Blackouts (4) Convulsion (2)
Interview 2	**Epilepsy (17)** Epileptic (8) Epileptic (6)	Dizzy (4) Headaches (2) Flutters (1) Epilepsy (1) Seizures (1) Fits (1)	No second interview	**Seizure (13)** **Myoclonic (12)** Absence (10) Epilepsy (8) Day dreams (3) Fit (2) Tonic clonic (2) Complex partials (3) Blank (2) Auras (1) Grand mal

1.1 Metaphoric language

Comments and phrases relating to the use of metaphor and similies were examined given the research findings of their diagnostic importance (Plug, Sharrack et al. 2009i). Although there was only one specific metaphor analysis, all participants used some form of metaphoric conceptualisation, be it about their seizures or their everyday lives.

Graham's use of metaphor reformulated his present difficulties, physical and mental into ways of seeing and understanding. They did not appear predominantly to be about his seizures although he utilised the metaphors of 'fighting', 'black out' and of being 'switched off' in this context. Mary's use of metaphor also related to her life and the shutting off of her emotions and when she did briefly describe how seizures felt to her she remained with this concept. Dave's use of electric shocks and black-out metaphors are indicative of epilepsy and his use of metaphoric predicates added greatly to illustrating his experiences. Vince used what the researcher termed, 'metaphoric approximations' as he attempted descriptions of his perceptions of alterations in his environment and consciousness.

Types and examples of metaphoric language used by participants are depicted in table 16.

Table 16

Types and examples of metaphoric language used by participants

Vince	Dave	Graham	Mary
Relating to seizure experiences **Approximations** It almost felt as if I'd had been somewhere else As if I'm got lifted up and away and Almost in an empty atmosphere. As if - the atmosphere that keeps you held down. I seem to lift away and, I'm not me.	**Metaphor relating to seizures** An electric shock going through your whole body' The black outs Blackness for a while Me brain just seems to turn off One quart less intelligent Daisy dream worlds **Metaphoric predications relating to seizures** It's just 'bumph' to me The frazzle type Flashing lights 6 Stiff 11 Violent 4 Shaking 26 Passed out 2 Going stiff 3 Jolts 4	**Metaphor relating to seizures/life** Me light goes out. Someone just, just blacks me out in a way Getting into gear On the right track Let's go guns at the ready My mind goes into like overdrive	**Metaphoric constructs relating to seizures** I feel like I'm on the outside looking in. It feels like it's not me. **Metaphoric constructs relating to her life** 'It's like a two, you understand what I mean? It's like split in half'

1.2 and 1.21 Elucidating levels and contents of consciousness

A general exploration of participants' statements about these experiences was undertaken using the Ictal Consciousness Inventory (ICI) (Cavanna, Mula et al. 2008) (see table 17, below). This validated self report measure aims at identifying and relating impairment of consciousness and the subjective contents of consciousness to differing neural mechanisms. Being a quantitative measure it did not allow for an expansion of replies but formed a basis from which to ask participants further questions and to expand upon their replies.

Both Vince and Dave appeared to experience altered levels of consciousness (Johanson, Valli et al. 2008). Vince never appearing to lose consciousness completely as he was able to access and constantly reflect on his subjective experiences during a seizure, although he could not respond to 'exogenous stimuli' (Johanson, Valli et al. 2008)(p170).

Dave's sense of time appeared to alter and his cognitions were also affected as depicted in his final drawing and accompanying phrase of feeling 'one quart less intelligent'. Vince's 'floating', 'being lifted away' were indicative of out of body experiences while Dave's 'daisy dream world' and his feeling of 'being in a different world' hinted at the 'dreamy state' identified by Hughlings-Jackson in epilepsies involving the medial temporal brain area. That both Vince and Dave were the main narrators of their own experiences was significant (Johanson, Valli et al. 2008). Dave succeeded in undertaking involuntary actions, in addition to understanding and reacting appropriately to environmental events, narrowly missing a road traffic accident, (Johanson, Valli et al. 2008).

Although Mary offered some subjective feelings about her levels of awareness, it was not entirely clear whether this related to the actual seizure experience or its aftermath. Graham also talked about different dimensions of experience in terms of the content of his consciousness and of being 'not there'.

A study previously mentioned highlighted the enhanced arousal, alertness and attention that people have as they expect or experience a seizure and also introduced a way of analysing these based on dream analysis finding experiences to be 'distorted and bizarre compared with normal waking experiences' (Johanson, Valli et al. 2008)(p178). Most distorted were people's perceptions of events, their sense of time, sensory experiences and cognitions. Emotions were experienced during the conscious part of seizures, along with bodily and visual sensations and, cognitive difficulties and a third of patients experiencing problems with their sense of reality. People felt their relationship with the external world altering as they descended into the seizure and were aware that they were experiencing illusions or hallucinations and were able to reflect on these, perhaps because they were so unusual - some having 'no counterpart in ordinary human experience' (Johanson, Valli et al. 2008)(p171).

Table 17 below, illustrates the mix of descriptions from participants in this study and that this level of description was available from people with seizures having the potential to be 'accumulated' in order for us to understand this phenomenon more fully (Johanson, Valli et al. 2008).

Table 17

Elucidating levels and contents of consciousness [117]

Levels of awareness During the seizure were you ...	Vince	Dave	Graham	Mary
1 aware of what was happening to you?	I seem to lift away and, I'm not me You almost feel as if you're floating Aware something was happening to him but his perceptions were not matched by witness statements.	One quart less intelligent When it starts, yes Depends on what type of level. I might be aware of the stiffness for a while, pass out, then I might come to, and be aware of the clonic for a while, pass out	No. 'passed out' 'not there' Not during but just before and afterwards Complete absolute, gap, out like a light.	No Totally out I feel like I'm on the outside looking in. It feels like it's not me.
2 aware of your surroundings?				
3 aware of time passing by?		There's one time, it took me 3 days, 3 days, - before I recovered, three days	Don't know how long it took. Complete absolute, gap, out like a light. Got up, wife got up in the kitchen talking. Went backwards Knew he had moved from a chair to the settee	
4 aware of the presence of anyone around you?	Knows people are 'there' Aware of something happening outside of the	Yes. All of a sudden somebody breaks that world,	Only before, talking to wife, then afterwards when 'came round'. just a little buzzing sound there, but	

[117] Based on the ICI. (Cavanna, Mula et al. 2008)(p87).

	seizure experience		you can still hear around you.	
5 able to understand other people's words	No	Yes. 'are you alright?' really, 'are you alright?'	No	
6 able to reply to other people's words?		No Everybody's screaming at you for attention and you're not able to respond to any of em.'		
7 able to obey other people's commands?				
8 able to control the direction of your gaze?	No. Drawn away from the company was talking to	No. they (eyes) seem to go - yeah over there (drawn towards something)		
9 able to focus your attention	No. Attention forced inwards and towards seizure experience	I can roll a cigarette. Constantly doing this to reduce the possibility of have a seizure and so can stay on the computer longer.		
10 able to take any initiative		I can roll a cigarette.		
Subjective content **During the seizure did you ...**				
11 feel like you were in a dream?	Feeling of being with but totally apart from; there but not there		Light out no one in.	I was on the outside looking in
12 feel like you were in an unusually familiar place?				
13 feel that things around you were unknown?	It almost felt as if I'd had been somewhere else		I'm in a different dimension	

14 feel like everything was in slow motion or sped up?		Daisy dream world, everything's starting to slooow down		
15 feel the presence of another person who was not there?		There's the good one the D**** locked inside that's always screaming to be let out. Please man - let me out		
16 see or hear things that were not real?				
17 see people/objects changing shape?		No		
18 experience flashbacks or memories of past events (as though you were reliving the past?)		Yes. Experienced déjà vu as a child		
19 experience unpleasant emotions?				
20 experience pleasant emotions?				

2 Coping

Having spent some time with participants the researcher became aware of their domestic and financial circumstances, aspects of their family lives, how participants thought about their condition and justified its onset to themselves and others. Participants revealed various distancing strategies such as: the use of second person narrative, conscious distancing from emotional trauma, and medication and its effects were also monitored by participants.

3 Range and variety of perceptions

Phenomenological psychology has not traditionally, taken into account the
social and cultural factors present when considering people's phenomenological
experiences. However, it is important to address the messiness and complexity
of 'life as lived' (Landridge 2007)(p164). Differing perceptions about seizures
were reflected in the differences, divergences and convergences across and
between participants (Smith, Flowers et al. 2009). Each individual had their
own personal interpretations, understandings and beliefs about the causes of
their seizures, sometimes more than one linking these to their personal
biographies and subjective experiences.

Vince and Dave had insights into the role of their brain and its functioning in
their condition. Vince suggested that parts of his brain were stronger or weaker
than other parts and Dave depicted similar divisions in two of his drawings.
Graham also questioned how his brain was functioning. In view of their
epilepsy diagnoses, this preoccupation with brain processes could be considered
significant.

4 Participants' reflections

The nature and length of conversations and seeing some participants twice
enabled personal reflective processes of their individual situations. Some
seizure experiences were transient, some became more of a burden, some
disappeared altogether and participants entered periods of resolution and
acceptance.

5 Etiological factors and health beliefs

Precursors, precipitating and perpetuating factors in seizure patients has been
found useful in treatment (LaFrance, Gates et al. 2008) and may be very
important to listen out for in diagnostic conversations.

Mary had factors present in her life which could mean a diagnosis of NES or epilepsy. It was difficult to tease out whether the trauma of her brother's death had caused her NES or whether ceasing to smoke the cannabis had triggered epileptic seizures. Her discharge from the clinic, due to her non attendance precluded any more information being available from her. Graham also had huge stresses in his life and his whole conversation style around these suggested that his seizures were not epilepsy. Both Mary and Graham gained attention from others and responsibility for their care was somewhat delegated to others.

Table 18

Etiological factors emerging from interviews.

Issues present in interviews	Vince	Graham	Mary	Dave
Domestic situation at the time of interview	Married	Looking after terminally ill wife, and son with autism	Unmarried, living with two children and her parents are residing temporarily	Lived alone
Events suspected as causing seizures	First believed that he had mini-strokes	Stress of new role of being the palliative carer for his wife Previous head injury	From Mary - family trauma and resultant stress From mother - hormones, and hinted at the role of illicit drug use	Year of caring for grandfather, subsequent death of grandfather and, as a consequence of this, a lack of any connections with any remaining family members.
Relate seizures to past injury	Former RTAs	Former RTA and former brain injury		
Considers relationship between brain and behaviour	Considers his brain function where some parts damaged and other parts are not	I wanna know what's between my two ears. Have I got a brain?		Metaphoric representation of his brain function in which some parts control others
Sustains physical injuries	No		Significant injuries	Significant scalding, falling
Social or secondary gain		Attention from medical services. Secondary gain of social security benefits for the family as a whole	Secondary social gain from family and neighbours Delegates to others responsibility for her own personal safety	On social security benefits
'Other' factors	Recalls previous events in sleep which could have been seizures	Son with autism and epilepsy	Concealment of drug and alcohol abuse from neurology services	
Process of understanding	Comparison of stroke outcome to that of epilepsy Brain damage and why this took so long to manifest itself	Seizures could cause/ lead up to another stroke again		

Summary

These superordinate and subordinate themes illustrate what IPA excels in - idiosyncratic experiences and perceptions. Across cases they had the potential to contribute towards information for patients, a screening tool, ideas for clinical practice and further research. These ideas are expanded upon in chapter 6 which also outlines how an IPA could be considered a new paradigm in exploring these various areas and how the approach itself fits into the study of seizure experiences and differential diagnosis.

6 Conclusions and implications for practice: Exploring diagnosis. The basis for a new paradigm

This chapter offers ideas for exploring and delivering a diagnosis in the clinic, fledgling ideas for a screening tool, a patient information sheet and for furthering research. Figure 14, at the end of this section illustrates the overall place of IPA in relation to other disciplines in the study of seizure experiences and differential diagnosis.

The conclusion consists of the following sections and subsections;

1 Shifting the context and multi disciplinary working
1.1 Silence is golden and the patient as another expert

2 Educating patients
2.1 Draft patient information leaflet

3 Ideas for a screening tool
3.1 Communicating a diagnosis of NES

4 Research ideas with a different lens

1 Shifting the context and multi disciplinary working

It appears that altering the context of doctor/patient interaction and multi disciplinary working could be useful. Talking to patients in various different settings and with different professionals will inform practice in that different details and information not forthcoming from patients in a traditional clinical encounter may emerge in alternative settings. Different clinicians have different training backgrounds and philosophies and may have more time allocated for patients than neurologists do (Langfitt 2007).

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Conducting conversations or consultations in a consulting room or EEG monitoring suite may signal to a patient that the talk will be, essentially, about seizures with other things concerning them being of peripheral importance to the doctor. Moving out of the 'office' and shifting the context physically may relax and give more power to the patient in that they may feel that the agenda of a conversation is not pre determined. If the neurologist does not lead the conversation this may give patients more confidence and opportunity to ask questions and receive answers.

This communication could be called a mutual discussion and/or left to another health professionals such as; trained epilepsy nurses, clinical and health psychologists to explore patients' concerns and beliefs. Details of the conversation can be recorded for neurologists or other health professionals and for later identification of anything present which could inform a diagnostic decision and the ways in which this can best be relayed to a particular patient.

1.1   Silence is golden and the patient as expert

> 'We do not claim that doctors and patients have an identical expertise or that they are equally competent in the sphere of biomedical knowledge – that is, after all, the doctors' 'raison d'être'. However, it will be apparent that the findings that we have reported so far suggest that patients might best be treated by doctors as biomedical experts, albeit possessed of different, rather than inferior or superior sources of knowledge.'
> (Tuckett, Boulton et al. 1985)

Returning to IPA as an approach mirroring that of ethnomethodology, doctors listening to patients with seizures and vice versa (patients listening to doctors) could seen as two tribes trying to make sense of each other's language. One is initially 'alien' to the other and one language does not readily translate into the other.

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'No knowledge in two different languages can be regarded as completely the same; not even A=A.' Schleiermacher (1811) cited in (Bowie 1998)(pxxi).

In any case, simply translating what people are saying, the words have to be understood in terms of the thoughts behind them (Bowie 1998) and in the context of the other person's life.

If a neurologist is conducting the conversation, adopting an attitude whereby they can put aside their clinical knowledge and let the patient take the floor may offer them a different view of that patient's seizures. Shrugging off pre conceptions can open up new ideas to explore (Polyani, 1961). Family and/or friends can be invited into the consultation as they may offer more information or clues about a patient's life, this intervention not notably adding to consultation time (Gilliam, Penovich et al. 2009) and can also help if anyone has difficulty expressing experiences. Viewing a person anew each time can highlight temporal alterations in experiences.

Patients could be offered a conversation 'opening' which does not challenge them or allude to a particular focus in the conversation but simply enquires thus leaving the stage open for them to talk about what is of important to them. For example, ' How are things with you today?' is a question which could allow the interview to evolve into one in which the patient determines the topics to be discussed.

The study undertaken by Johanson, Valli et al (2008) suggested that socioeconomic and demographic factors could also affect epileptic seizure experiences, thus adding in etiological factors appears justifiable for both conditions. Defects, infection, injury, poor nutrition, low educational achievement and poor housing can put both adults and children at risk of developing epilepsy (Banjeree et al, 2009) thus knowing about these aspects of patients' lives could offer pointers for diagnosis.

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Living with NES appears to be inextricably linked to an individual's personal background and biography and it is suggested that a diagnosis needs to take this into account. Patients' experience before diagnosis not only 'shapes and frames the post diagnosis response' but can result in significant social isolation (Thompson, Isaac et al. 2009)(p512). The environment and social context around seizures in people with NES could be particularly important if identified as it could be a positive pointer to diagnosis. People in employment experience less negative emotions about losing control during seizures, and being in employment is an indicator of psychological well being, less depression and anxiety (Johanson, et al, 2008).

As already mentioned, constructing 'lists' of precursors, precipitating and perpetuating factors for patients has been found useful in treatment (LaFrance, Gates et al. 2008) and diagnosis. This has also been found to be the case in other conditions. An IPA study examining etiological influences found that women with eating disorders (ED) identified factors which they believed had contributed to their ED. Their illness beliefs were also found to be important in the onset of ED (Kally and Cumella 2008). Non sexual trauma and sexual abuse in the family as children, as well as abuse in marriage and divorce were significant as; 1) proximal/immediate triggers, 2) distal-background causes/contributors and, 3) perpetuating factors/sustainers, significant triggers and sustainers of ED (ibid).

It has been acknowledged that, in addition to the Bethel diagnostic conversation procedure, further, factual questions would need to be asked of a patient as people can have conditions alongside their seizures which could affect diagnosis such as depression.

Whatever their diagnosis, people are all very different and details of their lives deserve attention and could be useful. Complete immersion in what a person is

saying in real time and, if possible recording these conversations is vital in order to identify clues to diagnosis.

2 Educating patients

There is more to seizures than physiology, and people seek explanations for them be they epileptic or non epileptic. There is a case for giving patients with seizures some technical/biological information about their condition and its treatment. Vince in particular questioned this:

> 'Yeah, and it's trying to work out what are the natural part movements of
> – these ... epilepsy, what exactly are they? Well the mechanisms are all a
> part of the brain, and it's a part of the brain itself, but it causes other
> things to happen within the brain, a lot of puzzlements, trying to work
> each other out? Causing a greater confusion, and then you're on the
> deck.' V: 580-585(2)

A simple description of the nature of the mechanisms involved in seizure manifestations could prove useful in terms of people s understanding, coping and even control over seizure occurrence. How medication affects this function, for example, may help with adherence in people with epilepsy. A cost/benefit analysis with them on side effects compared to seizure control facilitated by neurologists and pharmacists could also be beneficial.

Apart from Mary who preferred a psychological explanation of her seizures, all other participants mulled over the role of the brain in their seizures. Vince and Dave perceiving their brains as being divided into good/bad, functioning/non-functioning parts, Dave depicting his cognitive abilities as being drastically reduced. Gavin also perceived a link between his brain and his experiences and would have welcomed some level of explanation or a picture symbolising this.

Simple drawings could be given to patients depicting epileptic activity. Indeed such 'anatomical' drawings are increasingly being used by clinicians for medical

conditions in the NHS nationwide pilots on information prescriptions for patients. [118]

2.1 Draft patient information leaflet

Although there is a plethora of leaflets already published for patients with epilepsy, people with NES are less well supplied with information. Also, given that NES are so common there is very little 'scientific' attention devoted to them (Bodde, Brooks et al. 2009), not least in the area of information for these patients.

Leaflets already published include one by some authors involved in the Bethel project (Reuber 2006). This is comprehensive and clear and designed to be given during diagnosis. Another is rather lengthy and written in an academic style (Benbadis and Heriaud No date). Further information hails from epilepsy organisations, (Epilepsy No date) and some offer accounts of people living with NES (Growingstrong No date).

However, none of these leaflets give examples from people having seizures of various types. Because they have been relatively unexplored thus far, words to describe seizures are hard to find, describing synesthetic sensations for example is not everyday parlance for most people (Petitmengin 2006). In terms of the practical uses for this study and for patients with seizures and the problem of differentiating these, what may be difficult for one person to describe can be put into words by another.

Ideas for the production of an information leaflet for lay and professionals involved in this clinical area which contains words and phrases of participants was considered at the beginning of this work. The data produced in the thesis offered some contributions to this idea.

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[118] http://www.informationprescription.info/resource/1-introduction/1-2_whatisIP.shtml

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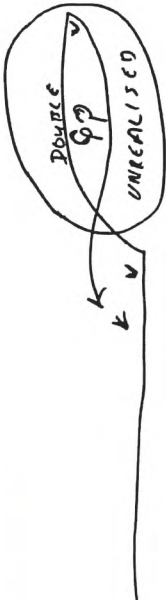
Once patients have firm diagnoses of epilepsy or a positive one of NES, they could be asked to formulate descriptions of their experiences (this would not necessarily require any intensive training - the descriptions from participants in this study is evidence of this). These could then be used to create an information leaflet along with clinical commentaries relating to the type of seizure they represent. This would be a particularly useful resource for patients who have difficulty describing their seizures.

A draft example of this potential source of information [119] is below (figure 11) and contains some poems and phrases voiced by participants in this study.

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[119] The leaflet is designed to be back to back and to fold into three sections.

Take a look at these
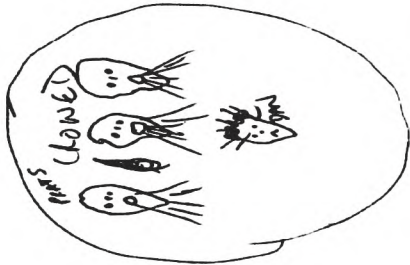descriptions
or get someone
to read them
with you.

I'm in auto pilot.

Me brain just seems
to turn off and I can walk around.

Not know where I am.
Not know where I've been.
Not know what I've done.

I started to feel rough like
something's pressing down,
pulling down my head or
whatever.

It's like being in a football crowd
and everybody's screaming at
you for attention but you're not
able to respond to any of them.

It's basically em, how can I put it?
Em, half awake, half asleep

The whole circle around that
there, that's me

Questioning going in, questioning
coming out.

You don't really feel, it's so bloody
confusing.

Other people realise you have gone
in, you come out with no realisation.

Like gulping, gasping for air, and me
eyes went like, a cod.

I can see everything but I've got to
concentrate,

look straight ahead or, sort look round

and a slight buzzing sound in me ears,

I still hear people talking.
I still hear noises around,
but I'm like, erm – frozen!
I try and try and swallow, I feel that
dry and try and swallow.

oooooooooooooooooo

They say I was, convulsing, and er, you
know, erm making funny noises, erm, I
think me eyes was rolling and stuff like
that, but I was yelling on the floor, like
convulsing and stuff like that, me Mum
obviously will be able to describe it to
you, better, er, so and when I came
round, I don't even remember coming
round.

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What are your seizures like?

Describing your seizures to other people can be difficult.

Here are some pictures, words and poems from other people having seizures.

I could see, I could see, feel, but not totally understand. Becoming, you know getting on the train or a tube in London and going towards somewhere but going the wrong way, but getting on the tube, you're suddenly thinking, I'm going the wrong bloody way, get the tube back.

When that happens, it's like a loss or it's like, you come out, you go to get in your car, another car, there's another car, the exact same car, put your key in, you wonder why you can't open it

oooooooooooo

I feel like I'm on the outside looking in.

It feels like it's not me.

It almost felt as if I'd had been somewhere else

    you seem to lift up,

as if I'm got lifted up and away and

almost in an empty atmosphere
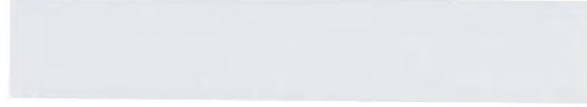
as if - the atmosphere that keeps you held down.

it lifts you up and you almost feel as if you're floating …

it's this thing where I seem to lift away

they seemed to have gone further away from you

I'm not me, I seem to have changed

I can't really say whether the thinking is positive or negative

3 Ideas for a screening tool

In view of study findings and the extant literature, it is speculated that there could be three potential questions to be asked of newly referred patients which may offer some indication of their diagnosis.

The relationships between attributes of art work and seizures so far is fledgling but promising and worthy of further exploration given that this has been found to offer insights into underlying neurophysiology (Schachter 2008). Three recommendations are put forward as being appropriate in a consultation or interview:

1   Ask patients if they can draw their seizures. If they cannot do a free drawing on a large sheet of paper, the male/female body outline drawing test similar to one which offered a positive predictive value for people with NES (Anschel, Dolce et al. 2005) could be offered to them as an alternative (see figure 12, draft screening tool below, p 342). Any words the patient uses during this drawing should, ideally, be recorded or at least noted down.

2   Ask patients to choose examples of seizure descriptions, drawings and comments presented in leaflet form, which best mirror their own experiences. Material given to them would be in the form of the draft leaflet above. These would need to be read out for patients with literacy issues.

Another way to do this would be with a self completion task and this has already been suggested by Plug, et al, (2009). Patients would select items which they personally identify with and which pertain to different epilepsies. An example of this is in table 19, below and contains words from my participants in relation to their particular diagnoses.

Table 19

Please circle any of the words and phrases below if they help you to describe how you feel when you have a seizure, or describe what other people tell you.

When I have a seizure it feels like:

| Complex partial with and without generalisation	Idiopathic generalised epilepsy	Focal onset with secondary generalisation	Undiagnosed
I have been somewhere else	An electric shock is going through my whole body	Someone just, just blacks me out in a way	I'm on the outside looking in
I got lifted up and away	Daisy dream worlds	Me light goes out	It's not me
I am almost floating	My brain just seems to turn off	I cannot really take in what people are talking to you about	I wonder what *is* going on
I am not me	My mind goes into overdrive	I can see everything but I've got to concentrate, look straight ahead or, sort of look around	I can't really tell you anything about afterwards
I was drawn away the company I was with and talking to	Blackness for a while	I still hear people talking.	I don't really remember coming round
I was there but, indeed, I wasn't	Everything slows down	I'm frozen	It's just all like a big question-mark
the *contact* seemed to be broken	It's just 'bumph' to me	It took over me	I'd fell off the chair, you know and obviously gone

---

3   Ask patients what they think is the root cause of their seizures; this may lead to the identification of previous head or other trauma. It was noted in the case of Graham upon reading his notes from the neurologist that, at one time point, they did not have this information and thus were uncertain whether the temporal lobe damage discovered was vascular or due to trauma.

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Figure 12. Draft screening tool for patients new to this clinic

Please draw how your seizures feel to you on the large pad. Choose any of the drawing materials provided. Or, add anything you like to these drawings below which show how your seizures feel to you.

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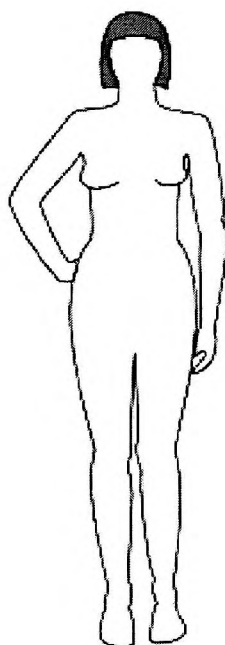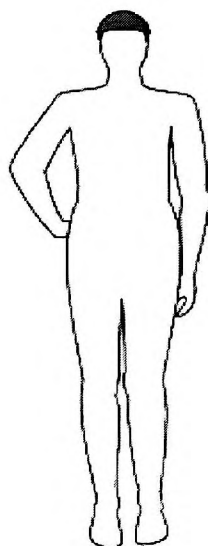
3.1 Communicating a diagnosis of NES

Before delivering a diagnosis of NES, it may be useful to talk to the patient more than once before offering them the diagnosis in order to explore and gather information about how they may react to this. A health professional other than a neurologist could undertake a non clinical interview prior to the diagnosis being given. This may elicit health beliefs and ideas about what a person considers is causing their seizures for example.

Examining patient accounts of their condition can help elucidate illness perceptions, (Green, Payne et al. 2004). Not only do people with NES need a 'positive' diagnosis but they need one which explicates the psychological factors and mechanisms which have caused the condition. Given that people with NES continue to experience social and interpersonal problems following their diagnosis, these should be considered in their assessment (Bodde, Brooks et al. 2009)(p5).
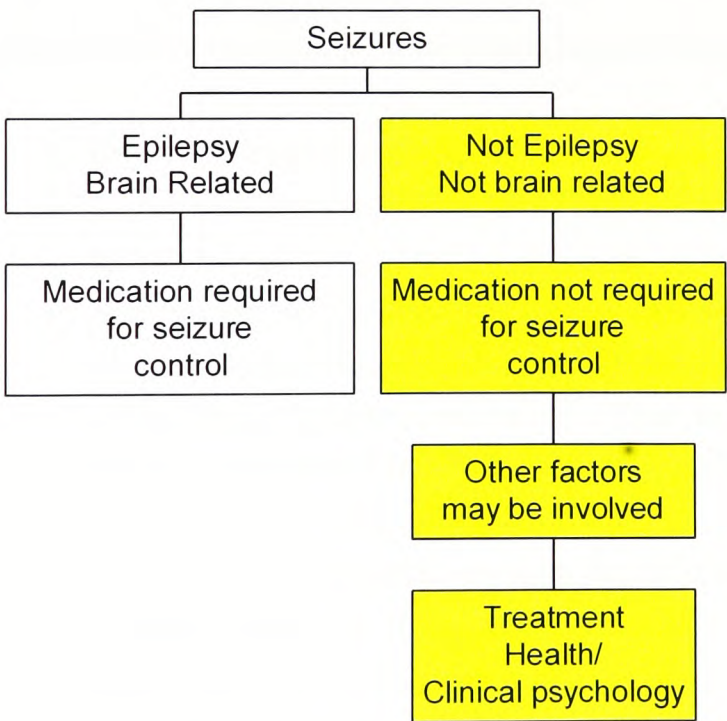
Living with NES appears to be inextricably linked to an individual's personal background and biography and a patient's response to their diagnosis is affected by their personal history (Thompson, Isaac et al. 2009)(p512). Knowing the patient from various perspectives will help in identifying their individual prognosis/potential 'cure'. Patients with NES have put forward the idea that having access to vignettes of patients who have had successful outcomes could be helpful in resolving their own diagnoses (Reuber, Monzoni et al. 2009).

A recent study by Karterud, Knizek et al., using phenomenological interviews explored how people react to a change in diagnosis from epilepsy to NES. This can be a demanding process cognitively and emotionally in terms of understanding that seizures do not have clear biological causes attached to them. People can feel abandoned, hopeless and helpless with their new status. They need help to redefine themselves in relation to a new diagnosis or

additional stress can ensue. The way in which the diagnosis is given can be decisive in how a person copes with the diagnosis and takes up subsequent treatment. Maintaining contact with the patient is essential (Karterud, Knizek et al. 2009).

However, this particular researcher suggests that removing them from an *'epilepsy* environment' and related links or information may help in their engagement with a different condition. NES needs to be kept apart from epilepsy, patient information already in use emphasises this [120]. Figure13 below, illustrates the divide in the condition and treatment which could be transmitted to patients.

Figure 13 - The divide between epilepsy and nonepileptic seizures

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[120] http://www.shef.ac.uk/nest/downloads.htm

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4. Research ideas with a different lens

Over a decade the CA research built on single cases and multidisciplinary working, i.e. beginning with observations by neurologists and combining this with linguistic work and which was considered a 'heroic enterprise' in its time (Gülich and Schöndienst 2005). CA identified things that were not immediately recognisable thus far. Interpretative research can, potentially, develop heuristics, principles and perspectives incrementally which could be developed in terms of connecting personal subjective accounts, cognitions and physical states and may be just as important as pure, neurological 'medical' information (Petitmengin, Navarro et al. 2007). In addition to producing rich insights, this thesis has already identified some roots of what could, given more 'cases', contribute to 'comparative matrices' (Gülich and Schöndienst 2005) and models of talking which may eventually relate to different seizure types.

Some practical suggestions for the beginnings of IPA research in the clinic:

- Involve patients in research ideas.
- Gather and record 'anecdotes' from patients on a continuous, systematic basis.
- Note phrases, words, ideas, metaphors, metaphoric predicates, approximations, descriptions of consciousness/unconsciousness, awareness/unawareness and feelings. These may, over time, offer patterns of additional linguistic features which eventually pertain to particular seizure diagnoses.
- Have regular multidisciplinary team meetings. These may cross cultivate different world views of patients' experiences.
- Record and transcribe all meetings so that they can be kept towards an accumulating data set.

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- Video analysis of professional/patient conversations. [121]

- Exploring alternative and different ways of gaining knowledge from patients may offer the potential for further interpretations. For example, visual representations of people experiencing seizures could contribute towards 'testable hypotheses' (Schachter 2009)(p 14).

- Talking to people definitely diagnosed with NES long term would contribute to a confirming discourse for this condition.
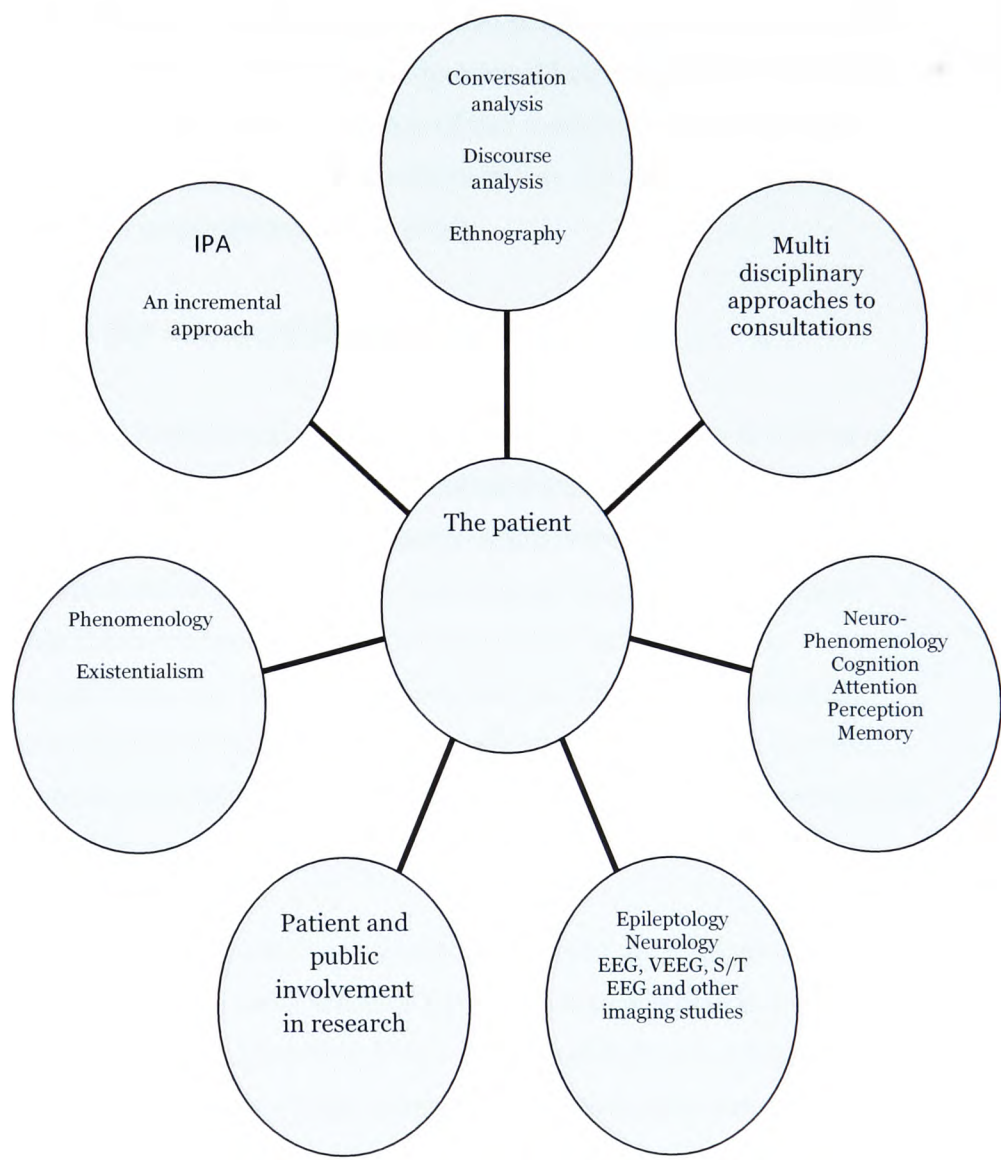
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[121] Although alluded to in the CA research this element of conversations has not been exploited to its full potential and is ripe for development.

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Figure 14

The place of IPA in the study of seizure experiences and differential diagnosis.

7 Discussion: Not only do we not know what we know, but we do not know that we do not know. Petitmengin (2006)(p234)

This is the first time that an IPA has been applied to people with seizures. There are some aspects of the data that lend themselves to different sorts of analysis, such as the use of the second person narrative in people's talk. The concept of embodiment in relation to seizure experiences would also benefit from further exploration. The reflections and the stance of the researcher as a Chartered Health Psychologist are important to elucidate before the main discussion which focuses on the implications of this study.

Reflections and the stance of the researcher

A phenomenological interpretation is one in which the researcher is central and their personal insights, reflections and understandings are crucial (Landridge 2007). As a part of an existential phenomenological research process, it is important to state some of the influences affecting an interpretations (Koch 2006b). Within the hermeneutic circle the researcher had attempted temporarily to put aside any fore conceptions and pre understandings of the topic of seizures, leaving these behind with a 'reflexive turn' inwards in order to enter the life world of participants, engaging, empathising and questioning them (Smith, Flowers et al. 2009).

This 'turn' privileged participants' views, preoccupations, preconceptions and beliefs as they attempted to make sense of their experiences. Also listened to were those intimately involved in their lives. Despite at least one of the participants having been given a 'clear diagnosis' the researcher sought to background any diagnostic preconceptions she may have been holding, although features were identified in interviews which could have been associated with a particular diagnosis. The type of conversation experienced with Mary and Graham, for example, were seen in the Bethel work as

Chapter 7. Discussion: Not only do we not know what we know, but we do not know that we do not know.

harbouring important diagnostic clues for NES (Schoendienst, Surmann et al. 2005). In the case of Graham, this was not the neurologist's diagnosis, and in Mary's case although NES or drug related seizures were suspected, there still remains the possibility of epilepsy.

The experiences participants described had already 'lost the quiver of their undisturbed existence' and were not 'identical to the lived experience itself' (van Manen 1998)(p54). Returning to 'the office' and with new information about seizure experiences, the researcher began to interpret participants' experiences in this light and it was important to consider whether this challenged and changed her existing knowledge and pre-understandings and whether new fore understandings became more important in the light of what participants had told her (Smith, Flowers et al. 2009).

It is also possible to go beyond what is in the text of an interview and access the complexity of what is behind the 'face of patient experience' (Miczo 2003)(p487) especially with the addition of contextual data. For example, some of the meanings participants communicated were non verbal and some co constructed (Miczo 2003) as researcher and participants talked about their experiences together. Sharing participants' private lives and emotions influenced subsequent interpretations and themes emerging from these helped navigate through their talk (van Manen 1998)(p90).

The interpretations included poetry and art work, which captured something of the array of 'essences, [122] aspects, properties and qualities' of Vince's and Dave's experiences (van Manen 1998)(pxv). The art work represented pictorially their bodily experiences and the meanings they ascribed to these (Gillies, Harden et al. 2005). The poems succeeded in 'showing authentic original living'

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[122] From the verb, to be, an essence is what something 'is' for someone. van Manen, M. (1998). Researching Lived Experience: Human Science for an Action Sensitive Pedagogy. Ontario, The Althouse Press.

Chapter 7. Discussion: Not only do we not know what we know, but we do not know that we do not know.

(Landridge 2007)(p162) and allowed the experiences of Dave and Vince to 'shine forth' as IPA intends them to do. The words of Mary's mother were also heard.

Discussion

Findings from this study have shed more light onto subjective seizure experiences and form the beginnings of a corpus of data in this respect and which is missing in the literature to date. The nature of the findings are such that they can also contribute towards a seizure discourse and have the potential to be developed further in the following areas:

1   **Subjective verbal descriptions as key to constructing a seizure discourse**

2   **Subjective experiences and research into consciousness**

2.1   The concept of agency in seizure experiences

3   **The advantages of an IPA approach to seizure experiences with recommendations for extending the method**

4   **The scientific value of this work**

1 Subjective experiences

> 'Phenomenological accounts of the structure of experience and their counterparts in cognitive science relate to each other through reciprocal constraints'. (Varela 1996)(p343)

In order to gain a fuller picture of seizure experiences, it is important to combine objective 'medical' information with subjective findings. However, at present they are vaguely described and do not attempt to cover the temporal progression of seizures (Johanson, Valli et al. 2008). Subjective seizure experiences are considered as being 'reliable' evidence in locating seizure foci (Johanson, Valli et al. 2008; Nakken, Solaas et al. 2009)

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The difficulties involved for anyone in verbalising subjective experiences are addressed below and how these could be developed into descriptions which contribute to a seizure discourse for lay and professionals. This discussion is underpinned by ideas in neuro-phenomenology and how phenomenology and neurology can be combined in terms of identifying behaviour and its neurological correlates in seizure experiences.

Neuro-phenomenology utilises the ideas of systems theory, i.e., that an epileptic seizure, for example, is not a sudden and unexpected occurrence but one which can be anticipated being the result of a elements of a system and 'its general (spatial and temporal) dynamics' (Petitmengin, Navarro et al. 2007)(p747). New mathematical tools can detect the 'dynamical structure of the neuro-electric activity of the brain' and 'pheno-dynamic analysis', using new interview techniques can access the 'pre-reflective micro-structure' of the subjective process which mirrors this (Petitmengin, Navarro et al. 2007)(p746).

The analogy of the different instruments within an orchestra striking up at the same time is illustrative here (Petitmengin, Navarro et al. 2007). Using the example of complexity theory, seizure onset is seen as an ongoing, dynamic processes which can begin days, hours or minutes beforehand, challenging the belief that epileptic seizures occur without warning (Petitmengin, Navarro et al. 2007)(Le Van Quyen, 2001). It follows that the subjective cognitive experiences of epileptic seizures also unfold, being lived through but happening 'below the threshold of consciousness' and this takes time to become aware of and to describe (Petitmengin 2006)(p230).

It is possible to analyse both neural (medical) and subjective experiences, as part of the same dynamic system with the aim of developing 'a dynamic approach to cerebral activity as well as to subjective experience' (Petitmengin, Navarro et al. 2007)(p747). As this study has shown, there is the potential for subjective descriptions to be 'collected' over time, to compare them to other

people having the same seizure types and to correlate them with objective measurements such as EEG, brain imaging and behaviour. The study of seizures can thus shift from being subjective to intersubjective (Gallagher and Brøsted Sørensen 2006).

Half of people with epilepsy have warnings of a seizure, some several minutes before. Phenomenological methods have been assimilated into studies exploring patients' experiences before epileptic seizure onset in an attempt to relate these experiences to EEG reports which show abnormal activity, and whether patients can anticipate, recognise and describe signals that a seizure is about to occur (Le Van Quyen and Petitmengin 2002) [123]. This is with a view to illustrating that these brain patterns are not random events, but related to people's 'subjective states' (Gallagher and Brøsted Sørensen 2006)(p125), descriptions being correlated with 'neuronal dynamics of the electro-clinical onset of a seizure' (Gallagher and Brøsted Sørensen 2006)(p124). It is clear that data from neuroimaging are often not enough to give a complete picture of seizure experiences, requiring additional, verbal descriptions of *how* they were experienced in order for a full interpretation to be reached (Petitmengin 2006).

The 'paucity of vocabulary for describing these subtle sensations' is considered a main stumbling block to gathering these subjective descriptions (Petitmengin, Navarro et al. 2007)(p751). This is a chicken and egg situation however, if these experiences are not explored, a vocabulary cannot be developed. This work is now underway within neurophenomenology and this thesis has also offered examples. Although there is also not, as yet, an established method which analyses seizure experiences, studies are developing these (Johanson, Revonsuo et al. 2003; Johanson, Valli et al. 2008).

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[123] The Le Van Quyen-Varela group (Groupe de neurodynamique, Laboratoire de Neurosciences Cognitves et Imagerie Cérébrale, CNRS UPR 640, Hopital de la Pitié-Salpêtrière.

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Graham in particular struggled with this lack of descriptive language for what he was experiencing. If there had been words and phrases available to him he may have found these helpful. The difficulties he had describing his experiences were posited by him as a reason he was not taken seriously by doctors at the hospital, resulting in him focussing on his stress as a main issue, and the researcher considering his seizures as being non epileptic in origin. The lack of a seizure vocabulary could underlie the difficulty people like Graham might have in describing these and, as a consequence, the time taken to diagnose them.

The task of 'knowing' and describing subjective experiences is not an easy one. To develop descriptions requires a phenomenological reduction and a direction of attention exclusively to one's own personal experience of the world, not taking into account other ideas, beliefs or theories about that experience (Gallagher and Brøsted Sørensen 2006). It has been suggested that individuals may need training in order to become aware of their own subjective experiences in order to describe them (Petitmengin 2006)(p230).

Such training has already been formalised into a staged interview process developed in neurophenomenology (Petitmengin, Navarro et al. 2007) [124] The interview begins by asking a person to focus on a particularly memorable/vivid/recent seizures and a temporal marker of this experience. An evocation of this is then attempted by asking the participant to rediscover images, sensations, sounds associating with this so that they feel as if they are reliving it. The participant's attention is then directed towards visual, kinaesthetic, auditory or olfactory triggers, emotions felt or internal dialogues, all of which may have been pre-reflective until this point. These can be accessed, for example, by exploring non verbal gestures people make in relation to these triggers, such as a hand being brushed across their eyes as they are

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[124] Very much like Wundt's participants in his experiments on introspection in the 19th century who were asked to 'describe the 'pure' perceptions as they appeared in 'their consciousness. Gallagher, S. and J. Brøsted Sørensen (2006). "Experimenting with phenomenology." Consciousness and Cognition 15(1): 119-134.

speaking about experiences. Delving into why someone made such a gesture can help them become aware of the pre-reflective sensations which are behind this movement, and being those which mark the beginning of their seizure. Sensations are then explored in depth so that a feeling of panic for example, can be broken down into a detailed description of a headache which develops, through visceral sensations and physical pain, increased heart rate, dizziness and nervousness into the feeling of panic. Although this is not unlike the CA interview formulation, the increased focus on cognitions in relation to phenomenological experiences is more amenable to an IPA interview approach.

This neuro-phenomenological interview has also been found to have other positive implications. It can be useful in that people learn to recognise symptoms and subjective states leading up to their seizures which they can then use to exert some level of control over them in terms of inhibiting strategies. This shift can also result in a shift in people's relationship to their seizures and the way they affect their life and the lives of those around them. Vince voiced concerns over this control with concepts of inhibiting these neural mechanisms:

> V: I suppose one of the other part of it is, is very good is that I myself
>   are learning to understand exactly what it is, or why I can't catch
>   this the times it happens.
> VF: You can't catch it.
> V: No, in other words, can't stop it.
> 594-597 (2)

Studies have shown that epileptic activity can be modulated by cognitive acts and can inhibit neurons from being recruited into epileptic activity Fenwick (1994) in (Petitmengin, Navarro et al. 2007). This challenges the assumption in cognitive science that cerebral activity determines subjective experiences and supports the argument that subjective experiences may be just as important as pure, neurological 'medical' information (Petitmengin, Navarro et al. 2007).

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The idea of the need for in-depth training is challenged by this researcher however, given participants in this study offered insightful, unadulterated descriptions of their experiences some of which accurately mirrored their seizure semiology. They were acutely aware of their feelings representing them more than adequately. In addition, capturing these at an early point mitigated against 'losing' these early intuitive descriptions.

Given the lack of knowledge about subjective seizure experiences and a lack of words for them, a NES/epilepsy discourse being produced from IPA based subjective accounts could be valuable. Participants have produced a plethora of information about different epilepsies. These could be used as the beginnings of such a discourse relating to particular seizure types and could be developed and added to, to include other seizure types. Following up additional people with NES would contribute to a discourse for this particular condition.

2   Subjective experiences and research into consciousness

Subjective experiences and descriptions are fundamental to understanding consciousness, a major issue in defining seizure types. The distinction between unresponsiveness in NES and epilepsy has always presented a problem in terms of diagnosis for clinicians (La France, Gates et al. 2008). Taking consciousness/ unconsciousness, awareness/unawareness, responsiveness/unresponsiveness as umbrella terms for what is something not fully understood in seizure experiences, this section will briefly explore this major attribute of both NES and epileptic seizures.

Epilepsy and NES are ideal conditions for the exploration of consciousness. Epilepsy 'represents a privileged window over basic neurobiological mechanisms of consciousness' (Monaco, Mula et al. 2005)(p157), people being rendered so because of a disruption to 'normal neurological function' (LaFrance, Gates et al. 2008)(p319). NES, having the 'neurophysiological diagnostic

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correlates' of epileptic seizures but lacking the biological correlates, nonetheless represents a condition through which to consider the concept of consciousness (LaFrance, Gates et al. 2008)(p321).

Epilepsy being a disruption of brain activity, a disruption in consciousness would be expected. Since NES does not involve this disruption it might be expected that consciousness would be maintained. This is not the case however, as people with both conditions have apparent lapses in consciousness (Reuber 2008i). Although the Bethel work shows the nature of people's comments has the potential to reveal their diagnosis, the task remaining to distinguish between these (LaFrance, Gates et al. 2008) and until more is known about consciousness, it will be difficult to reach defining criteria [125].

When NES are conceptualised as a conversion disorder, the alterations in consciousness are the result of unconscious processes and can be mistaken for epilepsy, i.e., being 'unconscious' means different things to patients and doctors (LaFrance, Gates et al. 2008). Moreover, dissociation as 'both a mechanism and a disorder' can occur in both epilepsy and NES (LaFrance, Gates et al. 2008)(p317). Dissociative symptoms such as, derealisation, depersonalisation, autoscopy (out of body experiences), déjà vu and jamais vu, in temporal lobe epilepsy (TLE) can be more vivid and repetitive than those in conditions with psychologically related symptoms - such as NES (LaFrance, Gates et al., 2008).

It has been noted that mental states in epilepsies originating in the temporal lobe are very similar to those seen of psychosis in schizophrenia (Elliot, Joyce et al. 2009). The experiences described by both Dave and Vince resonate closely with the anomalous subjective experiences of people at risk of schizophrenia; those of experiencing electrical sensations for example, -Dave's 'frazzle' type seizures (Parnas, Møller et al. 2005) and of cognitions, Dave's description of being in 'autopilot', and Vince's anomalies of self awareness (Vollmer Larsen,

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[125] Informal conversations with C.M., a neuropsychologist in July 2009.

Handest et al. 2007). For the purposes of illustrating how subjective experiences of seizures could be applied to the study of consciousness, studies which have explored consciousness as a subjective experience in people with schizophrenia - rather than using experimental methods - will be described briefly here.

Like IPA this particular research reifies the descriptions of how people experience their world, being informed by similar phenomenological backgrounds and recognises the use of linguistic devices by people, including metaphor (Parnas, Handest et al. 2005). Studying the personal subjective experiences of patients at risk of schizophrenia has resulted in a reliable interview technique which could be a 'phenomenal extension' to other methods in this field (Vollmer Larsen, Handest et al. 2007). What emerges is a combination of both medical and subjective information which combine to offer more than the parts of a whole.

Gathering details of the subjective experiences of consciousness of people with epilepsy could generate a set of descriptions which point to the organic root of their experiences. Items within a corpus of data about seizure experiences, including those of recent studies described above and in further IPA interviews, could be combined to develop a tool specifically for the purpose of exploring people's descriptions (verbal and non verbal) of their experiences of consciousness. Moreover, given that the way to a diagnosis of NES is to first eliminate epilepsy, if the subjective experiences described by a person do not correlate with these collected descriptions or 'symptoms' and there are no major EEG abnormalities or damage identified by MRI, the possibility that seizures are NES could then be pursued with more certainty.

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2.1 The concept of agency in seizure experiences

Recent findings have clearly distinguished a major difference in metaphor use and the concept of agency, in that people epilepsy feel that the seizure acts upon them whereas people with NES perceive the seizure as being more of a backdrop, and of having more 'semantic agency' over it (Plug, Sharrack et al. 2009i). Again, links between epilepsy and schizophrenia emerge in terms of this concept. Seen as the ordered self becoming unstable has been found useful as an indicator present in people at risk of schizophrenia (Parnas, Handest et al. 2005).

In terms of the sense of agency felt by seizure patients, it is argued that different levels of consciousness reflect different neural functions (Cavanna, Mula et al. 2008). Explorations in neuroimaging are attempting to determine the neurological processes responsible for generating this sense of agency and how people experience the sense of agency and ownership in movement at a first order level rather than at a higher order level. That is, if someone else moves your body you experience a sense of ownership for this (yes, your body is moving) but not a sense of agency (you did not move voluntarily). This work is also being guided by phenomenological findings and by identifying activity and location in the brain which relates to motor control (Cavanna, Mula et al. 2008). Work in this particular area may have the potential to help in locating the neurological correlates associated with 'owning' one's movements and whether this aspect of embodiment could help with differentiating between epilepsy and NES.

Psychology, neurology, and philosophy, often working in isolation from each other (Campion 2009) having differing conceptualisations and explanations of consciousness or awareness - major issues in seizure experiences - and one which can result in multidisciplinary, complex views of the same process (Zappulla 1997). People experiencing seizures have expert knowledge to impart

which needs to be taken into account. The wealth of expertise emerging from different perspectives needs to be combined and realised (Depraz and Gallagher 2002). In terms of allying phenomenology and neurology this idea has already been mooted by 'veteran' IPA researchers (Smith, Flowers et al. 2009). The value of an IPA interview in generating in-depth subjective descriptions of various seizure experiences is reiterated below.

3   The advantages of an IPA approach to seizure experiences with recommendations for extending the method

'What might be straightforward might not be so straightforward.' A.M.,(29) [126]

Different attributes in phenomena may be 'noticed' from different perspectives. The philosopher Polanyi (1961)(p461) gives the insightful example of how the development of the aeroplane showed up prehistoric settlements on the ground when these had been totally missed by people *on* the ground they stood on.

In terms of seeing something from one perspective but missing it from another, there are different ways of appropriating meanings and different ways of seeing. The CA interview method has already undergone further development since the beginnings of the research over ten years ago. It has also been found that a purely qualitative assessment of linguistic features reliably identified as positively differentiating between seizures types, has greater accuracy than when these observations were translated into a statistically acceptable numeric 'score' (Reuber, Monzoni et al. 2009).

A traditional clinical interview has to gain information appropriate for a diagnosis, explanations and treatments, other issues also having to be addressed at the same time (Reuber, Monzoni et al. 2009). However, this may also impede the discovery of something that could be noticed in the context of a different

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[126] See theses appendices file 'C'

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interview. Neurologists supporting this study recognised that a relatively short consultation time with new patients would always be of concern in terms of reaching a satisfactory diagnosis:

> 'I think what Val has highlighted is something that frightens most of us as clinicians is we spend 20 minutes seeing a new patient and, you know with all of these, there's clearly going to be doubt – are these all epilepsy, how many of them are non epilepsy because there's all these social issues which we don't delve into within 20 minutes.' A.M.,(4-8) [127]

It appears that their data could be incomplete in terms of personal and social histories of patients which may offer additional insights into their seizure experiences which may, in turn, help to throw more light on their diagnosis. Following individual interpretations the neurologist supporting this study provided the information used to inform the diagnoses of my participants. The depth of information in such letters and reports had been noted in a previous study (Featherstone 2004). Notwithstanding this detail the insights gained through interviewing participants using an IPA approach were very different to those gained by the neurologist meeting these individuals in the clinic:

> 'I must see the notes, must go through the notes of this one, because that one smacks totally of non epileptic seizures and one has to, and you just get a totally, I think you get a different view in the room, since your presentation.' A.M.,(245–248) [128]

For Mary, the participant referred to in the previous quote, her neurologist was unaware of details of her life which may have impacted on her seizures including her illicit drug and alcohol abuse and her brother's murder. Instead he concurred with the diagnosis of epileptic tonic clonic seizures given to her on admission to an A & E department and given the lack of time and resources in the clinic. However, Mary was discharged from the clinic for not attending and her eventual diagnosis not confirmed.

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[127] See theses appendices file 'C'
[128] Please see thesis appendices, document C

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Neurologists involved in this study also recognised the perspective of the patient and the importance of the opportunity to talk:

> 'I think my brief experience as a patient gave me my huge insight into that, because when I went to see my doctor for a complaint, I had this overwhelming burning desire to express how I felt about it, how it was affecting me, and to me that seemed so important whereas you know, we're often not really that interested.' Neurologist (420–424) [129]

It has been suggested that individual autobiographical aspects of people's lives and their mental and emotional states could be useful to know in terms of how they may affect seizure occurrence, manifestation and location (Reuber 2008). In people with both epilepsy and NES seizure frequency correlates with quality of life and in people with NES this effect is mediated by psychological distress (Lawton, Mayor et al. 2009). As demonstrated in research with women with eating disorders (Kally and Cumella 2008) biographies of participants helped elucidate their words in that they make more sense when located within the context of their lives.

Talking in a GP surgery, the patient's home or another venue outside of a clinic, not necessarily with a neurologist and without time constraints, may result in liberating patients' thinking beyond their immediate condition. This could result in a richer picture of their situation which may in turn impact on their demeanour and confidence:

> 'And does it make a difference and then it's like. I can see differences in people that come to the hospital, when I see them in the hospital and when I see them in the GPs' rooms. It's just that they're more relaxed in the GPs' rooms' A.M.,(203–211) [130]

Graham's experiences reinforced this when he described his talks with A.M., in a community clinic:

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[129] Please see thesis appendices, document C

[130] Please see thesis appendices, document C

'In here you've got like a one to one, you can, explain and talk about, things over the table you know, you can put questions across and get, answers back.' G: 1138–1140 (1)

It has to be established however, whether this more time consuming approach to diagnoses is justifiable in valuable clinic time (Reuber, Monzoni et al. 2009). One recent study which audio and video recorded consultations (Gilliam, Penovich et al. 2009)(p1) i.e., in a community based setting, identified 'communication gaps'. These included patients not always disclosing side effects of medication and, interestingly, in follow up interviews with both neurologists and patients issues were addressed by both parties which were not addressed during joint, 'office visits' (ibid)(p4).

In particular neurologists stated that some concerns (such as mood related topics) were out of their comfort zone. This issue also reflecting doctor/patient communications in general and who initiates topics. In terms of consultation length, a 'visit companion' being present added significantly to information imparted to doctors but did not significantly add to consultation time (ibid). This offers an opening for an IPA of recorded conversations between patients and neurologists in 'real world office visits' could uncover such concerns.

4   The scientific value of this work

The argument has been put forward that data generated in qualitative research is 'moulded according to the ideological position' of a researcher (Archer 2004)(p133) and, because of 'an insistence on regarding anecdotes as evidence' this will lead 'to the rejection of empirical science in favour of ideologically motivated pseudoscience' (Archer 2004)(p136).

Much of what is known about illness narratives is based on people's recollections of this or on 'anecdotes' of their experiences (Miczo 2003). It has

been proposed that 'anecdotes are a special kind of story.' (van Manen 1998)(p115) and constitute, 'a methodological device in human science to make comprehensible some notion that easily alludes us' (ibid)(p116). van Manen maintains that anecdotes are a valuable resource in phenomenological research, revealing what was previously concealed in people's stories and he attributes to them a number of functions. They can act as a counterweight to abstract theoretical thought, as a counter to scholarly discourses, are solid illustrations of 'wisdom, sensitive insight and proverbial truth' and importantly for seizures experiences, could acquire significance in that they may exemplify the character of a phenomenon (Landridge 2007)(p167). In terms of the phenomenology of the body, van Manen (1998) has distinguished between 'various modalities of bodily experience' (ibid)(p23), identifying five experiential dimensions occurring in the literature, and rooted in 'anecdotes' gathered from the illness experiences of many people.

It is argued that anecdotes can be 'scientific' evidence. The etymology of the word is French from the Greek word 'anekdota', which means unpublished. [131] The autopathographies and interviews published within the Health Experiences Research Group [132] (formerly the Dipex project), for example are, essentially, anecdotal but are based on evidence of patient experiences of various conditions and accessible to practitioners and patients alike.

This researcher strongly opposes Archer's ideas, and argue that safeguarding a subjective view will ensure that 'social reality will *not* be replaced by a fictional non-existing world constructed by the scientific observer' Schutz (1964) in (Holstein and Gubrium 1998)(p138). Subjectivity should not be a marginal research activity but aim to 'interpret and explain human thought and action' (Holstein and Gubrium 1998)(p140). Some qualitative research may appear initially to be so esoteric as to have little practical input even when offering

[131] http://www.merriam-webster.com/dictionary/anecdote. Accessed 16/09/2009
[132] www.healthtalkonline.org and www.youthhealthtalk.org

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valuable insights. However, Yardley (2000) cites the example of Foucault's (1989) work on how the body is socially regulated by the practice of medicine which strongly influenced future critiques of health promotion practices. Similarly the work of Lusardi regarding patients' experiences in Intensive Care Units contributed to the beginning of the development of a theory or consciousness specific to the intensive care patient (Hunter, Lusardi et al. 2002).

Thus it is perfectly feasible that the anecdotes of these four participants could become in time, part of an accumulating corpus of 'seizure discourse' data. The words, phrases, drawings and poems of Dave and Vince are living examples of people trying to explain their 'epilepsy-related experiences' (Schachter 2009). Subjective experiences can no longer be viewed as unscientific data, the dimension they represent are first person direct descriptions of cognitive processes and it is these that can help with the interpretation of other data such as that being recorded with neuroimaging techniques. Anecdotal descriptions of seizures are invaluable, they could form the basis of new 'paradigm' for the neuro-scientific approach to epilepsy (Johanson, Valli et al. 2008)(p171) and by default NES.

Answers just generate further questions. [133]

In the field of differentiating between epilepsy and NES, it is becoming increasingly clear that a multi method interdisciplinary approach is needed. Findings from different approaches can improve conceptualisation in the area of differentiating NES and epilepsy (Metcalfe 2004). As well as existing quantitative measures contributing to seizure differentiation being reinforced (Mazza, Marca et al. 2009), novel areas of exploring these are being introduced (Azar, Tayah et al. 2008). The CA research and development has gone far in identifying linguistic hints relating to either diagnosis and this research

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[133] I overheard this comment from someone in a nearby office when I was writing this chapter.

continues to evolve and develop. The art work of people with epilepsy could draw attention to themes such as psychiatric comorbidity and the psychosocial aspects of epilepsy (Schachter 2009).

In addition to the medical knowledge we have about seizures, this thesis has offered some 'base line' knowledge about individual subjective seizure experiences as well as stretching the methodology of IPA. IPA allows a close focus on an experience, not letting prior judgements, thoughts or theories interfere with this. This is one aspect of seizure experiences which is not, to date, fully considered in differential diagnosis and one which does not always fit in neatly with medical ideas. It illustrated the usefulness of gathering subjective experiences before a diagnosis is reached given that a person's experiences can alter with medication and/or as they become more familiar with the language of seizures.

This approach, like the CA research before it, IPA has the potential to build up knowledge in an incremental process. The approach at present is open to conceptualisations of seizure experiences previously unheard. The descriptions such as these accessed in the interviews in this thesis have the potential to contribute to a lay and professional discourse on seizures, to contribute to consciousness research and thus towards a differentiation of epilepsy and NES. As figure 14 above illustrates, an IPA approach connects with metaphor and other research in the field of linguistics with the addition of 'approximations' of experiences and the use of metaphoric 'predicates' being added to the 'mix'.

With its commitment to cognition IPA could contribute to neuroscientific work on seizures as a rigorous method of accessing subjective descriptions. The empirical studies above are challenging 'the very concept of phenomenology' (Gallagher and Brøsted Sørensen 2006)(p124) and it is to this paradigm shift that IPA could contribute. Although this use of phenomenology was not envisaged by philosophers such as Husserl (Gallagher and Brøsted Sørensen

2006) it has exciting potential for the study of differentiating seizure experiences.

For IPA to contribute to seizure differential diagnosis of seizures a methodological shift/adaptation would need to occur. Currently, in terms of answering a specific research question that is, towards an approach of 'motivated looking', is not one IPA researchers currently advocate. However, the development of 'pure' CA in the Bethel work did result in clear findings over a period of time. An IPA of this area could be in the form of a more finely detailed and guided exploration about seizure experiences with participants and thus towards the potential differentiation of two very different phenomena.

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