Patients diagnosed with non-epileptic seizures: their perspective and experience

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ABSTRACT

Patients that suffer from psychogenic non-epileptic seizures are confronted with many obstacles in seeking effective treatment for their illness. Underlying many of these obstacles is the divergence between the medical model and the patient's perception of their illness. The objective of this qualitative study is to elucidate, through semi-structured interviews, the subjective illness and treatment experience of these patients, in order to answer the research question: *How do non-epileptic seizure patients make sense of their illness experience?* This may allow a better understanding of the impediments to proper care that the patients encounter. The results showed that the participants that implicitly incorporated epilepsy as an illness prototype demonstrated less effective treatment expectations and imposed greater life constraints on themselves, than the participant that utilized anxiety attacks as an illness prototype. The participants that defined an explanatory model with a psychosocial basis for illness onset were receptive and demanding of psychotherapeutic intervention. The importance of early diagnosis and improved diagnostic strategies is emphasized. Two overarching interconnected themes that emerged, *loss of control* and an *inability to communicate* appeared to characterize the underlying internal struggle that permeated the illness and treatment experience of the study participants.

RÉSUMÉ

Les patients qui souffrent de crises non épileptiques psychogènes doivent faire face à de nombreux obstacles dans la recherche d'un traitement efficace de leur maladie. L'origine de beaucoup de ces obstacles est la divergence entre le modèle médical et la perception du patient de sa maladie. L'objectif de cette étude qualitative est d'élucider, au moyen d'entrevues semi-structurées, l'expérience subjective de la maladie et du traitement de ces patients, afin de répondre à la question de recherche : *Comment les patients non épileptiques donnent-ils un sens à leur expérience de la maladie?* Cela peut permettre une meilleure compréhension des obstacles aux soins appropriés que rencontrent les patients. Les résultats ont démontré que les participants qui ont implicitement accepté l'épilepsie comme prototype de la maladie s'attendent à des traitements moins efficaces et s'imposent des contraintes de vie plus sévère que les participants qui ont accepté les crises d'angoisse comme prototype de la maladie. Les participants qui ont défini un modèle explicatif avec une base psychologique dès les débuts de la maladie ont été plus réceptifs et enclins à demander l'intervention psychothérapeutique. L'importance d'un diagnostic précoce et de l'amélioration des stratégies de diagnostic ressort de l'étude. Les deux grands thèmes qui ont émergé de l'étude : la *perte de contrôle* et *l'incapacité à communiquer* la détresse caractérisent l'apparent conflit interne sous-jacent et relié qui imprégnerait l'expérience de la maladie et le traitement des participants à l'étude.

I. INTRODUCTION

Psychogenic non-epileptic seizures (NES) are disorders that resemble epilepsy, but do not result from abnormal electrical discharges in the brain (Krumholz 1999). NES patients account for approximately 20% of all intractable seizure disorders referred to epilepsy centres (Krumholz and Hopp 2006). NES is a well-known but poorly understood phenomenon in neurological settings. Although many theories as to the aetiology of the illness have been presented, current speculation suggests a psychosocial origin for the illness (LaFrance and Devinsky 2002; Schwabe, Howell et al. 2007). A multi-factorial model for NES has been proposed (Reuber 2009), but a specific aetiology or mechanism by which NES develops has yet to be generally accepted or established.

The absence of an identifiable medical cause for NES may lead to a discord between the patient's illness model and that of biomedicine. This may complicate communication between NES patients and practitioners, and create a barrier to proper care. The difficulty in diagnosing NES and differentiating it from epilepsy may also result in a long delay before accurate diagnosis (Reuber 2008). Misdiagnosis as epilepsy may further result in ineffectual drug treatment that can have adverse side effects (Kanner 2003). Patients that suffer from NES are consequently confronted with many potential obstacles to care.

In order to address these issues and improve the quality of care, the meaning NES patients ascribe to their illness and the impediments they confront in health seeking need to be better understood. One objective of this study is therefore to elicit the illness representations of NES patients, along with accounts of their treatment seeking experiences. The analysis of the themes that emerge from the patient accounts may lead to a better understanding of NES patients' illness and treatment experience. This may lead to strategies to improve communication between NES patients and practitioners, and create pathways to better care.

A qualitative approach is useful when existing theories do not apply with a particular group under study (Creswell 2003). Since the goal of qualitative research, and that of this study, is to make sense of phenomena in terms of the meanings people bring to them (Schwandt 2001), this cross-sectional qualitative study will incorporate a multiple-case study design and analyze cross-case themes that emerge from the data.

II. LITERATURE REVIEW

History:

The conceptual and etiological understanding of NES has developed and changed over the centuries. Current theories invoke psychological and psychosocial processes to explain the illness, and differentiate between epileptic, psychogenic and other types of seizure activity. Historically, the manifestation of seizures was often understood to carry religious, spiritual and even mythological meaning. Seizure activity has been recounted throughout history and has been reported to have afflicted many influential figures including Hercules, Julius Caesar and arguably Alexander the Great (Hughes 2004). In his account of Heracles in discussing *Problem XXX*, Aristotle links genius with seizures and melancholia, along with the belief that both afflictions emanate from the same source (Klibansky, Panofsky et al. 1964). He describes the illness affecting the men of great power and intellect, as suffering from illness of melancholy, or black bile disease (Klibansky, Panofsky et al. 1964).

> *"Why is it that all those who have become eminent in philosophy or politics or poetry or the arts are clearly of an atrabilious temperament (melancholic), and some of them to such an extent as to be affected by diseases caused by black bile, as is said to have happened to Heracles among the heroes? For he appears to have been of this nature, and that is why epileptic afflictions were called by the ancients 'the sacred disease' after him."* (Klibansky, Panofsky et al. 1964)

An association between seizures and mitigating external factors influencing their onset, such as childhood sexual abuse, has been traced to the Egyptians, the Greeks, the Romans and the Navajo (Krumholz 1999; Sharpe and Faye 2006). During the middle ages with the massive witch-hunts in Europe, signs of seizures, convulsions or grotesque bodily distortions were considered symptoms of possession (Ferber 2006). Interestingly, convulsions in this context were not only considered a sign of the demonic possession, but were also incorporated as a therapeutic part of the healing process (Ellenberger 1970). When the convulsions arose spontaneously they could be considered both an indication and confirmation of possession (Ellenberger 1970). When the convulsions were induced during an exorcism, the foremost treatment for possession at the time, they would be considered a form of healing (Ellenberger 1970). This healing procedure was based on demonstrating strength over the demons by inducing or stopping their presentation by the will of the exorcist and his connection to higher powers, which would eventually bring about their release (Ellenberger 1970). In fact the induction of *voluntary possession* or seizures within the healer himself is a technique that has been practised in other cultures as well, as part of the ritual treatment of possession of an afflicted individual (Ellenberger 1970). In the infamous case of possession in Loudon, France in 1632, nuns reported extraordinary convulsions, along with other symptoms that were believed to fit perfectly with the symptoms of possession. It was later suggested by Bernheim, among others that these women were in all likelihood simply suffering from hysteria, in what was then recognized as hysterical conversion (Spanos 1978). Likewise Pinel and Charcot made reference in their writings to cases of possession in the Middle Ages and to the case of the *Devils of Loudon* as forms of hysteria (Ellenberger 1970; Drinka 1984). The term ‘hysterical conversion’ was popularized by John Ferriar in 1795 in his book on ‘conversion of diseases’, but it seems to have originated in Edward Jorden’s 1603 *A Brief Discourse of a Disease Called the Suffocation of the Mother* in which he argues in favour of mental representations becoming represented symbolically in the body, independent of conscious motivation (Littlewood and Bartocci 2005).

The use of exorcism to treat cases of possession, which entailed symptoms of seizures, continued to be practised until the end of the 18th century. The principles behind the method of treatment were outlined by Gassner in 1774 (Ellenberger 1970). In it he described that the ability to induce seizures in an individual was proof of possession, since it was believed only those possessed by demons could display such characteristics (Ellenberger 1970; Drinka 1984). This distinction of a vulnerability to seizures produced by induction continued to be a sign of *hysteria* even after the concept of possession was no longer applied to explain their occurrence (Ellenberger 1970). At the end of 18th century Mesmer developed a system referred to as *animal magnetism* and began to treat many ills, including hysterical type symptoms, by inducing seizures in his patients using his own influence, or with the use of *magnetized* baths, trees or other objects. The theory was that these *magnetized* objects were believed to have the power to induce convulsions in his patients to restore the proper flow of *magnetic fluid* through their bodies (Darnton 1968). Although, treatment with the induction of seizures was similar to that of an exorcism, the rationale behind the treatment appeared at the time to be based on a scientific principle, hence the ideas behind possession and exorcism faded, while *animal magnetism* became popularized (Ellenberger 1970). Mesmer's theory was staunchly supported and highly criticized, and alternately gained and receded in popularity over the next decades until the mid-19th century (Darnton 1968; Ellenberger 1970). Royal commissions were established to test the veracity of Mesmer's theory regarding the existence of an invisible *magnetic fluid*. The focus of these commissions, however, was always on the scientific rationale of his theory, and not on the efficacy of his therapy (Darnton 1968; Ellenberger 1970). In fact, it was generally accepted that his treatments provided some benefit, in spite of his unsubstantiated theories as to the mechanism of the illness and treatment effects (Ellenberger 1970). Mesmer's attempt at explaining the illness and treatments by scientific means is seen as the precursor to the concept of hypnotism and dynamic psychiatry (Ellenberger 1970).

Puységur, a contemporary of Mesmer discovered *the perfect crisis*, also referred to as *magnetic sleep* or artificial somnambulism (Ellenberger 1970). This state or condition was given the name of *hypnotism* by Braid in 1843 (Ellenberger 1970). This practise of hypnosis became the root of the 19th century technique for dismissing or inducing physical hysterical symptoms, and was utilized specifically at two French schools; Bernheim's Nancy School and Charcot's Salpetrière (Littlewood and Bartocci 2005). Charcot and initially Freud continued to induce seizures in hysterical patients as a therapeutic method, often through the use of hypnosis or suggestion. In earlier writings, Freud and Breuer outlined that in order to cure hysteria, there necessitated a catharsis or abreaction of affect before embarking on any associative discourse (Freud and Breuer 1966).

> *'If one can succeed in getting into rapport with the patient during an attack such as this of generalized clonic spasms … or if, better still, one can succeed in provoking the attack under hypnosis – one finds that here, too, there is an underlying memory of the psychical trauma'…*(Freud and Breuer 1966)

The belief that convulsions may offer a therapeutic benefit has been proposed since the time of Hippocrates (Nahas, Lorberbaum et al. 2004). This technique of healing by seizure induction has been utilized throughout the centuries, as described above from exorcisms, mesmerism to Freud, and throughout cultures with shamanism, possession cults, and other cultural rituals (Ellenberger 1970). The induction of seizures has not been limited to suggestion or hypnosis. The use of chemical means to induce seizures was recorded with the introduction of camphor by Paracelsus in the 16th century and by various physicians in the 18th century (Faedda, Becker et al. 2010). Weikhard, in 1796, documented the successful treatment of psychosis using this method (Faedda, Becker et al. 2010). In the 1930s somatotherapies that employed seizure induction were reintroduced and developed to treat psychiatric patients (Endler and Persad 1988). Insulin-shock therapy was introduced by Sakel and camphor oil was reintroduced by Meduna, which he eventually replaced with cardiazol. Once these techniques became successful and began to be used more widely, Cerletti and Bini began experimenting with the use of electricity to induce seizures (Faedda, Becker et al. 2010). They developed what is now referred to as electro-convulsive therapy, which of these methods, is the only one currently still in use (Enns, Reiss et al. 2010). The basis for the current use of electro-convulsive therapy (ECT) for the treatment of some drug resistant psychiatric disorders was built on the same premise that spontaneous seizures, whatever their origin, had a therapeutic benefit, in particular for psychotic patients (Kalinowsky 1986). In fact, a recently published study examined the use of ECT for NES patients (Blumer, Rice et al. 2009). The theoretical basis for seizure induction has varied depending on the historical period in which it occurred, but no scientific explanation has been established to justify the perceived therapeutic benefit.

At the end of the 19th century Charcot understood hysteria to be an organic disease, and was the first to describe hysteria as a clinical disorder (Alsaadi and Marquez 2005). He classified it as hysteroepilepsy, an organic disorder of the brain, but still used hypnosis and seizure induction as a therapy (Ellenberger 1970). Babinski, a disciple of Charcot, contradicted him by declaring that all hysterical conversion was suggestion, and resulted from feigning and imitation and was not due to an unknown mind-body interaction (Ellenberger 1970). Janet, also a student of Charcot, rejected the purely neurological theory, as well as the suggestion that the symptoms were feigned (Ellenberger 1970). Janet considered hysteria a psychogenic illness, developed as a result of an abnormal psychological disposition (Ellenberger 1970). He proposed that traumatic events such as sexual abuse could produce hysterical symptoms if the patient dissociates from the memories of the events and focuses attention on certain bodily sensations (Sharpe and Faye 2006).

Freud and Breuer similarly characterized such seizures as resulting from the repression of sexual abuse that converted into physical symptoms (Freud and Breuer 1966). Thereby, according to Freud and Breuer the seizures were the result of emotional disorders of the mind that were the consequence of the conversion of repressed sexual abuse histories (Freud and Breuer 1966). In a letter to Fliess in 1897 Freud for the first time wrote that the stories of his patients' sexual abuse histories were fantasies and as such he believed the whole theory of hysteria no longer had a proper foundation (Ellenberger 1970). As a result Freud revised his theory with the belief that it was the suppression of unspeakable sexual urges, specifically from unresolved Oedipal fantasies that resulted in a conversion of the unspeakable sexual desire and *energy* to physical manifestations of hysteria (Ellenberger 1970). This new interpretation, he believed to be reinforced by the observation of seizure activities such as pelvic thrusting and other movements manifested by hysterical patients that appeared to mimic sexual intercourse (Sharpe and Faye 2006).

As a result of this fundamental change in how the aetiology of hysterical seizures was understood, the treatment of patients by hypnosis and seizure induction to address underlying psychical trauma no longer made sense, since according to Freud's theory this memory of traumatic events was in actuality a fantasy. Instead Freud proposed a purely discursive approach to treatment that addressed the associations made from patient fantasy of apparent memories of sexual abuse in relation to their childhood history (Ellenberger 1970).

The current definition and the theory behind *hysteria* have developed very little since this time, while the nomenclature has undergone numerous transformations (Devinsky 1998; Brooks, Goodfellow et al. 2007). In spite of only minor changes in the definition, there has been difficulty establishing consensus as to how to classify the illness (Reuber 2009). According to the DSM-IV non-epileptic seizures or *pseudoseizures* are classified as a *conversion disorder with seizures or convulsions* which falls under the classification of somatoform disorders. The ICD-10 classifies pseudoseizures as *dissociative convulsions*, a dissociative disorder (Reuber 2009). The difficulty of classifying NES has continued to present problems to clinicians and it has been suggested that the current diagnostic criteria are considered unreliable or even at times invalid (Kanaan, Carson et al. 2010). With the advent of the DSM-V the psychiatric community is searching for a way to update or replace the diagnostic criteria and classification of the illness (Mayou, Kirmayer et al. 2005). As Halligan noted,

> *"There is no generally accepted explanation for how a psychological stress can convert into (often highly selective) symptoms. In this respect, conversion hysteria retains 'the doubtful distinction among psychiatric diagnoses of still invoking Freudian mechanisms as an explanation'"* (Halligan, Bass et al. 2000)

Since there is currently no measurable physiological marker available to diagnose the illness and its manifestation can take many forms often only perceived by the patient, NES is defined in part according to illness perceptions (Reuber 2008). As a result Reuber suggests it is not surprising that NES cannot be categorized easily in a single diagnostic category (Reuber 2008). Considering the current definition of NES relies on illness perceptions, the advantage of understanding these perceptions from a patient's as well as a clinician's perspective is unmistakable.

Terminology:

The terms used to describe NES have changed over the years, and with the use of words such as *hysteria* and *pseudoseizures* have often been perceived as pejorative by many patients (Stone, Campbell et al. 2003). Some of the terms that have been used more recently are pseudoseizures, non-epileptic attack disorder, hysteria, non-epileptic events, as well as seizures defined as dissociative, conversion, psychogenic, functional and hysterical (Reuber 2008). Although psychogenic non-epileptic seizures is a term commonly used between clinicians, non-epileptic seizures is a more neutral term since there is no presumption of aetiology nor an underlying implication the seizures are consciously being created by the patient. According to a survey of American Epilepsy Society clinicians, the term non-epileptic seizures is used at least six times more frequently than any other term when communicating with the patient about the illness (LaFrance, Rusch et al. 2008). Since this investigation involves a discourse with patients regarding their illness perspectives and experiences, the term non-epileptic seizures (NES) will be used throughout.

Diagnosis:

The difficulty of accurately identifying and diagnosing NES is a challenge for both psychiatrists and neurologists. The diagnosis of NES currently relies on the exclusion of other disease possibilities; hence extensive testing is often required before a final diagnosis of NES may be imparted with confidence. The main complexity in the diagnostic process lies in excluding the possibility of epileptic seizures. Complicating matters, patients with confirmed epilepsy may also suffer co-morbid NES (Betts and Boden 1992). This confounds accurate diagnosis and treatment for such a patient, as well as for NES patients that do not suffer from co-morbid epilepsy. The gold standard for ruling out epilepsy in the diagnosis of NES is video-electroencephalogram (video-EEG) telemetry in tandem with bedside observation (Teo and Choong 2008). Through video-monitoring the patient is constantly observed and brainwaves are measured to monitor for epileptiform activity during any seizure events. Observation of the type of seizure activity along with the type of brainwave activity is believed to lead to accurate diagnosis up to 90% of the time (LaFrance 2008). It has been suggested by Reuber, however, that since some forms of epilepsy are not easily measurable by EEG, and may only appear 10-20% of the time during analysis, the diagnostic picture may be even more complicated than believed (Reuber 2008).

Other techniques of diagnostic testing have been proposed, such as using the personality scale of the Minnesota Multiphasic Personality Inventory, physiological measures including prolactin levels and the use of single photon emission computed tomography (SPECT) scans, along with observations of the characteristics of pre-ictal pseudosleep, and symptoms during ictal and postictal states (Cuthill and Espie 2005). These diagnostic techniques have had varying success for sensitivity and specificity, but none to the extent of video-EEG telemetry (Cuthill and Espie 2005). More recent proposals such as an analysis of NES patients communication behaviour is currently being tested for validity and reliability. (Schwabe, Reuber et al. 2008; Plug, Sharrack et al. 2009).

More provocative methods that involve seizure induction with the use of placebos, suggestion or hypnosis have been proposed. These include the use of intravenous saline, a tuning fork applied to the forehead, an alcohol pad placed on the skin or the carotid artery, hypnosis, anhydrous ammonia and head-up tilting (Slater, Brown et al. 1995; Zaidi, Crampton et al. 1999; Gates 2001; Roelofs, Hoogduin et al. 2002). A survey of members of the American Epilepsy Society showed that 40% of the respondents used some sort of provocative testing for seizure identification (Gates 2001). There remains, however, an ethical debate as to the use of provocative testing, in addition to questions about the reliability, concerns of injury to the patient, and the potential negative impact on the trust between doctor and patient (Gates 2001; Iriarte, Parra et al. 2003; Benbadis 2009).

The complexity and controversy regarding the diagnosis and the techniques involved can result in a delay before accurate diagnosis. A study with over 300 NES patients found a mean delay of 7 years between first seizure manifestation and accurate diagnosis (Reuber 2009). Once the diagnosis of NES has been established there may still remain disagreement between practitioners. Although psychiatrists have been expected to accurately diagnose NES, they may often be more reluctant than neurologists to accept a negative video-EEG telemetry test outcome as indicative of NES (Kanner 2003). In a study of NES patients seen in primary care, it was observed that a significant number of primary care physicians did not agree with the diagnosis and hence continued to prescribe drug treatment despite evidence and recommendations to the contrary (Carton, Thompson et al. 2003).

Treatment:

The lack of a coherent framework to understand NES maintains a conceptualization of the illness somewhere between neurology and psychiatry (LaFrance, Alper et al. 2006). Due to the difficulty in excluding the possibility of epileptic seizures during the diagnostic process, physicians have tended to respond prudently by treating patients suffering from undiagnosed seizures with anti-epileptic drug (AED) medication until a diagnosis has been confirmed (LaFrance 2008). Approximately three-quarters of NES patients may have received inappropriate AED treatment before the correct diagnosis is made (Reuber 2009). Although AED treatment is provided with concern to epilepsy prevention, such treatment is unnecessary for NES patients and may result in potentially adverse side effects while offering no treatment benefit (LaFrance, Rusch et al. 2008). These side effects may vary with the class of drug administered, however, commonly observed side effects include excessive fatigue, nausea, vomiting and dizziness, along with other neurotoxic and behavioural effects (Aronson 2006; Hung and Shih 2011). A further risk exists for NES patients that manifest seizures that mimic status-epilepticus. In a study from Howell, over one third of the patients diagnosed with NES had been misdiagnosed with status-epilepticus at least once (Howell, Owen et al. 1989). The most frequent cause of morbidity, and on very rare occasions mortality, seen in NES patients may be related to their misdiagnosis as epilepsy patients suffering from status epilepticus and the resultant aggressive treatment in intensive care units (Howell, Owen et al. 1989; Kanner 2003; Reuber, Baker et al. 2004).

Upon a confirmed diagnosis of NES it is understood that AED treatment of the patient should be gradually tapered and discontinued, unless the AEDs are being used for another purpose (Binder and Salinsky 2007). In an outcome study from Sullivan, 35% of patients diagnosed with NES continued to receive AED treatment at a median follow-up of 21 months after diagnosis (O'Sullivan, Spillane et al. 2007). Although the majority were tapering their medication 10% of the patients remained at the same dosage (O'Sullivan, Spillane et al. 2007). In a survey to American Epileptic Society clinicians, 17% reported they did not taper AED therapy in NES patients with no co-morbid epilepsy (LaFrance, Rusch et al. 2008).

While AED treatment offers no benefit to NES patients and increases the risk of toxicity and other resultant side effects, there is no generally accepted treatment protocol that has been rigorously evaluated to demonstrate successful treatment of NES (LaFrance and Devinsky 2004; Brooks, Goodfellow et al. 2007). In fact, in spite of improved diagnostic tools, very little treatment advances or improved understanding have occurred over the last century (Devinsky 1998). Consequently, patients that suffer from NES are confronted with few treatment options that can confer a successful outcome and often require further hospitalization due to their episodes, even after their diagnosis (Ettinger, Dhoon et al. 1999).

Various studies have attempted to examine and assess the quality of treatment options and outcomes (LaFrance and Devinsky 2004; Brooks, Goodfellow et al. 2007). A major drawback that has been noted, is the poor research design in the majority of the studies, which makes generalizability virtually impossible (Brooks, Goodfellow et al. 2007). Treatment approaches are currently based on anecdotal evidence and no randomized controlled trials have been conducted (LaFrance and Devinsky 2004). Results from a recent pilot study of cognitive behavioural therapy with a randomized controlled design suggest that the therapy may benefit NES patients, however, contact with the therapist was not controlled for in the standard care group, making accurate comparison unfeasible (Goldstein, Chalder et al. 2010). In the Cochrane Database review of NES only three studies were deemed rigorous enough for analysis (Brooks, Goodfellow et al. 2007). Two studies involved hypnosis, while the other involved *paradoxical therapy*.

Although each of the studies claimed positive treatment results, none of the studies included the data necessary to ascertain the quality of the treatment outcomes (Brooks, Goodfellow et al. 2007). Other treatments that have been explored more or less rigorously include psychodynamic therapies, eye movement desensitization and reprocessing, group therapy, family therapy, multidisciplinary inpatient treatment, relaxation, meditation, counselling, biofeedback, pharmacotherapy of co-morbid conditions, electro-convulsive therapy and simply methods for communicating the diagnosis (LaFrance and Barry 2005; Barry, Wittenberg et al. 2008; Reuber 2008; Blumer, Rice et al. 2009).

Some evidence suggests that long-term seizure cessation may depend more on the absence of underlying psychiatric co-morbidity, than on treatment (Lempert and Schmidt 1990; Lesser 2003). Patients with NES are consistently diagnosed with co-morbid major depressive disorder, post-traumatic stress disorder, and cluster B personality characterized by impulsivity or hostility (LaFrance and Devinsky 2002). This has led some researchers to contend that treatment of these underlying co-morbidities should be a priority for NES patients (Walczak, Papacostas et al. 1995; LaFrance and Devinsky 2004).

A current conceptualization proposed by Reuber describes NES as a complex multi-factorial model in which predisposing, precipitating and perpetuating factors may all play an important role in the manifestation and outcome of the illness, and hence the impact of any treatment interventions (Reuber 2008). As such, Reuber argues that treatment may need to be individualized or categorized by groups of patients depending on these multiple factors and the likely aetiology or manifestations of the illness (Reuber 2008).

Outcomes:

Studies have shown that outcome in NES patients is generally poor (McKenzie, Oto et al. 2010). In the longest follow-up study to-date it was found that more than 70% of the patients continued to have seizures after an average of more than eleven years following manifestation and four years following diagnosis (Reuber, Pukrop et al. 2003). Other studies have reported a range of 16 - 38% of patients with seizure cessation (Ettinger, Dhoon et al. 1999; O'Sullivan, Spillane et al. 2007; McKenzie, Oto et al. 2010). A reduction in seizure frequency has been noted in 23 - 56% of the cases, while a seizure frequency that remain unchanged or worsened was found in 25 - 40% of the cases (Ettinger, Dhoon et al. 1999; Reuber, Pukrop et al. 2003; O'Sullivan, Spillane et al. 2007; McKenzie, Oto et al. 2010).

Factors that predicted positive seizure outcome in a longer term study included a higher IQ, higher social status, greater educational attainments, a younger age and a less dramatic seizure manifestation (Reuber, Pukrop et al. 2003). Negative outcome was noted in patients with less effective communication and coping strategies such as social avoidance, withdrawn behaviour, poor assessment of reality, reluctant self-disclosure and restricted expression of affective sentiments (Reuber, Pukrop et al. 2003). Patients with NES that displayed borderline personality disorder traits likewise showed poorer outcomes (Reuber, Pukrop et al. 2004). It has been suggested that patients that report good childhood relationships or many current friendships have a better prognosis (Ettinger, Dhoon et al. 1999). Positive outcome predictors in a shorter-term study included no previous diagnosis of anxiety or depression, not receiving social security benefits at diagnosis, being of the male gender, and patients that reported antecedent bullying as a traumatic factor (McKenzie, Oto et al. 2010). NES patients that perceived themselves as having good health, as well as patients that were employed, were correlated with seizure resolution (Ettinger, Devinsky et al. 1999). Although long-term chronic seizure outcome appears to be associated with underlying psychiatric diagnosis, no statistically significant correlation between outcome and psychiatric intervention has been established (Ettinger, Devinsky et al. 1999; Lesser 2003). Rapid diagnosis of NES has been associated with a better outcome; however, a recent study from McKenzie did not observe this result (Reuber 2008; McKenzie, Oto et al. 2010).

Most studies have focused on seizure frequency as an outcome measure, however, it has been suggested that other factors should be considered (McKenzie, Oto et al. 2010). A recent NES Treatment Workshop proposed a number of possible outcome measures, however, stressed the selection of outcome measure should have a relation to the theoretical etiological pathways under investigation (LaFrance, Alper et al. 2006). Some of the measures suggested include: psychosocial outcomes (e.g. employment status, social functional status), psychiatric status, health-related quality of life and medical resource utilization (LaFrance, Alper et al. 2006). Larger outcome studies have included measures of health care utilization, along with social and employment outcomes (Reuber, Pukrop et al. 2003; McKenzie, Oto et al. 2010). In one study, after an average of 4 years following diagnosis 56.1% of NES patients were dependent on social security benefits (Reuber, Pukrop et al. 2003). This is supported by other results that reported an unemployment rate of 47%, which was double the unemployment rate that was reported for people suffering from epilepsy (O'Sullivan, Spillane et al. 2007). The same study similarly found that over one quarter of the adult patients were not living independently (O'Sullivan, Spillane et al. 2007). In a recently published short-term outcome study, a small minority of patients went back to work by follow-up; however, there was no change in the number receiving social security benefits (McKenzie, Oto et al. 2010). The return to work appeared to be largely dependent on the cessation of seizures, whereas those receiving social security benefits at baseline continued to do so at follow-up, independent of seizure outcome (McKenzie, Oto et al. 2010). Strikingly, according to this retrospective study, after diagnosis the use of emergency services dropped independent of seizure outcome (McKenzie, Oto et al. 2010).

This drop in service utilization after definitive diagnosis was similarly documented in an earlier study (Martin, Gilliam et al. 1998).

Some studies that have focused on specific treatments have also used other measures to assess outcomes such as psychiatric symptom scales and measures, psychosocial functioning such as employment status and mood, and health service utilization (Goldstein 2004; Barry, Wittenberg et al. 2008; Kuyk, Siffels et al. 2008; LaFrance, Miller et al. 2009; Goldstein, Chalder et al. 2010). In a treatment study for cognitive behavioural therapy (CBT), Goldstein measured patients for *Work and Social Adjustment Scales, Hospital Anxiety and Depression Scales*, and health service utilization and employment status for both 6 months prior to and after treatment with either CBT or standard medical care (Goldstein, Chalder et al. 2010). The only measure that showed a significant difference between the two treatment groups was the perception of the functional impact of the illness, which was rated less in the CBT group than the standard medical care group (Goldstein, Chalder et al. 2010). In another study on CBT treatment that did not have a control group, LaFrance found a significant improvement in scales assessing anxiety, somatic symptoms, quality of life and psychosocial functioning when comparing baseline to the final treatment session results (LaFrance, Miller et al. 2009). In a small study of NES patients receiving group therapy, Barry found that scores from the Beck Depression Inventory decreased significantly over the course of treatment but remained in the mildly depressed range (Barry, Wittenberg et al. 2008). Ettinger found that patient outcomes were not statistically different whether the patients received some type of psychiatric intervention, saw a psychiatrist and a counsellor, saw only a counsellor, a social worker, or a psychologist, or received no intervention at all (Ettinger, Devinsky et al. 1999).

Despite the chronic and recurrent nature of the illness, it has been suggested that simply a successful communication of the diagnosis may result in the cessation of seizures (Aboukasm, Mahr et al. 1998; Kanner, Parra et al. 1999; Farias, Thieman et al. 2003; Hall-Patch, Brown et al. 2009). Similarly, although there is little direct treatment a neurologist may offer, it has been shown that NES patients that continue to be observed concurrently by the diagnosing neurologist and psychiatrist have better outcomes than those patients who are followed by the psychiatrist alone (Krumholz and Hopp 2006). Spontaneous remission may arise in approximately 10% of the cases, although it is not clear how consistent this result may be and the degree to which the communication strategy for the diagnosis may play a role (Kanner 2003; Hall-Patch, Brown et al. 2010; McKenzie, Oto et al. 2010). Using a specific communication strategy that involved providing patients with an information leaflet and discussing the diagnosis with attention to 14 core points that were believed to address the major aspects of patients' illness representations, Hall-Patch found that 6% of patients were seizure free after two weeks, and 14% after 11 weeks (Hall-Patch, Brown et al. 2010). The perception that longer duration of PNES before diagnosis may limit spontaneous recovery (Walczak, Outcome After Diagnosis, 1995) is not supported by more recent studies that report the delay to diagnosis does not negatively impact short-term outcomes (O'Sullivan, Spillane et al. 2007; Reuber 2008; McKenzie, Oto et al. 2010). Conversely, NES patients that suffer from less psychiatric co-morbidity are more likely to show better short-term outcomes than those with greater psychiatric co-morbidity (Walczak, Papacostas et al. 1995; Gene-Cos and Ring 2005). Similarly, patients that do not receive AED treatment are more likely to recover spontaneously, than NES patients that do receive AED treatment (Carton et al., 2003). In spite of the encouraging outcomes found in short-term follow-up studies, this has not been demonstrated by longer term outcome studies, nor is there a current explanation for this discrepancy (Reuber 2008).

Costs:

It is estimated that in simple financial terms the cost of NES when left undiagnosed may be equivalent to the cost of treating intractable epilepsy over the lifetime of the patient (Gene-Cos and Ring 2005). On average correct diagnosis occurs only 7 years after the onset of NES (Reuber, Fernandez et al. 2002). Due to this delay in diagnosis patients receive unnecessary AED treatment and follow-up observation that is costly to both the patients and the healthcare system (Gene-Cos and Ring 2005; LaFrance, Rusch et al. 2008). In addition an estimated 40% of NES patients are admitted to an ICU at some point in the course of their illness (Kanner 2003).

Before and after diagnosis, the cost of patients returning to neurology clinics places a largely avoidable burden on these services. An increased use of primary care is seen in patients with greater illness worry and emotional distress (Frostholm, Fink et al. 2005), and patients suffering from somatoform disorders such as conversion disorder, tend to incur twice the medical costs, through both inpatient and outpatient medical care utilization, as compared to medical controls (Barsky, Orav et al. 2005). In addition to costs in primary care, patients suffering from somatoform type disorders tend to utilize alternative medicines to a far greater degree (46%) than other primary care patients (18%) due apparently to their lack of satisfaction of effective care in the medical setting (Garcia-Campayo and Sanz-Carrillo 2000). In two studies specific to NES, however, it has been suggested that medical resource utilization decreased upon diagnosis, regardless of the impact on seizure frequency (Martin, Gilliam et al. 1998; McKenzie, Oto et al. 2010). This, according to McKenzie, emphasizes the importance of early diagnosis and communication in order to reduce the demand for, and cost of, unnecessary emergency health care (McKenzie, Oto et al. 2010). It has not been established how the recurrence of seizures over the long-term may impact medical resource utilization.

There are also extensive, difficult to quantify indirect costs resulting from lost workdays and resultant unemployment that impact NES patients (Reuber 2008). In one study, after a four year follow-up over half the NES patients were either retired or unemployed, with an average age of just under 40 years (Reuber, Pukrop et al. 2003). These costs impact the social support system, the family and the individual, and may similarly result in a significantly decreased quality of life.

Patients:

Typically patients with NES experience onset of their illness in their late twenties (Ettinger, Devinsky et al. 1999; Stone, Binzer et al. 2004). Patients with NES have been characterized as having co-morbid psychiatric diagnoses, personality disorders, a history of abuse, lower cognitive functioning and family dysfunction. Patients with NES are believed to suffer from anxiety, and greater cognitive and somatic distress that they find difficult to express (LaFrance 2008). Ettinger found that just over half of NES patients suffered from significant depressive symptoms, based on the *Beck Depression Inventory* (Ettinger, Devinsky et al. 1999). Similarly, just over half the NES patients were found to meet the criteria for an anxiety disorder, including post-traumatic stress disorder (LaFrance, Miller et al. 2009). Based on a number of small studies, the percentage of NES patients that display features of post-traumatic stress disorder has been estimated from 22 to 100% (Fiszman, Alves-Leon et al. 2004). Personality traits or disorders including borderline, histrionic, avoidant, and antisocial personality have been associated with NES (Goldstein 2004).

A history of trauma appears to be a common factor within an otherwise heterogeneous population. Reuber et al. found a history of severe trauma in 90% of the NES population studied, of which 41% of the women had suffered trauma from sexual abuse (Reuber, Howlett et al. 2007). This is extremely high considering the rate of sexual abuse is estimated to be 15 to 25% in the general female population (Leserman 2005) and only 15% of women with other functional neurological symptoms reported a history of sexual abuse (Reuber, Howlett et al. 2007). In two thirds of the NES patient population Reuber found significant problems in the family or social environment including bereavement

(Reuber, Howlett et al. 2007). Tests with the Minnesota Multiphasic Personality Inventory have shown NES patients to have elevated scores of hypochondria, hysteria, and depression (Cragar, Berry et al. 2002; Schramke, Valeri et al. 2007). Family dysfunction or discord have been found in over half of NES patients, with affective disorders in over 40%, and health anxiety or hypochondriasis found in close to 25% of NES patients (Reuber, Howlett et al. 2007).

Patients that reported a persistence of seizures six months after diagnosis were characterized by a history of chronic abuse of any kind: physical, emotional or sexual. They were also characterized by personality disorders, recurrence of major depressive illness, dissociative and somatoform disorders, and denial of the impact of psychosocial stress on the illness (Kanner, Parra et al. 1999). Of these patients many showed positive initial outcomes to various interventions, yet the seizures returned in the majority of cases (Gene-Cos and Ring 2005).

The NES population has shown many heterogeneous manifestations, suggesting that there may be clusters of traits or patterns of illness within the overall category (Reuber, Howlett et al. 2007). Cragar listed three personality clusters that emerged, showing different levels of functioning and suggesting that interventions should be differentiated within NES, based on cluster types (Cragar, Berry et al. 2005). These cluster types were listed as *depressed neurotics*, which showed high neuroticism and agreeableness, and low extraversion, openness and conscientiousness; *somatic defenders* which had average outcomes on all test domains; and *activated neurotics*, which showed high neuroticism, average extraversion and conscientiousness and low openness and agreeableness (Cragar, Berry et al. 2005). Reuber noted three personality pathology clusters categorized as borderline personality disorder, an overly controlled personality, and an avoidant personality (Reuber, Pukrop et al. 2004). Researchers have also tried to categorize NES patients by seizure semiology, differentiating between *motor seizures* that involve clonic, hypermotor movements of extremities, pelvic thrusting, head movements, and tonic posturing of the head; *minor motor* or *trembling seizures* such as trembling of the upper and lower extremities; and *atonic seizures* that involve falling to the floor, unresponsiveness and limpness (Groppel, Kapitany et al. 2000). When NES patients that displayed a type of *motor seizure* were compared to NES patients that displayed *atonic seizures* there was no significant difference between the frequency of depression, anxiety, post-traumatic stress disorder, or malingering; however, only patients with a motor manifestation had a history of sexual or physical abuse, in contrast to none of the patients manifesting *atonic seizures* (Abubakr, Kablinger et al. 2003).

Although onset of NES typically occurs in the late twenties, there are cases that afflict both young and old populations (Patel, Scott et al. 2007; Acar and Salinsky 2010). In older populations with late-onset NES, there have been no major demographic or historical differences that have been noted compared to a young adult population, however, the diagnosis appears to be significantly delayed in the older patients (Acar and Salinsky 2010). In paediatric cases of NES difficulties in school, family discord (often conflict between the parents), interpersonal conflicts and less commonly sexual or physical abuse were considered stress factors in illness manifestation (Patel, Scott et al. 2007). There appeared to be differences based on age of onset, whereby equal gender prevalence, subtle motor activity manifestation, cognitive dysfunction and epilepsy were noted in patients less than 13 years; while female predominance, greater motor activity manifestation and depression were reported in children that were 13 years and older (Patel, Scott et al. 2007).

NES tends to affect women to a greater degree than men with 75% of the patients diagnosed with NES being female (McKenzie, Oto et al. 2010). Some studies, however, have shown a greater prevalence in males (almost 40%) than is generally suspected (O'Sullivan, Spillane et al. 2007). In a study examining different characteristics associated with gender, Oto found that men were more likely to attribute their NES to predisposing factors for epilepsy and more likely to be unemployed (Oto, Conway et al. 2005). Women were 8 times more likely to report sexual abuse and were more likely to weep after seizure events (Oto, Conway et al. 2005). Interestingly, the families of the men or people charged with their care were three times less likely to accept a diagnosis of NES (Oto, Conway et al. 2005). O'Sullivan also found that men had a higher seizure frequency, more AED use and a longer delay before diagnosis (O'Sullivan, Spillane et al. 2007). McKenzie found that men were two and a half times more likely to become seizure free than women (McKenzie, Oto et al. 2010). Reuber found that sexual trauma was only reported by women, and family or social stress or discord was more prevalent with women, whereas health anxiety and hypochondriasis was more common in men (Reuber, NES, 2007).

With the use of various measures, patients with NES have been evaluated in comparison to patients suffering from epilepsy, motor conversion and functional neurological syndromes, as well as to healthy controls. On neuropsychological tests, NES patients have been found to perform roughly the same as epilepsy patients, but worse than healthy controls (LaFrance 2008). Reuber, using the *dimensional assessment of personality pathology – basic questionnaire,* found that NES patients had significantly more personality abnormality than either epilepsy patients or healthy controls (Reuber, Pukrop et al. 2004). Patients with NES scored greater on emotional dysregulation tests than both healthy and epileptic controls, but scores for dissocial behaviour, inhibitedness and compulsivity differed only from the control group and not the epilepsy patients (Reuber, Pukrop et al. 2004). Similarly, NES patients have been found to perform at the same level as epilepsy patients on tests of intelligence, learning and memory, but lower when compared to healthy controls (Binder, Kindermann et al. 1998). In measures of motor function, patients with NES had less motor speed and grip strength when compared to healthy controls (Sackellares and Sackellares 2001). When compared to epilepsy patients, NES sufferers were found to have personality disorders that clustered as *paranoid, schizotypal, schizoid* or *borderline, histrionic, antisocial, narcissistic*, whereas epilepsy patients were more likely to have personality disorders clustered in the *avoidant, dependent,* *obsessive-compulsive* category (Harden, Jovine et al. 2009). Patients with NES were also more likely to be found to have borderline personality disorder than epilepsy patients, but did not differ statistically in the rate of current psychiatric disorders (Binzer, Stone et al. 2004). Compared to epilepsy patients, NES sufferers described more paternal rejection and less parental warmth than epilepsy patients (Binzer, Stone et al. 2004). Interestingly, patients with NES have frequently witnessed seizures prior to onset and are preoccupied with somatic concerns to a greater extent than epilepsy patients (Brown, Miller et al. 1991). The age of onset of NES is later than for epilepsy, but earlier when compared to patients that have motor conversion symptoms (Brown, Miller et al. 1991; Stone, Sharpe et al. 2004). Compared to motor conversion patients, NES patients were more likely to have a borderline personality disorder, a lower perception of parental care, to report incest and to have reported more life events in the year preceding onset of the illness (Stone, Sharpe et al. 2004). More life events were also reported by NES patients than epilepsy patients in the three months before onset (Binzer, Stone et al. 2004). Reuber found that a history of trauma was seen significantly more often in NES patients than in patients that suffered from other functional neurological symptoms (Reuber, Howlett et al. 2007).

Communication:

In spite of the historical attention that has been paid to the illness, NES has largely been ignored in clinical research (Mazza, Martini et al. 2006). This may result from the heterogeneity of the patient population, the low incidence of the disorder, the difficulty in classifying the illness, the lack of effective treatment alternatives, as well as a general clinical perception that such patients themselves are difficult and challenging (Krumholz and Hopp 2006). As a result, NES patients may perceive a disinterest from the medical establishment that may be deepened with the historical and current use of seemingly pejorative terminology such as hysteria and pseudoseizures (Stone, Campbell et al. 2003; Mellers 2005).

Patients diagnosed with NES have been characterized with a greater external locus of control (Stone, Binzer et al. 2004), indicating a perception that the illness arises from external, likely medical, causes that they are unable to modify through their own behaviour. Patients tend not to identify themselves as needing psychiatric care and are typically resistant to psychiatric explanations and forms of treatment (Stone, Binzer et al. 2004; LaFrance, Alper et al. 2006). This may result in part from feeling that they are not being taken seriously and are considered to be “crazy”, or “faking their spells” (LaFrance, Alper et al. 2006). This distrust of the diagnosis is reinforced in patients that have initially been presented with somatic explanations for their illness (Kanner 2003). The longer NES patients are misdiagnosed, particularly when receiving antiepileptic drug treatment, the more difficult it may be for them to change their understanding of the illness, and the poorer the resultant outcomes (Carton, Thompson et al. 2003). Upon diagnosis many patients react with anger and confusion (Ettinger, Dhoon et al. 1999), while firmly believing they still have epilepsy, as this comment from a patient receiving a diagnosis of NES indicates: “How could it not have been epilepsy. I had previously been taking five AEDs” (Carton, Thompson et al. 2003).

Communication between patients and clinicians is always of importance but this is particularly the case in NES, where patients may fear being stigmatized and disregarded if they are considered to have a non-somatic diagnosis (Kanner 2003). Neurologists on the other hand, often suspect the patient is feigning (Kanaan, Carson et al. 2010). This perception, along with the patient’s concern that they will be characterized as being *crazy* or *faking*, makes it all the more challenging to establish a mutually acceptable understanding of the illness. It has been shown that when NES patients believe the diagnosis and perceive themselves as having good health and occupational functioning, there is strong correlation to the resolution of NES (Ettinger, Devinsky et al. 1999). For patients that suffer from illnesses with medically unexplained symptoms such as NES, many patients have developed their own explanations for the illness (Kirmayer, Groleau et al. 2004). When these accounts are not addressed by the physician the clinical encounter is often counterproductive (Dowrick, Ring et al. 2004). Patients resort to seeking alternative therapies to a much greater extent than patients suffering from more easily classifiable illnesses (Garcia-Campayo and Sanz-Carrillo 2000). The reasons given by the patients for this choice is most commonly dissatisfaction with the medical care or dissatisfaction with the diagnosis that they had received (Garcia-Campayo and Sanz-Carrillo 2000). Patients seeking alternative care were reported to value longer lasting and more frequent consultations and a better relationship with their practitioner (Garcia-Campayo and Sanz-Carrillo 2000). The initiative for seeking alternative therapy appeared to result from the failure to establish a diagnosis and treatment that was acceptable to the patient (Garcia-Campayo and Sanz-Carrillo 2000).

It has been suggested that for the most part general practitioners lack the confidence or knowledge to deal with NES patients (O'Sullivan, Sweeney et al. 2006). Psychiatrists, when discussing NES patients in greater depth, recognize they are generally unprepared for the demands such patients will place on them (Quinn, Schofield et al. 2010). Neurologists, generally present the diagnosis and make psychiatric referrals, and feel their responsibility ends when a neuropathological explanation has been excluded (Kanaan, Armstrong et al. 2009). This may create a dilemma for the NES patient, as this may lead them to doubt their sense of importance in the clinical context, while believing a psychological explanation insinuates they are feigning their symptoms (Stone, Wojcik et al. 2002). There is evidence to suggest that the manner in which a NES patient reacts to their diagnosis may have an impact on outcome, particularly when the reaction is one of anger (Carton, Thompson et al. 2003). Since the illness is largely managed by neurologists (Mace and Trimble 1991), these factors emphasize the importance of effective communication by the neurologist to influence a positive prognosis. Recent studies have focused on strategies to effectively communicate the diagnosis to the NES patients (Kanaan, Armstrong et al. 2009; Kanaan, Armstrong et al. 2009; Thompson, Isaac et al. 2009). An earlier study has likewise detailed a strategy for communicating a diagnosis effectively with NES patients (Shen, Bowman et al. 1990). The initial communication may then contribute to a quick resolution of the symptoms, or contrarily to reinforce the patient's sense of isolation from the treatment process.

Illness Perspectives:

Research on illness perspectives has found an important link between the patients' illness perceptions, the manner in which the patient coped with the illness and the eventual outcome (Hagger and Orbell 2003). Further, it has been shown that patients whose illness perspectives are in line with that of the physician will tend to be more compliant with prescribed treatment, while patients that are more compliant and adhere more readily to the treatment protocol have been shown to have better outcomes regardless of the actual treatment (Moerman 2000).

Utilizing a biomedical approach to generate knowledge about illnesses that have no objectively measurable correlates can create a predicament for practitioners (Kirmayer 1999; Groleau and Cabral 2009). Scientifically generated knowledge is based on a theoretical foundation of objectivity, and hence considered more accurate than the subjective knowledge of lay persons (Caron-Flinterman, Broerse et al. 2005). Since the understanding of NES is based almost exclusively on subjective interpretation and etiological theories, as opposed to quantifiable physiological correlates, there is a danger of developing a bias based on preconceptions and predispositions. Biomedical knowledge is generated by objective and impersonal observation, whereas a patient's experiential knowledge is developed through personal and bodily experience (Caron-Flinterman, Broerse et al. 2005). This latter body of knowledge is different from, yet complimentary to the biomedical knowledge of health professionals (Popay and Williams 1996). In fact when utilized effectively, the experiential knowledge of patients has been shown to play a vital role in directing and improving the relevance and quality of biomedical research (Caron-Flinterman, Broerse et al. 2005).

In the absence of an identifiable medical cause, the biomedical framework by which NES is currently approached has not been sufficient to develop an effective treatment for NES patients. In order to understand health problems from a broader perspective, theoretical and conceptual insights derived from the subjective experience of lay people should be considered (Popay and Williams 1996).

Qualitative Research:

A goal of qualitative research is to make sense of phenomena in terms of the meanings people bring to them (Schwandt 2001). Qualitative methods have been recognized as an important research methodology for health care (Popay and Williams 1998) and may respond to the need for understanding differing perspectives that are elemental to illness experiences (Green and Thorogood 2004). There have been very few studies on NES patients that have incorporated a qualitative methodology.

Aside from studies examining patient reactions to diagnosis (Ettinger, Dhoon et al. 1999; Carton, Thompson et al. 2003) only two known qualitative studies have examined NES from the patient's perspective (Green, Payne et al. 2004; Thompson, Isaac et al. 2009). The Green et al. study confirmed the frustration and difficulty patients faced when seeking treatment, although the study was not designed to elicit the patient's model of illness (Green, Payne et al. 2004). The recent publication from Thompson et al. examined the patient's reactions to their diagnosis, along with their impressions leading up to and upon being diagnosed with NES. This study did not examine patients that refused psychiatric care, nor followed up on the patients after diagnosis but it highlighted the need for more extensive qualitative research in NES (Thompson, Isaac et al. 2009).

There are a range of approaches that may be utilized when performing qualitative research. The methodology best suited for a given study is governed by the goals of the research and the research question to be answered (Green and Thorogood 2004). The qualitative studies from Green et al. and Thompson et al., described above, both incorporated an interpretative phenomenological analysis (IPA) methodology. This methodology focuses on exploring in-depth the lived experience of the participants and the sample size of such studies may range from one to ten participants (Fade 2004; Biggerstaff and Thompson 2008). The researcher that developed the IPA methodology, Jonathan A. Smith, has emphasized the importance of single case studies (Smith 2004). He also recommends studies between three and six participants to allow for an effective and in-depth examination of the details of each case (Smith, Flowers et al. 2009).

Another qualitative research methodology that has been used in healthcare is grounded theory. This methodology may be incorporated to develop formal, substantive theory to explain how people are experiencing a phenomenon (Creswell 2007). The methodology follows a rigorous set of procedures to develop social theory (Schwandt 2001). The sampling method is very rigorous and demands a relatively large sample of participants to draw from, since later sampling requires a purposive selection of participants to allow the development of theory from the data (Glaser and Strauss 1967).

Case study methodology is a qualitative research approach with a history of use in healthcare research (Yin 1999; Anthony and Jack 2009). A case study design is appropriate for an in-depth exploration and description of naturally occurring phenomena in a real-life context (Green and Thorogood 2004). In such research a single case study is often utilized to provide an in-depth and detailed representation of a phenomenon or experience. Multiple case designs may also be considered, whereby an individual case study would be equivalent to a single experiment and a multiple-case study would be representative of multiple experiments (Yin 1999). Each case may then shed light on the problem being studied (Stake 1995). Case studies allow the use of various analytic methods to examine the data (Yin 1999).

These three methodologies: IPA, grounded theory and case study, represent an overview of the variety of qualitative methodologies available for healthcare research.

Research Problem:

An epistemological barrier to the understanding of NES and the acceptance of the diagnosis is that, as with other somatoform disorders, it is defined by the absence of underlying medical explanation of the symptoms more than by the presence of a positive explanatory model (Kanaan and Wessely 2010). Thus, health practitioners have the challenge of treating what appears to be an absence of illness, for which only contradictory evidence exists regarding the efficacy of any available treatment (Kanner 2003). With no conclusively effective treatment options and an underlying reluctance to accept psychiatric explanations, it is perceived that patients will often drop out of treatment and not return for further psychiatric care (Marcangelo and Ovsiew 2007). Furthermore, following diagnosis some NES patients apparently no longer seek any form of medical treatment even when their condition does not improve (McKenzie, Oto et al. 2010).

Successfully negotiating with the patient by addressing their concerns, beliefs and suffering may be as important as establishing the medical diagnosis when it comes to developing a workable treatment plan (Kirmayer, Groleau et al. 2004). Patients tend to feel a lack of validation when excluded from their own care and when the diagnosis subsequently diverges to a large degree from their understanding of the illness. A greater sense of autonomy and empowerment is fostered by clinical encounters that share power and incorporate the patients conceptualization of the problem (Piippo and Aaltonen 2008). Improving a sense of communication and empowerment in patients to enhance therapeutic results has been demonstrated with other illnesses. In patients suffering from medically unexplained symptoms, of which NES is one form, the patients' ability to adapt to the illness may be facilitated with communication that specifically addresses the patient population (Frostholm, Fink et al. 2005). Likewise, a patient that does not accept the illness diagnosis may perceive it as a threat to their identity and self-esteem, as has been observed in patients that suffer from mental illness (Sayre 2000).

Although diagnostic measures have improved over the last century, there has been little development in understanding the aetiology of NES or improvements in treatment (Devinsky 1998; LaFrance, Alper et al. 2006; Brooks, Goodfellow et al. 2007). Currently, much of the research on NES is limited to clinical observation describing visible or behavioural phenomena, or retrospective studies that are subject to significant bias (Reuber 2008). As Reuber notes, in order for NES research to progress a clearer understanding of the patient's subjective seizure manifestation experience and the biographical context in which it occurs is a necessity (Reuber 2008).

III. METHODOLOGY

Research Question:

The research question this study intends to answer is: **How do non-epileptic seizure patients make sense of their illness experience?**

In order to answer this question I will investigate not only the subjective illness and treatment experience of NES patients, but the different representations and forms of reasoning NES patients use to make sense of their illness. Specifically I will explore three different forms of reasoning (causal, analogical and metonymic) and the consistencies and inconsistencies that arise in the patients' construction of meaning. In order to effectively answer the research question I have outlined four objectives:

1. To elicit the illness and treatment narrative of NES patients
2. To elicit the illness prototypes of self, others and media of NES patients.
3. To elicit the illness explanatory models of NES patients.
4. To identify the convergence and divergence of themes relative to the treatment and illness experience of NES patients.

By investigating the illness narrative, reasoning and meaning NES patients give to their experience, this study may reveal dilemmas that confront NES patients, illuminate strategies for communication and treatment, uncover unexpected clues that may reframe illness conceptualization and indicate research directions worthy of further investigation. Likewise, by understanding the impediments that NES patients face when seeking treatment, a pathway to bridge divergent perceptions and reinforce complimentary observations between practitioner and patient may be initiated.

Research Design:

This cross-sectional qualitative study incorporates a multiple-case study design with an analysis of the cross-case themes that emerge from the data. Data for each NES patient case study was collected using a semi-structured interview based on the McGill Illness Narrative Interview schedule (MINI) (Groleau, Young et al. 2006). Due to the rich character of qualitative data, descriptions that locate the meaning that people place on the events, structures and processes in their lives may reveal the underlying complexities of their experience (Miles and Huberman 1994). Each case study entails a detailed description that will offer insight into the illness experience, illness narratives, explanatory models and treatment experience of the individual patient. A within-case thematic-content analysis will generate emergent themes from the data collected from each participant (Creswell 2007). A cross-case analysis of the multiple cases will examine interrelated themes that emerge and reveal the commonalities and divergences in the experience of the NES patients. Since existing theories cannot be applied effectively to NES patients, the challenge of improving our understanding of the patients' perspective of illness may be addressed using qualitative research methods (Creswell 2003). The goal of this study is to better understand the experience of individual NES patients and how they make sense of this experience, hence the use of qualitative case study methodology is well suited to this study. As such, this study incorporated a multiple-case design that focused on cross-case analysis (Yin 2003). Within each case there were sub-units of analysis to examine different forms of reasoning, treatment experience and illness impact. Due to the heterogeneous population, the cases were selected with theoretical replication in mind. Each case study was analysed individually before commencing the cross-case analysis.

Patient Population:

The patients were recruited from the Montreal Neurological Institute and the Jewish General Hospital. After a diagnosis of psychogenic non-epileptic seizures was confirmed by a neurologist the patient was informed of the study. After initial contact and confirmation the patient satisfied study requirements, an interview was arranged. Informed consent was obtained from each participant at the outset of the interview. Nine patients (five men and four women) were referred to the study, of which seven agreed to participate. No explanation was given for the two that refused. One patient was excluded from the study as his diagnosis could not be confirmed after he refused follow-up consultation. During the course of an interview it became clear that a second patient that suffered from co-morbid epilepsy had only rare NES events, and was excluded from the analysis. The final study sample comprised 5 patients that suffered from NES with no current co-morbid epilepsy. All patients were Canadian citizens or permanent residents; however, two were born out of the country. One was born in Europe and the other in South Asia. All patients were fluent in either English or French. Two of the interviews were conducted in French while the rest were conducted in English. The interviewer was fluent in both French and English. All patients were over 18 years of age and did not suffer from any severe cognitive deficits. The study participants comprised 2 men and 3 women in their thirties and fifties.

This study is designed to examine a clinical population of NES patients to better understand their illness and treatment experience. The goal of the study is to illuminate the experience of this patient population, rather than to produce social theory or identify cultural patterns. Hence, case study design is well-suited for this purpose. Although, there is no pre-defined number of cases deemed suitable in a multiple case study, a typical sample size is generally considered to be four or five cases (Creswell 2007). Due to the in-depth nature of the interview process and purpose of the study, the sample size is consistent with this methodology.

Data Collection:

Data for this study was generated with the use of a semi-structured interview, specifically an adapted version of the McGill Illness Narrative Interview schedule (MINI) (see Appendix 1). The MINI is designed to elicit detailed patient narratives that allow patients to explore their illness and treatment experience (Groleau, Young et al. 2006). The interview schedule specifically explores three distinct forms of reasoning and representations that patients may use when exploring their illness experience. These three forms of reasoning comprise metonymic, causal and analogical reasoning. The first part of the interview allows the participants to explore their illness narratives, during which their experiences are linked metonymically to their illness. In this case, metonymical reasoning corresponds to the intuitive associations that the participant draws between their current illness experience and previous life events and experiences, without however, explicitly attributing illness onset to any causal relationship with these past events (Groleau, Young et al. 2006). This temporal sequencing of events may be referred to as a *chain-complex*. The next part of the interview explores the participant's use of explanatory models (causal reasoning), whereby the participant identifies events or experiences that they attribute to their illness or symptom onset. The participants explore analogical reasoning by identifying prototypical illness experiences in themselves or others that they believe are similar to their current illness experience. Prototypical experiences may be used to gain understanding of current illness experience. For example, "*If I know an epileptic takes medication for seizures, then that must mean I need medication for my seizures*". The MINI likewise gives the patient the opportunity to explore their treatment seeking experience, treatment expectations and the impact of the illness has had on their life. The detailed histories that are produced from the interview may be explored in depth to examine the mechanisms the participants use to give meaning to their experience, along with the impact the illness has had on their lives. The duration of the interviews ranged between 1 and 2.5 hours.

Data Analysis:

Thematic-content analysis was used to examine each of the case study interviews. Thematic-content analysis may be used to search for emerging themes that may describe important relationships within the data. (Daly 1996). This type of analysis may then be utilized to identify meanings that may be valid across cases (Creswell 2007). This analysis technique is often utilized in clinical health research and is well suited to our interview method. Through the use of repeated reading of the data emergent themes can gradually be identified (Rice and Ezzy 1999). In this study the thematic codes were extracted using a data-driven inductive approach. In addition to this, a deductive approach was used incorporating the conceptual codes that were defined *a priori* on the basis of the structure and questions outlined in the MINI (Illness Narratives, Explanatory Models, Prototypes, Treatment Experience and Illness Impact). All interviews were audio-taped and transcribed verbatim by the interviewer, Philip Dickinson. Each transcript was re-read again by the interviewer, while listening to the interview, to ensure accuracy and to associate the tenor of the interview at each time point with the written transcript. The interviews were then transferred to a computer program for coding qualitative studies (ATLAST.ti 6.1, 2010). Each case interview was then re-read and coded. These codes were interpreted for overlapping themes and condensed into the most relevant thematic categories of each case interview. Each case interview was analysed again to note passages that documented the conceptual codes established deductively from the interview schedule. The interaction of these themes was examined in order to recognize the over-arching themes that were relevant to each case interview. Passages were then identified within the interviews that could highlight and convey these themes to the reader. After extracting detailed descriptions and emergent themes from each case interview, a cross-case analysis was undertaken. This final analysis allowed over-arching themes from the sample of NES patients to emerge. These convergent and divergent cross-case themes were then analysed and interpreted relative to the individual cases, as well as to the whole sample of multiple cases.

Ethics:

This study was conducted in accordance with the ethical principles stated in the McGill University Faculty of Medicine *Policies and Procedures for Research Involving Human Subjects*. Ethics approval was received from the McGill University Faculty of Medicine Institutional Review Board on August 11, 2008. The study involved patients diagnosed with non-epileptic seizures completing an in-depth interview. Consent to permit access to the patient's medical charts, to confirm the diagnosis and eligibility for the study was granted by each participant. Due to the sensitive nature of the interview it was possible that participants could have experienced some distress or discomfort. Before each interview the participant was informed of their rights, including the right to withdraw and the right not to answer questions at any time. Participants were also provided with a list of resources to contact in the event of subsequent distress or discomfort. These resources included the Info-Santé emergency hotline, the study supervisor who is a psychiatrist at the Jewish General Hospital, their physician and the emergency room of the nearest hospital. The consent form likewise provided contact information for the ombudsperson and the principal investigator. All interviews took place at a hospital, such that in the event of an emergency, the patient could have quick and direct access to medical services.

IV. RESULTS

As is commonly found in NES, the population in this study was quite heterogeneous. Of the five case participants, three were women and two were men. Both of the men and two of the women were between 30 and 39 years of age. The other woman was over 50 years of old. All the participants in their thirties were living with a significant partner. The woman in her fifties was divorced and living with and caring for her ill father and sister. Both men had a fiancée and were planning marriage, while one of the men was also in the process of a divorce. The other two women were married, or equivalently had a common-law spouse. The woman in her fifties had one child. The other participants did not have children. All of the women were employed but on extended sick-leave at the time of the interview. One of the women had a low income job working with developmentally delayed individuals. She was struggling to receive coverage from the provincial work insurance board at the time of the interview. The second woman had an office job and was in school. The third woman, employed in the technology industry, was in a higher income bracket and maintained a position of responsibility. One of the men was employed at the time of the interview but was taking many sick days. He had a minimum wage job that did not pay him benefits for his missed days. The other participant was unemployed at the time of the interview but was planning on entering his family's business. All of the participants were suffering from at least one co-morbid illness that included migraines, psoriasis, anxiety, depression and cancer.

In each case, analysis of the participant interview produced many themes relevant to the participant's illness and treatment experience. A breakdown of the illness experience of each participant case with regards to the conceptual codes is listed in *TABLE 1*. A breakdown of the treatment experience of each case is listed in *TABLE 2*. The emergent cross-case thematic codes are listed in *TABLE 3*. The results have been divided into three sections. The first section, *Illness Experience*, is divided into sub-sections that comprise the convergent and divergent cross-case themes that emerged from the participant accounts, along with their *Illness Narratives, Prototypes,* and *Explanatory Models*. The second section lists the results that emerged pertaining to the participants' *Treatment Experience*. The final section describes the emerging results from the participants' accounts of the *Impact on Life* the illness has had on them.

Illness Experience

In the following accounts, each of the case study participants has been given a fictitious name. In each Table the fictitious name is listed below the case number.

i. Illness Narratives

Highly stressful events characterized the chain of events that the participants felt may have had a relationship to the onset of NES (see Appendix 1). In each case these narratives revolved around highly stressful events that produced overwhelming physical, mental, emotional, or spiritual distress for the participant. These experiences seemed to be characterized by a fundamental *loss of control* that the participant may have perceived over their environment or self. The inability to communicate that resulted from an internal or external conflict often appeared to lead to further distress for the participant. Refer to *TABLE 1*

Chain-Complexes

In the case of Allan, he experienced many stressful life circumstances prior to the onset of his seizures. He described living with his fiancée and how her parents' first visit to their home had created an extremely stressful environment for him. He recounted that the parents were meeting him on *his turf* and described continued incursions of his boundaries by his fiancée's parents that he was incapable of addressing. He also reported feeling that he was always being judged and that his worth within the family unit was placed into question while he was unemployed.

> Allan: *"When her parents are there, or when somebody is trying to do something with me or to me, uhh, that I feel like I'm being picked on or something along those lines, that's what brings me the most stress. Is trying not to, disappoint people. Not trying to, it just, it's just building up, where it builds up to a point where everybody is counting on me to do something, and I can't. Don't, don't make me, it's, I can't."*

Shortly thereafter he began a new job where he described witnessing his superior severely assault a co-worker. He reported that the police were called to the scene and he was instructed, by the manager to lie about what he had seen. The seizures began after this event.

> Allan: *"He had broke his, his, his eye socket and broke his jaw in three places and right at the, the morning of that, my boss came to me and said, uhm, 'It was an accident, the kid slipped on the floor and it was a complete accident. That's what you're gonna tell the cops.' Like I'm not lying for nobody, I'm gonna tell them what I saw. 'You're not gonna say a word. We're gonna tell the cops that you didn't see anything. And just say you didn't see anything.' I'm like, I'm not gonna lie for, for nobody. He says, 'Well you just go home and think about it and you come work tomorrow.' I think it was that night, because I had a day off or two days off after that. And it wa-, I think it was that night or the night after that I had, had my attack."*

Other stressors he described included guilt he felt about leaving his grandparents to live with his fiancée. He had grown up with his grandparents for many years and he described returning to live with them to support them through difficult times. Later in the interview he contradicted his motivation for returning to live with them, by stating he moved back to his grandparents as a result of losing his job, girlfriend, apartment and driver's licence, and not due to their needs or demands.

In the case of Beatrice, she described a physical aggression at her workplace in which a woman that was developmentally delayed, and much larger and stronger than her grabbed and restrained her against her will. She was unable to release herself from the grip of the woman and subsequently suffered injuries from the assault that prevented her from working. At the time of the interview, almost a year after the assault, she was still receiving treatment for the injuries. She asserted that the assault that preceded the onset of her seizures was in fact similar to an attack she had experienced as a child. The recent assault preceded the onset of her seizures. On the night of seizure onset she described herself as being extremely tired and exhausted, and subsequently initially believed the seizures to be a result of fatigue.

In the case of Catherine, she described numerous stressful events that occurred in the year leading up to the seizures that included the self-described *gruesome* death of her grandmother in a car accident. This loss appeared to affect her at a deep spiritual level, as indicated in these comments:

> Catherine: *"I'm kind of a bit of a realist, I think about that. But when, uh, my granny passed away in such a gruesome manner in an accident. For some reason I kind of... probably I was more spiritual religious than I thought I was. I lost that kind of... you know... thing."*

She also discussed very difficult times in her relationship with her husband, caring for her brother in the United States, and an extremely demanding schedule at her workplace. In addition she described a roller coaster ride that she took about a month before seizure onset that left her feeling very discombobulated, with extreme fatigue, lethargy, nausea and emotion. After arriving home she described crying for at least an hour, and having continued feelings of odd sensations for days following the ride. Only later in the interview did she mention off-hand that her other grandmother died the month her recent seizures began. She did not seem as affected by this death, since as she described, this grandmother had lived to an old age and the death was expected.

In the case of Dominique, she reported that she had been battling with her ex-husband for custody of their son for the last 15 years. She described her son as developmentally delayed. She described the three years before the final court ruling as the most stressful. She accused her ex-husband of abducting her son from school and hiding him in order to give the courts the perception that he had fled her home of his own accord. She described feeling completely destabilized by these actions and powerless to change the outcome when the courts did not side with her. Her seizures began the next day. She spent a week in the hospital for testing, but all tests were negative and she was told her seizures were non-epileptic in nature. She reported her seizures returned later that year when her father was hospitalized in intensive care, but only after it became clear that he would survive and she could relieve herself from the responsibility of constantly being there. When she arrived home she began to suffer the seizures. She again was tested for a week, but all tests were negative for epilepsy and she was sent home. She suffered occasional seizures until 4 months before the interview when her seizures began to increase in frequency. Shortly before this increase she described how she had tried to contact her son on his birthday. Since her birthday is exactly one day following his, she indicated that it carried special significance for her. She was unable to contact him, or even find out where he was, as she was denied knowledge of his whereabouts by her ex-husband's family. She also reported conflict with a co-worker that had caused her a good deal of stress.

In the case of Edward, he reported being diagnosed with cancer of the esophogus at about the same time he split with his wife of 9 years. As he was recovering from the cancer operation he also reported having gastrointestinal bleeding, which turned out to be an ulcer. His seizures began about this time. After a few months his seizures abated. Again after a few months he had an unexpected encounter and significant conflict with his ex-wife and his seizures resumed again.

> Edward: *"I don't know whether it's coincidence or not, but, uhm… just prior, not long before uhm… they started happening again, uhm… I'd uhm…had a bit of a… run in with… I can't call her my ex-wife, because we're not divorced yet, but… my ex-partner, whatever you want to say. And uhm… there's a lot going on with lawyers, and all this rubbish. Stress again."*

Seizure Event

The common cross-case theme that emerged from the participants' description of their seizure events was an inability to communicate even while fully conscious of their environment. The theme of fatigue, overwhelming emotion and stress preceding seizure was common. Following a seizure event fatigue and an occasional sense of release were detailed. The participants' seizure characteristics are listed in *TABLE 4***.**

The participants described different feelings that warned them of the oncoming seizure. In two of the five cases (Catherine and Edward) reported occasionally having seizures that came with no warning. Feelings of anxiety, being overwhelmed, extremely tired or nervous were common themes that preceded a seizure event. Beatrice described the anxiety she felt preceding seizures that sometimes included a fear of death. This feeling overwhelmed her and carried beyond the seizure experience.

> Beatrice : *« J'ai même eu peur de mourir, oui, puis même je voulais partir ... Oui à cause des crises, j'avais peur de mourir, mettons que je savais plus ce que j'avais alors, et je disais à tout le monde autour de moi : je vous aime. Je savais pas qu'est-ce qu'il allait se passer. »*

All the participants described seizures where they retained consciousness, but three of the participants (Catherine, Dominique, Edward) also experienced a loss of consciousness for short (less than one minute) periods of time. During seizures with retained consciousness, the predominant feature the participants described was an awareness of their surroundings, but an inability to communicate. Allan described his perceived ability to speak during his first seizure, not realizing that he was completely incomprehensible to those around him. He reported that eventually his fiancée realized that he believed he was coherent, and asked whether he thought they could understand him. Once his fiancée communicated to him that he was not making sense he was able to communicate with her to some degree by blinking his eyes. This condition lasted for 24 hours during this first event. Aside from this example the other participants did not describe any ability to communicate, verbally or otherwise, during their seizures. Catherine describes this predicament in the following quote:

> Catherine: "*If I'm gripped with that feeling I will not be able to respond or do anything, in the sense like if somebody asked me a question. I know they're asking me a question, I know the answer to the question, I know who's asking, I know everything around me,*

> *it's just that I cannot tell them. I cannot open my mouth. I cannot respond, in any way. If somebody, if I'm gripped with the feeling and somebody… uh… wanna shake my hand. I won't be able to give it. So it was like that. It was, I couldn't speak, I couldn't move, I would just be there*."

Edward described how his body began shaking all over, but also how he would be able to direct himself to a chair to sit down. He reported his head would begin to feel funny, and then he would have a sensation of a *hot, raging head* and then begin shaking. As the seizures continued he claimed the convulsions became stronger and eventually he would begin to blackout during the events.

Following the seizures all the participants described feeling an extreme fatigue afterwards and felt it necessary to sleep or rest for a long period of time. Three of the five participants (Allan, Catherine and Dominique) described a sense of peacefulness and sometimes euphoria after recovering from the seizures.

> Allan: *"I can deal with stress up to a certain point ... and then it gets… the glass gets too full and it overflows. that's what I feel like it's, it is doing, where I'm overflowing all the time and as, as I'm overflowing it, it just getting to a point where it's getting too much and my body resets to where I have the seizure. I get that eur- euphoric sen- sensation. I will hurt for a couple hours. And then I don't, it will take time for my speech to come back. Once my speech comes back I'm sort, I sort of feel better."*

The participant accounts of the seizures events indicated they almost always seemed to occur in the presence of a significant relation or caregiver, or in a controlled environment. Allan described all of his seizures occurring in the presence of his fiancée or another family member. Although he feared that it may occur at his workplace he did not describe any such events. Beatrice indicated she once had an event at the physiotherapists and once feared she would have an event at a hypnotism show she attended, but left as a result. Otherwise, all her events occurred at home. Catherine described events outside of the home, sometimes while travelling, but in every case she reported her husband was with her. Edward also described some events outside of the home, but he always described a family member was always in his presence.

In the case of Dominique, unlike the other study participants, she was the primary caregiver for her ill father and sister and did not receive support in the home. She did not describe any seizures that occurred in the presence of her family members. Rather she described having seizures alone in her room or alone in public places. When her seizures occurred in a public place she described losing consciousness and only awaking once she arrived at the hospital, sometimes as long as 24 hours later. After her recent hospitalization Dominique reported a striking augmentation in seizure frequency and intensity shortly after admission.

> *« Mais je vous dire que des premiers semaines là, il était très 'raide', je pouvais même pas rester assis là, je comprends pas. Même assis dans mon lit je perdais connaissance je faisais des crises. O, c'était terrible. Terrible, terrible. »*

The impact the seizure events had on the way others treated the participants and the way they treated themselves will be discussed further in the section *Impact on Life*.

Emergent Themes

A number of recurrent themes emerged during each of the participants' illness narratives. These included self-described nervous or passive personality attributes, migraines and anxiety as a co-morbid symptom during seizure expression, potentially traumatic childhood events, head injury, previously witnessing epileptic seizures, seemingly positive events around the time of seizure onset, as well as highly stressful events that directly preceded illness onset such as death, cancer surgery, and family and work conflict that included violence and legal proceedings (divorce, child custody). Refer to *TABLE 3*.

a. Self-Described Personality Attributes

Each of the participants characterized themselves with certain personality traits throughout the interview. All three of the women described themselves as prepared to assert themselves in the face of conflict at least once during the interview.

> Catherine: *"My mother and I had a very close relationship, have a very close relationship for example and we fight and everything. Even my husband, we have a very close relationship, we fight and we get back together, that kind of thing, and argue, and both of us have. All of us in my family, all of us are dominant personalities, so there's always clashes."*

In spite of this each of the women described situations in which they made significant sacrifices for others in their social context. In the case of Beatrice, she described herself as having a low self-esteem and always looking after other peoples needs. After being instructed by her common-law spouse to take time for herself, she realized one of the benefits of the illness was in fact the opportunity to finally care for own needs. In the case of Catherine, she recounted travelling to care for her brother, while many aspects of her own life were overwhelming her. As well, although she described herself as a dominant personality, Catherine often acquiesced to her husbands concerns regarding her illness in order to keep him at ease. For example, after initially being diagnosed with epilepsy and remaining seizure free for 9 years her neurologist suggested tapering off the AED treatment. Due to her husband's concerns she agreed to taper off the drugs over a period of 3 years, as opposed to the 3 months suggested by her neurologist. In the case of Dominique, she was the primary care-giver for both her ill father and sister, both of whom lived with her. She described how her illness caused both her father and sister tremendous stress, and she in fact needed to support them to help them deal with their stress regarding her illness, instead of the other way around.

Both men in contrast described a more passive and less communicative approach to conflict.

> Allan: *"I keep everything inside. I'm a very, I'm very much internal. I keep everything to me. I don't externally verbalize being upset, until I reach my boiling point."*

Both described situations in which they had difficulty resolving interpersonal conflict. In the case of Allan, he described numerous encounters with his fiancée's family members during which he felt they were judging him or not respecting his personal space. He went through periods of unemployment and during these times he described his perception that his fiancée's parents thought him unworthy of their daughter as a result. Similarly, he recounted being angered by how his fiancée's sister had left all her belongings in their home for many years, yet never communicated his dissatisfaction to her. In the case of Edward, he also described himself as a nervous person.

> Edward: *"I've have had, I've got psoriasis, which I do, could still be a, related to, .. that flairs up when I'm nervous or if I feel … uh…uh… I do, I am a little bit of a nervous person to some degree."*

In each case the participants acknowledged feeling overwhelmed by stressful events in their life and considered they may lack the tools to manage the stress accordingly.

b. Co-morbidities

Each of the participants described co-morbidities that they suffered in addition to the seizures (see *TABLE 3*). Allan, Beatrice and Catherine all described suffering from migraines independently, but also in conjunction with the seizures. Allan indicated that his seizures were always preceded by a migraine, and in two out of every three times he had a migraine he reported that it would evolve into seizures. Beatrice listed many feelings before a seizure event including intense headaches or migraines, and anxiety. Catherine indicated that she suffers from migraines immediately following most seizures. She also indicated that her psoriasis usually acted up around the same time her seizure frequency increased, which she noted appeared to be timed in relation to her menses. In addition to Beatrice, Dominique also suffered anxiety, and noted it in relation to her seizures. She indicated she was suffering from depression as well. As with Catherine, Edward suffered from psoriasis but only connected it to nervousness and not directly to his seizures. He had also suffered from cancer of the esophogus and while recovering from his surgery he began to suffer from an ulcer, and around the same time his seizures began.

c. Childhood Events

In the case of Allan, he noted that his parents divorced when he was 7 years old and that he eventually was raised by his grandparents. He also indicated that he was born two months premature and had spent a great deal of time in the hospital after his birth. In the case of Beatrice, she described a physical assault perpetrated by her employer when she was 10 years of age. She reported her job, arranging clothes in a clothing store, earned her $10 a day. Her employer was a friend of her father and one day he grabbed her by her wrists and would not let go in spite of her pleas to be released. She explained that she did not report the incident to her parents because she feared losing her job. In the case of Edward, he simply described his childhood as very rough, where "*horrible*" things happened to him that to this day still prevented him from sleeping at night. The other two participants did not address any issues related to childhood experiences.

d. Head Injury

Although previous head injury was not a specific question in the interview, three of the five participants spontaneously reported some type of head trauma from their childhood. Allan described numerous occasions that he banged his head while playing.

> Allan: *"When I was kid, I was a, your typical boy. I was always ... getting into sc…sc…sc…scraping my knee, scraping everywhere. Uhm… but I want, I want to be more of a ... stuntman. Like I was watching all of these ... you know S… St… Starsky and Hutch and you know all of these TV shows and wanting to do the same stunts they're doing and I would get a lot of uhm… concussions when I was a kid, 'cause I would always fall on my head. And… uh… to the point where you know when you're having a concussion when you're all, your arms go numb and you get that you're knocked out type of thing. Uhm… that was early on when I was a kid."*

Catherine recounted a recent roller coaster ride during which she described her head being knocked violently around, as well as a head injury she suffered as a child that she attributed to her migraines.

> Catherine: *"I met with an accident when I was fourteen years old, and I had a head injury. Uh…and uh… and because of that I have really severe migraines."*

Edward also spoke of an injury to his head that he suffered in his early twenties.

> Edward: *"I got, I was gotten knocked off a bike, by a car… bump. But it was only a little, it was on a roundabout, so at least it wasn't going that fast, the car wasn't going that fast, but it, I hurt my back and I hurt my head, but it, I was okay, you know. I didn't crack my skull or anything like that."*

e. Witnessing Epilepsy

Four of the five participants reported previously witnessing the seizures of at least one significant family member (mother, brother) or their significant partner (see *TABLE 3*). Only Beatrice did not report observing seizure events in others. She did, however, report that she herself had suffered from epileptic seizures until the age of 5 years.

f. Positive Events

At or around the time of seizure onset three of the five participants described positive events in their life. Allan, after perceiving continued judgement from his fiancée's parents found employment. This occurred shortly before seizure onset. He also described the happiness he felt with regards to his current relationship and their future together. This was more pronounced when he compared it to his past relationships. Catherine recounted a promotion she had received from her workplace, as a result of successfully completing a major project. Her promotion also included a raise and time off to compensate for the extra hours she had worked to complete the project. This occurred shortly before her seizure onset. In the case of Edward, he reported the excitement he felt at the news of his fiancée's pregnancy and the joy he felt in this relationship.

> Edward: *"Like in general my life has just taken on a whole new direction. Like it really has, it's flipped on its head. And there's so many good things coming up in the future. It's all very positive things. All really good, good happy things that are going to happen. So, my fu(ture), my outlook on life is better than it's ever*

> *been in my whole life, I'd say. So, that side of it, is definitely not an issue, this is, maybe a slight blight on it, because it's going on, but I guess if it wasn't for the fact that I had that, I'd probably be a lot more down on it, but because I'm looking at the positive things."*

The other participants did not report any positive events.

Typical Narrative Description

The study participants maintain heterogeneous features yet many characteristics standout that may allow a common narrative description. In general the NES population is quite heterogeneous so there may be other variations on this scenario.

Some of the common features described by the participants of this study include a mild head trauma in childhood along with a stressful childhood event that may have resulted in a sense of loss of control. The participants described passivity in the face of others and co-morbid illness of anxiety or migraine was often expressed in relation to seizure events. Further the study participants recounted family members that suffered from epilepsy. They also reported positive events before seizure onset. The participants noted a highly stressful event that usually occurred very close to seizure onset, and may have been related to a past event. The participants described seizures that would tend to occur in the presence of those that could offer them the most support.

ii. Prototypes

In order to further understand the analogical reasoning the participants used to understand their illness, the participants were asked to compare their current illness experience with prototypical illness experiences in themselves or others. Please refer *to TABLE 1*.

All the participants, except Beatrice had previously witnessed epileptic events in others, yet the participants were often at a loss to select a prototypical illness or experience. This appeared to result in part from the fact that none of the participants expressed any previous knowledge of the illness whatsoever, which also led to varying degrees of confusion regarding their diagnosis. The participants were unaware of ever having heard, seen or read about non-epileptic seizures. Furthermore, two of the five participants (Catherine and Edward) were not fully convinced they did not have epilepsy and a third (Allan) did not perceive the explanation that he had received for his illness to be sufficient.

> Allan: *"They just pretty much write you off and say, 'You know you don't have epilepsy, go see somebody else' and don't tell you anything, don't give you any suggestions, don't say anything for you. It's very difficult, because they don't, nobody realizes what it's like to be like this, where you know it's not epilepsy, but what is it?"*

Due to the uncertainty and confusion of having been informed they did not have epilepsy, the participants appeared hesitant to identify epilepsy as a prototypical illness experience in themselves or others. When a comparison with epilepsy was prompted, the participants that had not identified another prototype used medical concepts to describe the differences between NES and epilepsy.

> Allan: *"I'm not sure how epilepsy exactly works, but I know that there's signals that are sent from the brain to, to walk to breathe, to talk, to do whatever, and in epilepsy what happens is they all fire at the same time, so that's what the epil…what the epi... seizure is. Mine are headaches that will lead into a seizure."*

Implicitly, however, each participant, except for one, used epilepsy as a prototypical illness for understanding and comparison throughout the discussion, yet when asked did not state it explicitly. In the above example the participant makes no differentiation except for onset. Later, Allan identifies his sense of awareness as a distinguishing feature of NES from epilepsy.

> Allan: "*The major differences between epileptic seizures that I've experienced with my brother, my friend that.., and this woman, was the fact that I can respond to people. Whereas, opposed to these other people, I can you know... They, they don't see me. Like it's... uhh...I... they know that I'm there, but they wake up freaked up, sort of like okay what happened to me. Where, sometimes I'll get that same experience but I'll know that I'll have had another seizure. uhmm... like I'll realize after what had happened to me, but people who have epilepsy don't realize.*"

The participants that implicitly used epilepsy as a prototypical illness for NES tended to guide their reasoning regarding treatment expectations and the constraints they placed on their lives within this analogical framework. This continued even after the participants communicated differences between epilepsy and NES semiology, and acknowledged a number of stressful events that may have influenced the onset of their symptoms that could also differentiate NES from epilepsy. For example, although Dominique was convinced of the direct relationship between the stressful events in her life and the onset of her NES, she expressed the opinion that seizure control would be a matter of drug management as would be expected in epilepsy treatment.

> Dominique : *« La semaine dernière ils l'ont encore réaugmenté. Fait que,… faut,… il fallait trouver le bon dosage. Puis je crois*

> *qu'on vient de le trouver, là, cette fin de semaine. »*

This was not unique to Dominique, as all participants except for Beatrice, would often return to drug management as a potential solution to resolving their symptoms.

The participants' apparent implicit use of epilepsy as an illness prototype may also have had an impact on the significant constraints they placed on their life. These constraints will be discussed further in the section *Impact on Life*, however, it is noteworthy that Beatrice placed fewer constraints on her life and continued to socialize with friends, whereas the others did not. Beatrice was differentiated from the other participants by the fact that she explicitly chose anxiety attacks *(crise d'angoisse)* as the illness that most closely resembled her experience. This choice of anxiety attacks as a prototypical illness experience may have been guided in part by the fact that she described her seizures as often preceded by anxiety and fear.

Of note, the participants that implicitly utilized epilepsy as a prototypical illness had all witnessed a family member or close friend that suffered from seizures, whereas Beatrice had reported suffering from epilepsy as a child until the age of five, but never having witnessed seizures in others.

iii. Explanatory Models

The illness narratives provided the participants an opportunity to discuss their illness experience and list events that preceded the onset of their illness. As noted in the *Illness Narratives* section the chain of events that the participants associated with illness onset were dominated by stressful experiences that included potentially traumatic childhood events, head injury, death, cancer surgery, family and work conflict, violence and legal proceedings. The participant's capacity or willingness to identify an explanatory model, or particular event that led to illness onset seemed to be independent of the existence of plausible explanations.

Only two of the participants (Beatrice and Dominique) definitively identified an explanatory model, in spite of the existence of clear self-defined possibilities from all of the participants. Beatrice identified her physical assault at her workplace and its relationship to the similar physical assault she suffered as a child as the explanatory model for her illness.

> Beatrice : *« Selon moi ça ce relier a,…mais, justement mon agression, mon agression physique, parce que j'ai vécue quelque chose de similaire quand j'étais jeune.* »

Dominique defined the loss of her ability to be with and communicate with her son that resulted from the court case and the actions of her ex-husband, as the primary explanatory model for her illness. She also recognized seizure onset as a direct result of other stressful events, such as the hospitalization of her father and the conflict with a co-worker. Neither of these participants' demonstrated any doubt about their reasoning regarding illness onset.

Although Allan noted the onset of seizures directly after witnessing the assault at his workplace he did not seem to attribute any particular explanation to seizure onset. He understood the seizures as a way of releasing his stress and resetting his body, more than as a result of any one particular event. Edward was hesitant to even consider stressful events as a factor in his illness onset, even though he readily outlined numerous plausible explanations including his divorce from his wife of 9 years. Catherine appeared to be at a loss to offer an explanation for her illness and deferred any interpretation to the perceived medical authority of the treating physicians. Her confusion may have arisen in part from the fact she had only recently been diagnosed with NES. She had reported that she suffered from epilepsy the previous 9 years (see *TABLE 2*).

Both participants (Beatrice and Dominique) that explicitly applied an explanatory model to account for their illness onset were receptive to psychotherapeutic interventions, as well as any other interventions that may have been offered. As described previously both the participants had a self-described assertive communication style that was also demonstrated in the face of adversity during their treatment experience.

> Dominique: *« À l'urgence ils ont pas fait de traitement. Ils voulaient même me retourner là, à la maison. Puis c'est moi qui y ai tenu mordicus. 'J'ai quelque chose, je reste à l'hôpital. Si vous ne trouvez rien, envoyez-moi en neurologie, envoyez-moi n'importe où, mais je reste à l'hôpital.' Et il a fallu que je me batte. Excusez, là... Il fallait réellement là que je tienne mon bout. Puis c'est comme ça qu'a là… se pu faire la transfère ici. »*

Had Dominique not demanded this attention she would have been returned home as with her previous treatment experiences. In contrast to this, Allan who does not identify a definitive explanatory model indicated a sense of repudiation in the face of his diagnosis and maintained a strong need for validation of his illness experience before a psychological approach to therapy could be deemed acceptable.

> Allan: *"It's more important and vital that doctors here and in other hospitals be vigilant in saying it's not fake. These problems are real … We're just as important as a person having epilepsy right next to us. We should be dealt with, with respect. That's the one thing that above everything else, deal with us with dignity and respect, because the moment that you just write us off, is the more depressed we get and the more desperate we get to get results. so, we, like I said, if they want me to go see a psychologist, I'll go see*

> *a psychologist, if they want me to do ten MRIs and EEGs I'll do that all of that with smile on my face, but as long as you tell me why I'm having these. Then I'll be more than happy, I'll be happy as a clam. But don't tell me, and I'll be like, 'Why are you wasting my time?'"*

Other factors that may have influenced the participant's treatment experience and receptiveness to psychological explanations were gender, language of use and communication style. Both participants that utilized an explanatory model had a self-described better overall treatment experience. Both were female, French speaking and described encounters in which they asserted their treatment expectations during their treatment experience. Both participants that did not use an explanatory model and described at least one acrimonious treatment experience were male, English speaking and described themselves as less assertive during their treatment experience. The final participant was impartial during her treatment experience and listed no treatment expectations. She was female, English speaking and described herself as relatively assertive, but in her descriptions she was often acquiescent to perceived authority.

Treatment Experience

The treatment seeking experience of each of the participants varied greatly. In *TABLE 2* a detailed account of each of the participants' treatment experience is listed.

i. Diagnosis

The diagnosis and treatment of the participants is likely complicated by a host of co-morbid conditions. Please refer to *TABLE 3* for a list of co-morbidities. The delay to a definitive diagnosis ranged from weeks to 9 years, with an average of

2.5 years. The participants reported varying degrees of frustration and confusion resulting from the delay for a definitive diagnosis, the demands of the testing process, as well as receiving what was perceived as an unsatisfactory diagnosis.

Allan reported first seeking treatment 2.5 years before the interview. He reported his first experience as positive, as he felt the doctors had taken the time to examine him and listen to him. He reported being told that his seizures were not epileptic in origin. He then described how his scheduled follow-ups were repeatedly postponed and eventually he reported giving up. He recounted that in spite of no longer seeking treatment that he continued to suffer intermittent seizures.

> Allan: *"I did call them to try to make appointments, but all the appointments I would make, they would call back and try to reschedule them. But at that point I said, I haven't had an attack in a while, so… you know… until something is wrong, maybe I should… But nothing was done as far as that I ... just sort of wrote it off. But having periodical attacks every couple of weeks."*

When he sought treatment a second time he described his experience unsatisfactorily and felt that he was not treated with respect or taken seriously. He continued to suffer periodical seizures until he sought treatment a third time when he reported the neurologist decided he should be monitored. He described frustration about extensive testing that did not seem to provide him with an answer or solution for his seizures.

Beatrice reported a delay of 6 months before receiving the NES diagnosis. She did not seek treatment immediately, but when the seizures had not stopped after 15 days she went to the hospital. She was referred to a neurologist and according to her due to the fact that as a child she had suffered seizures until the age of 5 she was prescribed *levetiracetam*, an AED treatment. She reported elevated anxiety with regards to the extensive testing.

> Beatrice : *« Ce qui a eu un effet sur les crises c'est qu'on savait pas ce que j'avais. Est-ce que c'est des crises d'épilepsie ou c'est d'autre chose. Fait que, tous ça mis ensemble c'est, c'est un phénomène anxiogène, alors c'a devenu de plus en plus lourd là, à supporter, parce que les médecins font des tests, des analyses, passent des résonance magnétique, des scanners, les tests endormi, des éveillés, et ils voyaient pas grand chose, voyaient juste des lésions, alors ça c'était un phénomène anxiogène. »*

Catherine reported her first seizure 17 years earlier. After experiencing a seizure 8 years later she underwent tests. Although no abnormalities were found during testing, she was treated with *carbamazepine*, an anticonvulsant often used in the treatment of epilepsy. She continued to be prescribed AED treatment for the next 9 years. The seizures returned 5 months before the interview. The intensity and frequency increased after a few months and during the holidays she was hospitalized while suffering dozens of seizures.

> Catherine: *"We had to go to an emergency and during the emergency they gave me uhh… Ativan… a whole bunch of medication apparently to you know sedate me and get the seizures under control, and while I was waking up from all those medication I was going into repetitive seizures. And uh… for me to actually get that medication, that entire medication out of my system, it took me about a week to a week and a half, so, during this time I was having, almost having, every day I used to have seizures."*

The medications she received appeared to have some effect; however, it did not stop her seizures as before. She was diagnosed with NES shortly before the interview and after 17 years of believing that she had been suffering from epilepsy, she was justifiably confused about the diagnosis and her understanding of the events that led up to her renewed seizures. She had been receiving drug therapy until days before the interview.

Dominique first had a seizure in 1987 and after seeking treatment, reported that she was told it was simply stress. She then ignored intermittent seizures over the following years. She only returned to seek treatment when they became more severe about 3 years before the interview. She reported that after a week in the hospital she was once again told it was stress. This process followed the same pattern again 6 months later. Once more she reported ignoring her intermittent seizures until the seizures became severe again. On this occasion she demanded treatment and was hospitalized for the 3 months preceding the interview. She described suffering a significant increase in seizures after admission, and reported suffering seizures simply while sitting in her bed.

Edward reported a delay of 7 months before a diagnosis of NES. He had received treatment in different hospitals and despite reporting that all of his tests came back negative for epilepsy, he described receiving contradictory diagnoses. He remarked at a lack of follow-up when he first sought treatment and eventually gave up as his seizures abated. He sought treatment 3 months later when the seizures returned. He reported that he continued to receive contradictory diagnoses in spite of repeated negative test results for epilepsy.

> Edward: *"They did a, they did a CT-Scan ... uhm… which came back fine, there was no problems whatsoever. Uh… and, then I got sort of conflicting, I got told by the neurologist at the, at the *** said, 'This as far as he's concerned it's epilepsy.' He, he wanted me to go on to medication. But then, I seen somebody else, who*

> *was another neurologist and they didn't think it fitted the pattern. It just didn't seem, there was something just not quite right about the way it was happening that it just didn't seem to be… So, they were, they were, I was starting getting contradiction, uhm…and I was waiting, again."*

At the time of the interview he reported he was still receiving AED treatment as a precautionary measure.

During the diagnostic process all of the participants had received AED treatment, although Allan reported only receiving AED treatment on one occasion during an acute attack at the emergency room. Since most of the interviews took place shortly after diagnosis, only three of the 5 participants had a follow-up psychiatric evaluation.

ii. Treatment

Although AED treatment is not an effective treatment for NES all the participants in this study received AEDs as a treatment. Aside from Catherine, the participants reported that AED treatment was prescribed as a precautionary measure. In Catherine's case she reported the AEDs were prescribed to treat her epilepsy that had been previously diagnosed in spite of negative test results. She had a significant history of epilepsy in her family, including her mother and uncle.

Beatrice reported receiving AED treatment as a precautionary measure as a result of her previous diagnosis of childhood epilepsy. She reported that she did not find the drug helped at all, and in fact she claimed it made her very aggressive. She noted that her seizures diminished after stopping the medication; however, this also coincided with a confirmed NES diagnosis.

> Beatrice: *« Puis-la … ça améliore depuis j'ai arrêté les médicaments. Sauf que moi dans le milieu que je travaille, faut soit sur que je sois correcte. »*

As noted in the *Prototypes* section, psychiatric follow-up was deemed a possibility by all participants; however, Beatrice and Dominique strongly endorsed it, while Allan and Edward were hesitant about accepting a purely psychological explanation for their suffering. Catherine appeared ambivalent and reported being prepared to embark on whatever treatment the doctors deemed necessary. When Beatrice had her first meeting with the psychiatrist she described how the therapist emphasized that she would need to place the onus on the psychotherapeutic process and not on the seizures, or seizure cessation.

> *« Elle m'a demandé de réfléchir, à si vous voulez venir en psychiatrie pour régler vos crises ça va pas dire qui vont se régler. Mais si vous venez en psychiatrie parce que vous voulez être mieux, puis travailler vraiment sur les différentes émotions puis suivre vraiment une psychothérapie ça demande beaucoup d'humilité et je vous demande de réfléchir. Mais si c'est juste le but de guérir vos crises ça va pas dire qui vont guéri vos crises. Si sont guéri tant mieux, c'est un bonus, mais ça veut pas dire qui vont se guérir. Vous allez peut-être rester avec ça. C'est ce qu'elle voulait me dire. Quand on commence à l'enfer, ça veut pas dire on règle l'enfer.* »

During Dominique's stay at the hospital she described being visited regularly by medical students and spoke extremely highly of the medical staff and of the teamwork they had displayed. She felt supported and remarked on how well all the medical team seemed to work together. She expressed her gratefulness to them, as she felt she had gained an understanding of her illness and believed this would allow her to face the seizures on her own and regain her strength.

> *« J'ai que a moment donné, j'ai-, j'aimerais réellement pas ça là, quand je perds connaissance… quand je faisais des convulsions régulièrement là, mais j'avais peur. J'avais peur j'disais qu'est-ce qui m'arrive? Je savais pas ou s'on allait, à ce moment là, oui, ça m'a effrayé, mais aujourd'hui non. Aujourd'hui ils ont bien su d'accord, me faire passer, mes peurs, mes craintes, mes angoisses. L'équipe était toujours là pour répondre à mes questions. »*

Although, according to her, hospitalization was not presented to her as an option, she demanded this type of care and appeared to be improving as a result.

iii. Information

All participants reported no previous knowledge of NES and most found it difficult to find information. Allan and Dominique did not investigate independently and relied on information from the medical professionals. Catherine was advised by her husband not to read about the illness for fear of provoking an attack. Edward found the quantity of information on the internet overwhelming and could not determine how to define his experience relative to the diagnostic criteria he read. He was directed by a neurologist to a specific website for NES patients that he found helpful. He particularly noted how the narratives of other patients' experiences could be helpful.

> Edward: *"I just, read a couple of people's, you know where the, like especially on the non-epileptic type seizures side, where people have, sort of described their little stories or whatever, and, I, I get the impression that a lot of people who just seem to be confused and lost and they just don't know what to do, and I, I can*

> *kind of relate to it to a certain degree, like that's how I felt last year."*

Beatrice received an information sheet from the hospital during her admission. She described it as a good introduction but not sufficient to give her a practical sense of how the illness originates and what can be done. She particularly wanted to know how it was different from anxiety attacks, since that was the illness she used as a prototypical illness to gain understanding of her experience.

iv. Patient Expectations

When given the opportunity to offer their own opinions regarding a potentially beneficial treatment each participant focused on some element of stress management. The majority proposed massage, even though, as Catherine noted, it did not really seem to make a difference. Other options for stress relief that were discussed included techniques, or counselling, for stress management, acupuncture, painting and simply taking time for oneself.

As with Dominique, Beatrice was very proactive in her desire to have psychotherapeutic follow-up, and one of her biggest complaints with regards to her treatment experience was the fact that she had not been offered psychotherapeutic treatment from the outset.

> Beatrice : *« Ma semble que moi, si, si, s'il avait plus complet j'aurais pas attendu de mai à novembre pour savoir je faisais des crises non-épileptiques. Je pense s'arrêtait plus cours. J'aurais pas attendu si longtemps pour m'aurait pas médicamenté par le…de mai à jusqu'à novembre avant de me référer. Elle a me disait tout le temps, elle m'a référé en psych, m'a référer en psych. Mais pourquoi elle n'est pas fait tout de suite. Non, elle était pas*

> *sûre de son jugement. »*

As noted previously, the participants that did not identify an explanatory model for their illness onset were more hesitant to accept psychiatric treatment. Likewise, the participants that utilized epilepsy as a prototypical illness had an underlying expectation of drug treatment.

Impact on Life

Each of the participants described the major impact the illness had on their quality of life. A full description of these impacts is listed in *TABLE 5*. All the participants except for Beatrice tended to isolate themselves and avoid socializing or social situations. None of the participants continued to drive and most commented that their licence had been revoked due to a possible epilepsy diagnosis. This resulted in a significant loss of independence, as each required family members to chauffeur them to their destinations. The participants described avoiding public transport due to the fear of having a seizure in a public place.

> Edward: *"... things like going on the metro and things like that, where it, you're a, you know, I, I would feel very vulnerable, because of this, I mean I would hate to, have anything happen when I was on the metro, you know, I just wouldn't feel safe, not in a safe environment as far as I'm concerned, from wake up and probably have half our possessions missing, but I'll still be on the floor..."*

All participants were impacted by the seizures in their workplace. At the time of the interview only Allan was currently working. He described how he frequently needed to take sick days. The other participants were not working or on extended sick leave. Catherine began to work from home and was on a 2 month sabbatical at the time of the interview. She was unsure of how long it could proceed if no solution for the seizures was forthcoming.

> Catherine: *"I'm just afraid that, what if, what happens to my life, if this doesn't stop, right. I'm not gonna work from home the rest of my life, I'm going to be cooped up in the house .. uh.. he's gonna have to get confidence."*

Catherine describes her concerns regarding the need to work from home and refers to her husband needing to get confidence in her. This response appears to underline the impact the response of family and friends can have on the participants' quality of life. Other family members used similar techniques as the participant to understand their loved one's illness experience, such as illness prototyping (of epilepsy) as implied above. All participants, except for Dominique, described being treated as fragile by their friends or family. Although the participants indicated they appreciated the support they had received, they described the cautious treatment as leaving them feeling limited, while serving as an unpleasant reminder of their illness. Since Dominique is the primary caregiver she described needing to paradoxically support her family members in their fear and lack of understanding of her illness. The overall impact of NES is well described by Dominique when she states:

> Dominique: *« Ca un effet dans tous les sens là présentement. Je peux même pas sortir dehors, seul, parce que je peux perdre connaissance puis faire une crise, puis tomber sur ciment. Je ne peux pas conduire. Je peux pas rien faire, là, je peux même pas traverser la rue, magasin, je ne peux pas travailler, fait que oui, la présentement, c'est, ça touche à tous les niveaux de ma vie. »*

The participants, excluding Beatrice, expressed extreme reservations about leaving their home unaccompanied, if at all. Beatrice on the other hand described one of the greatest sources of support was socializing with her girlfriends.

In spite of these constraints the illness did offer the participants some benefits. Beatrice spoke of the need to slow down and the support her common-law spouse gave her to remind her that it was time she took care of herself instead of others. It gave her an opportunity to pursue some of the pleasures she had never made time for and spend more time with her family. She planned on painting with her father, going for walks and treating herself with massage. Dominique spoke of the break she got from being the primary caregiver and the anxiety she felt at the thought of returning to her home. The time in the hospital was a time for her to relax out of necessity, as she described how much she had slept and how much she had needed it. The benefit of the closeness and caring of the family was expressed by the participants as gratitude for the tremendous support they had been receiving from their partners and families, and as a major source of strength.

V: DISCUSSION

The overarching themes that emerge from this study revolve around the question of a *loss of control*. This loss of control was perceived by the participants in many different ways, but it permeated the participants' narratives of their illness and treatment experiences. In the events that preceded seizure onset, the participants' descriptions comprised losses of autonomy, faith, self-respect, personal security and loved ones. The participants' seizure events appeared to embody their experiences in their physical, and sometimes conscious, selves. Ultimately, the participants' experiences seemed to be manifested in the loss of independence and isolation they experienced as a result of the constraints they placed on their daily lives. The theme of communication appears to be highly integrated with these questions of control. As with the integral loss of control the participants' *inability to communicate* appears to permeate every aspect of the illness experience. This extends from the chain of events leading to illness onset, the seizure event, the search for effective treatment options and their ultimate isolation.

In this discussion, I will examine the results of central importance and their relationship to the themes of a *loss of control* and an *inability to communicate*. These results include the chain complexes the participants described, the impact of the prototypical illness participants selected on their treatment expectations and self-imposed life constraints, the relationship between explanatory models and receptiveness to treatment, the difficulty of diagnosis and communication in treatment, as well as the emerging themes, characteristics and impact on life.

Illness Experience

During the illness narratives the participants described the events or chain of events that led up to the onset of their seizures. These events were characterized by extreme distress that resulted in a fundamental loss of control. This distress was often perpetuated by, or arose from an inability to communicate or assert boundaries. The entirety of the participants' narratives included a complex web of events that may, to varying degrees, have had an impact on illness manifestation. These events also comprise the emerging themes of *personality, childhood events* and *head injury.*

i. Illness Narratives: Chain Complexes

Using Allan as an example the participant described witnessing the distressing beating of a co-employee by his supervisor. He was instructed to lie to the police and not provide details of what he saw. The fact that first onset of his seizures began the next day is noteworthy. He likely felt unable to communicate his distress and act in a manner that he would have deemed appropriate (*tell the police his account of events*). Instead the fear of being physically assaulted and the potential loss of his job likely prevented him from acting. This situation was likely exacerbated by the presence of his fiancée's family for the first time on his self-described, *turf* and the judgement he recounted that they placed on him about his employment status.

This experience typifies reports of NES patients in the literature. Common events that have been referred to that precede NES onset, are stressful events, unresolvable dilemmas and traumatic life events such as death, assault, separation, or job loss (Reuber 2008). This matches the previous example as both an assault and an apparently unresolvable dilemma. Other events that were described by the remaining study participants included assault, death, separation from child and divorce; which all fit this pattern. Furthermore when examining the quantity of life events before illness onset NES patients report more events than either epilepsy or motor conversion patients (Binzer, Stone et al. 2004; Stone, Sharpe et al. 2004). As comparison groups, epilepsy, based on semiology, and motor conversion, based on perceived aetiology are standard for NES. The fact that NES patients report more events than both these groups is quite significant.

These results are consistent with the overarching themes that emerged from this study. In Allan's example he was placed in a dilemma that resulted in his silence.

Participants described events that touched on different aspects of their social, physical, emotional and spiritual worlds. These descriptions often crossed boundaries and touched on different aspects of the self. Catherine initially focused on her loss of faith and spirituality when she recounted the death of her grandmother. As she revealed more of her experience, gradually she touched on the impact it also had on her emotionally and physically as well.

ii. Childhood Events

Although it was discussed to a lesser extent, as the focus of the study was not on childhood experiences, the participants often spontaneously provided accounts of similarly distressing events that occurred in their childhood within the context of their narratives. In our study this included parental divorce and physical abuse.

In the case of Beatrice, she described as a child the assault by her employer and her inability to communicate distress to her parents. This type of childhood trauma along with family dysfunction is very prevalent in NES (Reuber, Howlett et al. 2007). Again, when NES patients are compared with patients suffering other functional neurological disorders a higher prevalence of childhood trauma in NES patients is consistently found (Reuber, Howlett et al. 2007). The multi-factorial model proposed by Reuber to conceptualize NES categorizes childhood trauma as an important *predisposing factor* to NES onset.

That chain of events that Beatrice described included the recent physical assault at her workplace, which she linked to her similar childhood event. The following citation notes the relevance of the interaction between present and past events, for illness onset:

> *"No hysterical symptom is ever caused by a real experience alone. The associative triggering of earlier memories always makes a contribution to the causation of the symptom."* (Kalogjera-Sackellares 2004; Reuber 2008)

This relationship reinforces the observation of a complex chain of events that are perceived as out of control preceding illness onset.

iii. Seizure Event

The expression of seizures in the study population was variable, as is found in the literature (Groppel, Kapitany et al. 2000). A fundamental theme that characterizes the study participants' experience of NES is the loss of bodily control and the inability to communicate during a seizure. This is often experienced while at the same time maintaining a complete awareness of the environment in which the participant was found. As one of the participants described it, she could hear a question, she could know who is asking the question, she could understand the question, but she could not speak or move. She would just be there. She described her sensation as being *gripped* by the feeling. In many ways this may portray an embodied expression of the stressful events that may have led to the illness. The term somatization, is defined by Katon, Ries and Kleinman as an "idiom of distress", in which psychosocial and emotional distress is expressed through physical symptomatology (Katon, Ries et al. 1984). The experience of distress and its manifestation is believed to be culturally mediated (Kirmayer 1989). The seizures, thereby may be perceived and interpreted according to psychiatric theory as both an idiom of distress, as well as an expression of an intrapsychic or interpersonal conflict (Kirmayer and Young 1998).

Prototypes and the Impact on Treatment and Quality of Life:

The majority of the participants appeared to implicitly use epilepsy as a prototype to guide their understanding of NES. The implicit use of epilepsy likely resulted from a differential diagnosis, and general confusion about the illness. The participants were aware of diagnostic differences, as well as possible stress related precipitating events that could differentiate NES from epilepsy, yet their treatment expectations and constraints they placed on their lives appeared to be governed by the meanings they drew from epilepsy as a prototypical illness.

This result is contrasted by Beatrice who associated *anxiety attacks* as a prototypical illness for NES. As a result her expectations for treatment and the limits she placed on her life were markedly different from the other participants. She described impatiently waiting for psychiatric follow-up and professed that she would ideally have started such a treatment from the outset. Similarly, she did not hesitate to go out and socialize with her friends in public places. In fact she depicted the socializing with her friends as the greatest source of support during her struggle with the illness. The positive impact that Beatrice experienced is supported in the literature. It has been reported that patients with many current friendships have better outcomes than those that do not socialize (Ettinger, Dhoon et al. 1999).

The notable difference between Beatrice and the other participants was the fact that she declared that she had not previously witnessed close family members or friends with seizures; rather she herself had suffered epilepsy as a child until the age of 5 years. It is not clear; however, whether her use of a different illness prototype resulted from the lack of an epileptic model, or rather it resulted from her ability to differentiate between her current illness and her experience as a child. Although two of the other participants had reported being diagnosed at one time with epilepsy, neither diagnosis had been confirmed through testing.

Recent research that has focussed on effective communication of the diagnosis of NES concentrates on clearly establishing with the patients that they are not suffering from epilepsy (Hall-Patch, Brown et al. 2009). Subsequently, the impact of predisposing, precipitating and perpetuating factors are discussed and a model using the brain overloading as an example is provided (Hall-Patch, Brown et al. 2009). In the current study the participants appeared to have been similarly instructed to differentiate their illness experience from epilepsy. Although the participants no longer explicitly associated epilepsy as a prototypical example of their illness, they seemed to continue to do so implicitly. This appeared to impact the participants' receptiveness to treatment, as well as the constraints they placed on their lives. This highlights the potential importance of establishing, in collaboration with the patient, an appropriate prototypical illness experience that carries meaning for them. It is not known whether an alternative theoretical model was discussed with the participants during their diagnosis, and if so whether it would carry the impact of a prototypical illness experience that already contains meaning for the participant.

These observations underscore the impact the meaning patients derive from the use of illness prototypes may have on patient attitudes. As a result, it may be of value to go beyond differentiating between epilepsy and NES with the patient, and in fact introduce a prototypical illness or experience that the patient may gradually incorporate in their effort to acquire understanding and meaning for their illness experience.

Explanatory Models, Communication and Treatment Experience

An explanatory model was utilized by participants that felt convinced that a certain event was the cause of their seizures. Although all the participants experienced a number of events that could have been interpreted as a cause of their illness, only two of the five actually definitively attributed a cause to their experience. The interesting result was that both participants that utilized an explanatory model demonstrated a proactive approach to treatment seeking and displayed receptiveness to psychological explanations for their illness. This opened the possibility for different psychotherapeutic treatment options. The participants' explanatory models were characterized by psychosocial explanations. This type of explanation likely influenced their receptivity to psychological treatment options. The other participants reported ambivalence or hesitancy regarding a psychological explanation.

Factors that were introduced in the results that may also have played a role in the positive treatment experience include gender, maternal language and the self-described, and observed, communication style.

The gender of the participant may play a role due to the historical association of NES with women. For a long period NES had been referred to as hysteria and was believed to be exclusively a female illness (Ellenberger 1970). Currently women are estimated to be 3 times more likely to suffer from NES than men (McKenzie, Oto et al. 2010). This along with varying cultural expectations on men and women with regards to emotion may lead to a greater stigma when a man seeks treatment for what has been portrayed as a female illness. In a study from Oto et al., he described how families of men tended not to accept the diagnosis and men tended to attribute their illness to predisposing factors for epilepsy (Oto, Conway et al. 2005). This may explain why the men in this study did not employ an explanatory model with their illness even after describing many distressing life events preceding onset. Similarly, the men may face a greater stigmatization from the medical community. This may underlie the impatient reactions by some medical staff the male participants described.

Unlike the women who identified an explanatory model and spoke French, both men were English speaking. Although French is the official language of Quebec, both men were treated at English speaking hospitals and were treated by English speaking medical staff. It is therefore unlikely that language would have resulted in a negative treatment experience in these cases.

The self-described communication style and actions of the participants may also have played a role in their treatment experience. Both women that were assertive and proactive described a positive treatment experience in spite of the resistance and adversity that they faced. The men, self-described as more passive and less communicative, encountered negative treatment experiences that were left unresolved. Allan expressed this dilemma with great frustration. Catherine described herself as a dominant personality, however, acquiesced to both her husband and her physician even when ambivalent to the treatment options.

It is also unclear whether the assertive communication style of Beatrice and Dominique arose due to their conviction in their explanatory model, or their conviction in their explanatory model arose from an underlying assertive style of communication. These two factors could also be unrelated.

The impact of attributing a definitive explanatory model to NES may also be analyzed within the context of the overarching themes of control and communication. By having a definitive explanatory model, the participants' may counteract the consequences of the illness to some degree. Having some level of understanding or knowledge of their illness could impart a sense of control and offer some comfort or stability. Likewise, by defining a cause, the participants were able to assert their treatment expectations. Simply the process of asserting themselves may have offered a therapeutic benefit. In fact, the more the patient takes a proactive approach the closer the patient may come to creating a power-sharing context. Caron-Flinterman proposes that patient knowledge, when directed in the form of demands and ideas may even positively impact biomedical research (Caron-Flinterman, Broerse et al. 2005).

Overall, this appeared to have an impact on the participants' (Beatrice and Dominique) ability to assert their demands and expectations even when faced with adversity. Following this line of reasoning, the participants that passively relied on answers from the medical establishment or reacted to perceived injustices may in fact be perpetuating an underlying characteristic of their illness experience. Results from the literature suggest this may in fact be the case. The NES patients that utilize less effective communication and coping strategies, and display withdrawn behaviour reportedly have been shown to have negative treatment outcomes (Reuber, Pukrop et al. 2003).

Treatment Experience

i. Diagnosis

The average delay to diagnosis of 2.5 years in this study was considerably lower than the 7 years described in the literature (Reuber 2009). The fact that all participants were treated with an AED treatment at least once is consistent with the literature (Reuber 2009), but it presents an obvious hardship on the participants. Antiepileptic treatment offers no benefit to the NES patient and may result in adverse side effects (LaFrance 2008). Catherine and Edward both attributed memory loss to AED treatment. One predicament lies in the fact that by taking precautionary measures to prevent epilepsy, neurologists are prioritizing epilepsy over NES. The converse would be to prescribe no medication until a definitive diagnosis is made, which is likewise unacceptable. This dilemma and the potential difficulty of an accurate diagnosis is highlighted by Edward, who has no positive results for epilepsy, yet according to him some, but not all, of the neurologists still believe he may have epilepsy.

Furthermore, in a clinical context practitioners are confronted with extensive demands that include patient and time constraints. A recent study that documented neurologists' attitudes toward NES found that many felt their responsibility ended when a neuropathological explanation could be excluded (Kanaan, Armstrong et al. 2009). This perception may result in impatience on the part of neurologists who may feel their limited time may be better served with patients with whom they feel their expertise can make a difference. Although the participants in this study recounted both very positive and negative treatment experiences, the negative perceptions may have resulted in part from the neurologist perceiving these constraints.

In both examples, the NES patient is placed in an inferior position. Since precautionary measures are understandably taken for epilepsy, NES patients inadvertently experience lesser importance. Furthermore, the administration of a drug treatment although well-intentioned is to the detriment of the NES patient. The patient loses control of the diagnostic process, and then again of their own bodies when AED treatment can offer them no benefit with potentially adverse effects.

An early and accurate diagnosis is therefore of likely importance for NES patients. Most of the literature supports the observation that a rapid diagnosis of NES is associated with better outcomes (Reuber, Monzoni et al. 2009). A number of studies have compared the reliability of various diagnostic techniques, as well as examined less invasive techniques, such as conversation analysis and analysis of seizure metaphors utilized by NES patients (Cuthill and Espie 2005; Plug, Sharrack et al. 2009; Plug, Sharrack et al. 2009; Reuber, Monzoni et al. 2009). Furthering research in this area may be significant to NES patients.

ii. Treatment

All of the participants except for one (Dominique) were interviewed shortly after diagnosis. As a result it is difficult to acquire any knowledge about the impact of any particular treatment. Although the participants described numerous occasions seeking treatment, after testing they described simply being told the seizures were stress related and sent home. Allan and Dominique described such experiences, while Edward described an inconclusive diagnosis with no follow-up. These participants then reported that although they continued to suffer from seizures they did not seek further treatment. This result has also been found in the literature, where NES patients will continue to suffer from seizures, but no longer seek treatment (McKenzie, 2010). In this study the participants described returning for treatment only when the severity or frequency of their seizures became a serious concern.

In these examples only once did the participant report the recommendation of a therapeutic option. In this instance Allan described rejecting a psychological consult, because he was concerned that his suffering wasn't being taking seriously. This seemingly creates a vicious cycle in which a negative treatment experience may serve to amplify the NES patients underlying distress and resistance to treatment seeking.

Interestingly, as previously described the participants that had established a definitive explanatory model for their illness appeared to break out of this cycle. When faced with discharge Dominique created a new framework to address her illness and demanded treatment. The assertive approach by these participants may give practitioners the sense they are difficult patients, as NES patients have previously been characterized (Krumholz and Hopp 2006), yet this in the end may also serve these patients needs better.

One difficulty the participants' reported in their search for treatment was a lack of existing knowledge that was available and readable. Edward noted that after being directed to a website specifically for NES patients he was able to read patient accounts of their experience and general confusion. He recognized how the shared experiences were beneficial and could provide him with a sense of support. The existence of available knowledge may offer a patient some sense of control. The current lack of available knowledge for NES appeared to foster confusion for the participants in this study. The dissemination of knowledge about NES that includes patient experiences is likely of benefit.

Emergent Themes

i. Positive Events and Impact

The majority of the results and data comprise adverse life events and impacts on the participants. Two observations of note were the report of positive events around the time of illness onset and the description of pleasant bodily sensations following a seizure event.

Three of the five participants described positive life events that occurred around the time of seizure onset. Allan described finding a job. This would have provided him extra relief from the judgement of his fiancée's parents. Edward learned of the pregnancy of his fiancée. Catherine received a promotion, a raise and a break from her work after toiling long hours to successfully complete a project.

The majority of literature describes adverse life events at the time of illness onset. It is possible that in spite of the positive nature of the events, they may still have evoked a stressful response from the participant. For example, Edward learned of the pregnancy of his fiancée. In spite of the joyousness of this event, there are also many responsibilities and stressful life changes that it entails. This may unconsciously augment the stress levels of the individual. This interpretation is supported by research on the impact of life events on stress and illness (Surtees and Wainwright 2010). The focus of life event research is on the changes an event imparts on an individual's life patterns, rather than the emotional or social desirability of the events (Holmes and Rahe 1967). As such positively perceived events such as marriage, pregnancy and job promotion would still be considered stressful life events by these standards (Holmes and Rahe 1967; Hobson and Delunas 2001).

Some of the participants described pleasant bodily sensations experienced shortly after a seizure event. Allan described how he perceived his seizures as a type of release that allowed him to reset and later return to his responsibilities. He described one of the sensations he experienced as *euphoria*. Catherine also described a sense of peace and relaxation after recovering from a seizure. The observation and belief that seizures may have a therapeutic benefit has been the source of many medical treatments as described in the *Introduction* (Ellenberger 1970). Likewise, seizure induction has historically been used as a cure for NES in its former characterizations as possession, and hysteria (Ellenberger 1970). Freud and Breuer also initially induced seizures as part of the therapeutic process. Although the induction of seizures is not part of current standard clinical practise, the use of seizures as part of the therapeutic process has been recently investigated in patients whose seizure events are characterized as *reenactment* of past trauma (Quinn, Schofield et al. 2010). The curious paradox of these observations is that the seizures may be considered both an illness and an element of the cure at the same time. A differentiation has been made between seizures that are spontaneous and seizures that are induced (Ellenberger 1970), however, the participants' reports of the positive impact of some seizure events suggests that some benefit may be derived even when they are spontaneous.

ii. Head Injury

Although a history of minor head injury was reported in 3 of the 5 participants and has been noted in the literature, it is not clear the significance of this observation (Westbrook, Devinsky et al. 1998). It is likely that patients seeking to explain an illness that they relate to the brain would focus on previous head trauma. It is unclear whether this result would deviate from the general population for unreported minor head injury. The two participants with head injury that also had migraines associated the migraines with the head injury. By extension these same participants also associated their seizures with their migraines. Allan always had a migraine preceding a seizure and Catherine claimed to regularly have a migraine that followed her seizures. This result suggests there may be some relationship, but the sample is too small to make any conclusions.

iii. Quality of Life

The negative impact of the illness on quality of life was reported by all the study participants. The impact is quite pronounced, but it is consistent with the literature (Reuber 2008). As described in the section *Prototypes* the constraints that were placed on the participants were often self-imposed. These constraints were governed by their own fears and concerns, as well as those of their family and loved ones. Catherine described how her isolation was partly in response to the concerns of her husband. Dominique described her own fears of falling on the pavement if she were to venture out alone.

An earlier result suggested that the prototypical illness chosen by the participants may impact the degree to which self-imposed constraints are placed on their life. This seemed to have an impact on the participants' quality of life based on the limits they placed on their independence. The participants' descriptions of leaving their home were accompanied by imaginings of possible seizures in unexpected places. For example, Edward spoke of the possibility of having a seizure in the

Metro and described how he would likely be robbed and left to suffer. He indicated he would never go on the Metro as a result. Dominique's stated fear of falling on the pavement was contrasted to her lamenting how much she wanted to go outside, but was afraid of what might happen. These constraints appear to originate largely out of the concern for harm in the event of a seizure outside the home. The result of these concerns may be characterized as a loss of autonomy. The result that Beatrice would socialize with her friends, unlike the other participants, suggests that the self-imposed constraints may be subjective. In this study the only noteworthy characteristics that differentiated Beatrice from the other participants, was the fact she had experienced epilepsy as a child, had not witnessed it in others, and utilized a different prototypical illness to acquire meaning for her experience. As a result she attributed the experience of socializing with her friends as the most helpful pathway in dealing with her illness.

In the literature the majority of NES patients have not returned to work and ultimately remained quite disabled (Reuber 2008). The impact of seizures has also been measured by comparing epilepsy with NES patients. It has been reported that NES patients were twice as likely to be unemployed as epilepsy patients (O'Sullivan, 2007). If seizures are the constraining factor for a loss in the quality of life, such a result is surprising. It suggests that NES patients impose more life constraints on themselves than epilepsy patients. The study from O'Sullivan; however, did not indicate the frequency of seizures the participants experienced, which may have influenced the results. The contradictory experiences between Beatrice and the other participants, suggest that some of the self-imposed life constraints may not be necessary. Researching the prototypical illnesses NES patients choose to gain meaning for their experience may lead to potential strategies that limit the negative impact on autonomy.

iv. Witnessing Epilepsy

All but one participant had witnessed seizures in their past, and the one that had not, had experienced epileptic seizures herself as a child. This observation is found in the literature. Patients with NES have been reported to witness an epileptic seizure previous to illness onset six times more frequently than patients with epilepsy (Bautista, Gonzales-Salazar et al. 2008). A common model utilized to explain this phenomenon is that exposure to seizures in other family members or people in their surrounding, may provide a template that patients utilize to recreate and communicate their distress (Sharpe and Faye 2006). Correspondingly, seizures may be perceived as an idiom of distress for the NES patient, in which the seizures, having been observed in other family members, become a locally acceptable way of indirectly expressing distress. As Nichter states, "idioms of distress are socially and culturally resonant means of experiencing and expressing distress in local worlds" (Nichter 2010).

This model may also touch on the concept of secondary gain in which the patient would benefit from the additional support derived from their family, friends and other social benefits (Sharpe and Faye 2006). Such a conceptualization has been criticized with regards to secondary gain, since this type of benefit can be observed in almost any illness (Kanaan and Wessely 2010). Furthermore, the commonly experienced loss of employment and independence, social isolation and diminished quality of life found in NES patients, would likely outweigh any perceived benefits from secondary gain (Reuber, Pukrop et al. 2003; O'Sullivan, Spillane et al. 2007).

The secondary gain theory also contradicts overarching themes that have emerged from this study. In these results the patient suffers repeated experiences in which they are unable to control themselves or their environment. The expression of seizures, rather than an attempt at control, is presently understood in this context as an utter loss of control. The characterization of benefiting from the illness highlights the barriers to care that NES patients often encounter: that underlying a clinical encounter is the perception they are somehow feigning or manipulating their symptoms for personal gain. This is symbolic of the breakdown in communication and another portrayal that serves to perpetuate a sense of inferior status for NES patients within a clinical context.

v. Loss of Control and the Inability to Communicate

In this study, the theme of a *loss of control* permeates every aspect of the participants' experience. This theme along with the *inability to communicate* characterized the accounts of the chain of events and explanatory models that led to illness onset. The accounts of seizure events revealed an embodied manifestation of these themes. The constraints that the participants then placed on their lives continued these themes with the creation of a self-imposed loss of autonomy and isolation. Based on their narratives, the participants portray a process that appears to result in the self-perpetuation of their underlying distress.

Following this thematic an intervention that reasserts the participant's sense of self, appears essential. The self-imposed life constraints may symbolize an attempt to control the environment in which seizures are manifested. Yet, the actual result tends to reinforce a loss of autonomy. As Beatrice demonstrated, the challenging of these limits, by socializing with her friends actually gave her the greatest sense of strength and relief.

In a clinical context this may reinforce the vulnerability of the participants. A treatment experience that the participant perceives as disempowering may serve to increase the distress that underlies their illness experience. This in turn may perpetuate the symptoms. An intervention strategy that enables the participant to experience a restored sense of control would be of benefit. Dominique demonstrated this possibility by challenging the medical authority about her discharge and demanding a treatment that suited her expectations. She described this treatment as the greatest source of her strength and relief during her healing process.

Although no long term outcomes are measured, both of these participants also seemed to perceive the medical model as complimentary to their own. With the participants that did not assert themselves, an intervention strategy that counteracts a passive approach to health seeking may offer a therapeutic benefit.

Limitations:

There are a number of limitations in this study. The purpose of this study was to examine and highlight the individual experiences of a small sample of NES patients; hence interesting relationships and observations would require larger studies designed to measure causality to determine their relevance. There was no follow-up interview to discover the actual course of treatment and outcomes of each participant. Patients that arrive at Epilepsy Centres are not necessarily representative of the whole population of NES patients. It is possible that some NES patients that do not pursue follow-up and do not arrive at an Epilepsy Centre may have different personality traits than those that pursue further treatment. The study participants may not remember important details or misrepresent their experience. The presence of the interviewer may influence the participants' responses. The bias of the researcher may influence the analysis of the results. This last concern was addressed by repeatedly reviewing the transcriptions for accuracy and authenticity of interpretation. The author acknowledges that he is not a clinician.

Future Research:

A study that examines the impact of establishing an effective illness prototype in collaboration with NES patients may be of interest. A study that examines the impact of empowerment techniques on NES patients may also be of interest. A follow-up study designed to determine whether patient outcomes matched initial observations may be of interest. An investigation that determines whether the experience of positive events before seizure onset is a consistent result may be of interest.

VI. CONCLUSION

The fundamental overarching theme that emerges from this study is *control* and its link to various aspects of the illness and treatment experience of the study participants. This theme has been broken down to into two highly interconnected sub-themes that include the *loss of control* as experienced by the participant as a precursor to NES onset and an *inability to communicate* that serves to characterize all levels of the illness and treatment experience of the study participants. This final theme appears to act not only as potential a barrier to care, but also as a perpetuating factor in illness manifestation.

The participants' choice of illness prototype appeared to impact their treatment expectations, as well as their quality of life. The selection of an illness prototype that promotes an effective treatment intervention and quality of life scenario for NES patients may be of benefit. Establishing illness prototypes that offer meaning to the patient and matching them with NES appropriate prototypes may help the patient find meaning in their experience and a pathway to recovery.

The participants that utilized a definitive explanatory model that incorporated a psychosocial explanation for their illness onset were receptive to and demanding of psychotherapeutic treatment. This reinforces the importance of exploring the patient’s explanatory process for their illness.

The lengthy diagnostic process and the precautionary use of AED treatment may be perceived as disempowering for NES patients. This experience may exacerbate the distress underlying a NES patient’s illness. The development of new diagnostic approaches may be of benefit. Seizure cessation may be an obvious goal of therapy, but it may be equally advantageous for questions of communication and knowledge sharing to be addressed in the clinical context. Strategies that restore NES patients’ sense of control in their lives may help them break the cycle of vulnerability and allow them to restore their health over the long term.

VII. REFERENCES

Abubakr, A., A. Kablinger, et al. (2003). "Psychogenic seizures: clinical features and psychological analysis." Epilepsy Behav **4**(3): 241-245.

Acar, G. and M. C. Salinsky (2010). "Demographic and historical backgrounds of the elderly with nonepileptic seizures: a comparative study." Neurol India **58**(1): 48-52.

Alsaadi, T. M. and A. V. Marquez (2005). "Psychogenic nonepileptic seizures." Am Fam Physician **72**(5): 849-856.

Anthony, S. and S. Jack (2009). "Qualitative case study methodology in nursing research: an integrative review." J Adv Nurs **65**(6): 1171-1181.

Aronson, J. K. (2006). Antiepileptic drugs. Meyler's Side Effects of Drugs: The International Encyclopedia of Adverse Drug Reactions and Interactions. J. K. A. Editor: . Amsterdam, Elsevier**:** 274-301.

Barry, J. J., D. Wittenberg, et al. (2008). "Group therapy for patients with psychogenic nonepileptic seizures: A pilot study." Epilepsy Behav.

Bautista, R. E., W. Gonzales-Salazar, et al. (2008). "Expanding the theory of symptom modeling in patents with psychogenic nonepileptic seizures." Epilepsy Behav **13**(2): 407-409.

Betts, T. and S. Boden (1992). "Diagnosis, management and prognosis of a group of 128 patients with non-epileptic attack disorder. Part I." Seizure **1**(1): 19-26.

Biggerstaff, D. and A. Thompson (2008). "Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research." Qualitative Research in Psychology **5**(3): 214-224.

Binder, L. M., S. S. Kindermann, et al. (1998). "Neuropsychologic impairment in patients with nonepileptic seizures." Arch Clin Neuropsychol **13**(6): 513-522.

Binder, L. M. and M. C. Salinsky (2007). "Psychogenic nonepileptic seizures." Neuropsychol Rev **17**(4): 405-412.

Binzer, M., J. Stone, et al. (2004). "Recent onset pseudoseizures--clues to aetiology." Seizure **13**(3): 146-155.

Blumer, D., S. Rice, et al. (2009). "Electroconvulsive treatment for nonepileptic seizure disorders." Epilepsy Behav **15**(3): 382-387.

Brooks, J. L., L. Goodfellow, et al. (2007). "Nondrug treatments for psychogenic nonepileptic seizures: what's the evidence?" Epilepsy Behav **11**(3): 367-377.

Brown, T. M., H. L. Miller, et al. (1991). "Characteristics of long-stay patients on the psychiatric service of a university hospital." Hosp Community Psychiatry **42**(7): 743-745.

Caron-Flinterman, J. F., J. E. Broerse, et al. (2005). "The experiential knowledge of patients: a new resource for biomedical research?" Soc Sci Med **60**(11): 2575-2584.

Carton, S., P. J. Thompson, et al. (2003). "Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome." Seizure **12**(5): 287-294.

Cragar, D. E., D. T. Berry, et al. (2005). "Cluster analysis of normal personality traits in patients with psychogenic nonepileptic seizures." Epilepsy Behav **6**(4): 593-600.

Creswell, J. W. (2003). Research design : qualitative, quantitative, and mixed methods approaches. Thousand Oaks, Calif., Sage Publications.

Creswell, J. W. (2007). Qualitative inquiry & research design : choosing among five approaches. Thousand Oaks, Sage Publications.

Cuthill, F. M. and C. A. Espie (2005). "Sensitivity and specificity of procedures for the differential diagnosis of epileptic and non-epileptic seizures: a systematic review." Seizure **14**(5): 293-303.

Daly, J. (1996). "Qualitative research methods." J Health Serv Res Policy **1**(3): 165-166.

Darnton, R. (1968). Mesmerism and the end of the Enlightenment in France. Cambridge,, Harvard University Press.

Devinsky, O. (1998). "Nonepileptic psychogenic seizures: quagmires of pathophysiology, diagnosis, and treatment." Epilepsia **39**(5): 458-462.

Dowrick, C. F., A. Ring, et al. (2004). "Normalisation of unexplained symptoms by general practitioners: a functional typology." Br J Gen Pract **54**(500): 165-170.

Drinka, G. F. (1984). The birth of neurosis : myth, malady, and the Victorians. New York, Simon and Schuster.

Ellenberger, H. F. (1970). The discovery of the unconscious; the history and evolution of dynamic psychiatry. New York,, Basic Books.

Endler, N. S. and E. Persad (1988). Electroconvulsive therapy : the myths and the realities. Toronto ; Lewiston, N.Y., Hans Huber Publishers.

Enns, M. W., J. P. Reiss, et al. (2010). "Electroconvulsive Therapy (POSITION PAPER)." Can J Psychiatry **55**(6): B1-B12.

Ettinger, A. B., A. Dhoon, et al. (1999). "Predictive factors for outcome of nonepileptic seizures after diagnosis." J Neuropsychiatry Clin Neurosci **11**(4): 458-463.

Fade, S. (2004). "Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide." Proc Nutr Soc **63**(4): 647-653.

Faedda, G. L., I. Becker, et al. (2010). "The origins of electroconvulsive therapy: Prof. Bini's first report on ECT." J Affect Disord **120**(1-3): 12-15.

Ferber, S. (2006). Possession, Demonic. Encyclopedia of witchcraft the Western tradition. R. M. Golden. Santa Barbara, Calif., ABC-CLIO. **pg 921:** 2 v. in 1.

Fiszman, A., S. V. Alves-Leon, et al. (2004). "Traumatic events and posttraumatic stress disorder in patients with psychogenic nonepileptic seizures: a critical review." Epilepsy Behav **5**(6): 818-825.

Freud, S. and J. Breuer (1966). Studies on hysteria. New York, Avon Books.

Garcia-Campayo, J. and C. Sanz-Carrillo (2000). "The use of alternative medicines by somatoform disorder patients in Spain." Br J Gen Pract **50**(455): 487-488.

Gates, J. R. (2001). "Provocative testing should not be used for nonepileptic seizures." Arch Neurol **58**(12): 2065-2066.

Gene-Cos, N. and H. A. Ring (2005). "Making sense of non-epileptic seizures." Epileptic Disord **7**(2): 123-130.

Glaser, B. G. and A. L. Strauss (1967). The discovery of grounded theory; strategies for qualitative research. Chicago, Aldine Pub. Co.

Goldstein, L. H. (2004). "Assessment of patients with psychogenic non-epileptic seizures." J Neurol Neurosurg Psychiatry **75**(5): 667-668.

Goldstein, L. H., T. Chalder, et al. (2010). "Cognitive-behavioral therapy for psychogenic nonepileptic seizures: a pilot RCT." Neurology **74**(24): 1986-1994.

Green, A., S. 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**(5): 331-339.

Green, J. and N. Thorogood (2004). Qualitative methods for health research. London ; Thousand Oaks, Calif., Sage Publications.

Groleau, D. and I. E. Cabral (2009). "Reconfiguring insufficient breast milk as a sociosomatic problem: mothers of premature babies using the kangaroo method in Brazil." Matern Child Nutr **5**(1): 10-24.

Groleau, D., A. Young, et al. (2006). "The McGill Illness Narrative Interview (MINI): an interview schedule to elicit meanings and modes of reasoning related to illness experience." Transcult Psychiatry **43**(4): 671-691.

Groppel, G., T. Kapitany, et al. (2000). "Cluster analysis of clinical seizure semiology of psychogenic nonepileptic seizures." Epilepsia **41**(5): 610-614.

Hagger, M. S. and S. Orbell (2003). "A meta-analytic review of the common-sense model of illness representations." Psychology & Health**.18**(2): pp.

Hall-Patch, L., R. Brown, et al. (2009). "Acceptability and effectiveness of a strategy for the communication of the diagnosis of psychogenic nonepileptic seizures." Epilepsia.

Halligan, P. W., C. Bass, et al. (2000). "New approaches to conversion hysteria." Bmj **320**(7248): 1488-1489.

Harden, C. L., L. Jovine, et al. (2009). "A comparison of personality disorder characteristics of patients with nonepileptic psychogenic pseudoseizures with those of patients with epilepsy." Epilepsy Behav **14**(3): 481-483.

Hobson, C. J. and L. Delunas (2001). "National norms and life-event frequencies for the revised Social Readjustment Rating Scale." International Journal of Stress Management **8**(4): 299-314.

Holmes, T. H. and R. H. Rahe (1967). "Social Readjustment Rating Scale." J Psychosom Res **11**(2): 213-&.

Howell, S. J., L. Owen, et al. (1989). "Pseudostatus epilepticus." Q J Med **71**(266): 507-519.

Hughes, J. R. (2004). "Dictator Perpetuus: Julius Caesar--did he have seizures? If so, what was the etiology?" Epilepsy Behav **5**(5): 756-764.

Hung, O. L. and R. D. Shih (2011). "Antiepileptic drugs: the old and the new." Emerg Med Clin North Am **29**(1): 141-150.

Kalinowsky, L. B. (1986). "History of convulsive therapy." Ann N Y Acad Sci **462**: 1-4.

Kalogjera-Sackellares, D. (2004). Psychodynamics and psychotherapy of pseudoseizures. Carmarthen, Crown House.

Kanaan, R., D. Armstrong, et al. (2009). "In the psychiatrist's chair: how neurologists understand conversion disorder." Brain **132**(Pt 10): 2889-2896.

Kanaan, R. A., A. Carson, et al. (2010). "What's so special about conversion disorder? A problem and a proposal for diagnostic classification." Br J Psychiatry **196**(6): 427-428.

Kanaan, R. A. and S. C. Wessely (2010). "Factitious disorders in neurology: an analysis of reported cases." Psychosomatics **51**(1): 47-54.

Kanaan, R. A. and S. C. Wessely (2010). "The origins of factitious disorder." Hist Human Sci **23**(2): 68-85.

Kanner, A. M. (2003). "More controversies on the treatment of psychogenic pseudoseizures: an addendum." Epilepsy Behav **4**(3): 360-364.

Kanner, A. M., J. Parra, et al. (1999). "Psychiatric and neurologic predictors of psychogenic pseudoseizure outcome." Neurology **53**(5): 933-938.

Katon, W., R. K. Ries, et al. (1984). "The prevalence of somatization in primary care." Compr Psychiatry **25**(2): 208-215.

Kirmayer, L. J. (1989). "Cultural variations in the response to psychiatric disorders and emotional distress." Soc Sci Med **29**(3): 327-339.

Kirmayer, L. J. (1999). Rhetorics of the body: medically unexplained symptoms in sociocultural perpective. In: Somatoform disorders : a worldwide perspective. Tokyo ; London, Springer.

Kirmayer, L. J., D. Groleau, et al. (2004). "Explaining medically unexplained symptoms." Can J Psychiatry **49**(10): 663-672.

Kirmayer, L. J. and A. Young (1998). "Culture and somatization: clinical, epidemiological, and ethnographic perspectives." Psychosom Med **60**(4): 420-430.

Klibansky, R., E. Panofsky, et al. (1964). Saturn and melancholy ; studies in the history of natural philosophy, religion, and art, by Raymond Klibansky, Erwin Panofsky, and Fritz Saxl. New York, Basic Books.

Krumholz, A. (1999). "Nonepileptic seizures: diagnosis and management." Neurology **53**(5 Suppl 2): S76-83.

Krumholz, A. and J. Hopp (2006). "Psychogenic (nonepileptic) seizures." Semin Neurol **26**(3): 341-350.

LaFrance, W. C., Jr. (2008). "Psychogenic nonepileptic seizures." Curr Opin Neurol **21**(2): 195-201.

LaFrance, W. C., Jr., K. Alper, et al. (2006). "Nonepileptic seizures treatment workshop summary." Epilepsy Behav **8**(3): 451-461.

LaFrance, W. C., Jr. and O. Devinsky (2002). "Treatment of nonepileptic seizures." Epilepsy Behav **3**(5 Suppl): 19-23.

LaFrance, W. C., Jr. and O. Devinsky (2004). "The treatment of nonepileptic seizures: historical perspectives and future directions." Epilepsia **45 Suppl 2**: 15-21.

LaFrance, W. C., Jr., M. D. Rusch, et al. (2008). "What is "treatment as usual" for nonepileptic seizures?" Epilepsy Behav **12**(3): 388-394.

Leserman, J. (2005). "Sexual abuse history: prevalence, health effects, mediators, and psychological treatment." Psychosom Med **67**(6): 906-915.

Littlewood, R. and G. Bartocci (2005). "Religious stigmata, magnetic fluids and conversion hysteria: one survival of 'vital force' theories in scientific medicine?" Transcult Psychiatry **42**(4): 596-609.

Mace, C. J. and M. R. Trimble (1991). "'Hysteria', 'functional' or 'psychogenic'? A survey of British neurologists' preferences." J R Soc Med **84**(8): 471-475.

Marcangelo, M. J. and F. Ovsiew (2007). "Psychiatric aspects of epilepsy." Psychiatr Clin North Am **30**(4): 781-802.

Mayou, R., L. J. Kirmayer, et al. (2005). "Somatoform disorders: time for a new approach in DSM-V." Am J Psychiatry **162**(5): 847-855.

Mazza, M., A. Martini, et al. (2006). "[Psychopathology in epilepsy and pseudoepilepsy: preliminary results in our experience]." Clin Ter **157**(3): 219-223.

Miles, M. B. and A. M. Huberman (1994). Qualitative data analysis : an expanded sourcebook. Thousand Oaks, Calif. ; London, Sage.

Moerman, D. E. (2000). "Cultural variations in the placebo effect: Ulcers, anxiety, and blood pressure." Medical Anthropology Quarterly **14**(1): 51-72.

Nahas, Z., J. P. Lorberbaum, et al. (2004). SOMATIC TREATMENTS IN PSYCHIATRY. Hoboken, N.J., Wiley-Liss.

Nichter, M. (2010). "Idioms of distress revisited." Cult Med Psychiatry **34**(2): 401-416.

O'Sullivan, S. S., J. E. Spillane, et al. (2007). "Clinical characteristics and outcome of patients diagnosed with psychogenic nonepileptic seizures: a 5-year review." Epilepsy Behav **11**(1): 77-84.

O'Sullivan, S. S., B. J. Sweeney, et al. (2006). "The opinion of the general practitioner toward clinical management of patients with psychogenic nonepileptic seizures." Epilepsy Behav **8**(1): 256-260.

Oto, M., P. Conway, et al. (2005). "Gender differences in psychogenic non-epileptic seizures." Seizure **14**(1): 33-39.

Piippo, J. and J. Aaltonen (2008). "Mental health care: trust and mistrust in different caring contexts." J Clin Nurs.

Plug, L., B. Sharrack, et al. (2009). "Conversation analysis can help to distinguish between epilepsy and non-epileptic seizure disorders: a case comparison." Seizure **18**(1): 43-50.

Plug, L., B. Sharrack, et al. (2009). "Seizure metaphors differ in patients' accounts of epileptic and psychogenic nonepileptic seizures." Epilepsia **50**(5): 994-1000.

Popay, J. and G. Williams (1996). "Public health research and lay knowledge." Soc Sci Med **42**(5): 759-768.

Popay, J. and G. Williams (1998). "Qualitative research and evidence-based healthcare." J R Soc Med **91 Suppl 35**: 32-37.

Quinn, M. C., M. J. Schofield, et al. (2010). "Permission to speak: therapists' understandings of psychogenic nonepileptic seizures and their treatment." J Trauma Dissociation **11**(1): 108-123.

Reuber, M. (2008). Are Psychogenic Non-epileptic Seizures an Expression of Neurologic Pathology?: *in* Psychiatric controversies in epilepsy. San Diego, Calif. ; London, Elsevier/Academic Press.

Reuber, M. (2008). "Psychogenic nonepileptic seizures: answers and questions." Epilepsy Behav **12**(4): 622-635.

Reuber, M. (2009). "The etiology of psychogenic non-epileptic seizures: toward a biopsychosocial model." Neurol Clin **27**(4): 909-924.

Reuber, M., G. Fernandez, et al. (2002). "Diagnostic delay in psychogenic nonepileptic seizures." Neurology **58**(3): 493-495.

Reuber, M., S. Howlett, et al. (2007). "Non-epileptic seizures and other functional neurological symptoms: predisposing, precipitating, and perpetuating factors." Psychosomatics **48**(3): 230-238.

Reuber, M., C. Monzoni, et al. (2009). "Using interactional and linguistic analysis to distinguish between epileptic and psychogenic nonepileptic seizures: a prospective, blinded multirater study." Epilepsy Behav **16**(1): 139-144.

Reuber, M., R. Pukrop, et al. (2004). "Multidimensional assessment of personality in patients with psychogenic non-epileptic seizures." J Neurol Neurosurg Psychiatry **75**(5): 743-748.

Reuber, M., R. Pukrop, et al. (2003). "Outcome in psychogenic nonepileptic seizures: 1 to 10-year follow-up in 164 patients." Ann Neurol **53**(3): 305-311.

Rice, P. L. and D. Ezzy (1999). Qualitative research methods : a health focus. South Melbourne, Vic. ; Oxford, Oxford University Press.

Schwandt, T. A. (2001). Dictionary of qualitative inquiry. Thousand Oaks, Calif., Sage Publications.

Sharpe, D. and C. Faye (2006). "Non-epileptic seizures and child sexual abuse: a critical review of the literature." Clin Psychol Rev **26**(8): 1020-1040.

Shen, W., E. S. Bowman, et al. (1990). "Presenting the diagnosis of pseudoseizure." Neurology **40**(5): 756-759.

Smith, J. (2004). "Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology." Qualitative Research in Psychology **1**(1): 39-54.

Smith, J. A., P. Flowers, et al. (2009). Interpretative phenomenological analysis : theory, method and research. Los Angeles, SAGE.

Spanos, N. P. (1978). "Witchcraft in histories of psychiatry: a critical analysis and an alternative conceptualization." Psychol Bull **85**(2): 417-439.

Stake, R. E. (1995). The art of case study research. Thousand Oaks, Sage Publications.

Stone, J., M. Binzer, et al. (2004). "Illness beliefs and locus of control: a comparison of patients with pseudoseizures and epilepsy." J Psychosom Res **57**(6): 541-547.

Stone, J., K. Campbell, et al. (2003). "What should we call pseudoseizures? The patient's perspective." Seizure **12**(8): 568-572.

Stone, J., M. Sharpe, et al. (2004). "Motor conversion symptoms and pseudoseizures: a comparison of clinical characteristics." Psychosomatics **45**(6): 492-499.

Stone, J., W. Wojcik, et al. (2002). "What should we say to patients with symptoms unexplained by disease? The "number needed to offend"." Bmj **325**(7378): 1449-1450.

Surtees, P. and N. Wainwright (2010). Life events and health: *in* Stress consequences: mental, neuropsychological and socioeconomic. San Diego, C.A. ; London, Academic.

Teo, W. Y. and C. T. Choong (2008). "Neurological presentations of conversion disorders in a group of Singapore children." Pediatr Int **50**(4): 533-536.

Thompson, R., C. L. Isaac, et al. (2009). "What is it like to receive a diagnosis of nonepileptic seizures?" Epilepsy Behav **14**(3): 508-515.

Westbrook, L. E., O. Devinsky, et al. (1998). "Nonepileptic seizures after head injury." Epilepsia **39**(9): 978-982.

Yin, R. K. (1999). "Enhancing the quality of case studies in health services research." Health Serv Res **34(**5 Pt 2): 1209-1224.

Yin, R. K. (2003). Case study research : design and methods. Thousand Oaks, Calif., Sage Publications.

TABLES and APPENDICES

TABLE 1: Illness Narratives

CASE # (pseudonym)	Chain Complexes	Prototypes Implicit	 Explicit	Explanatory Models
CASE 1 (Allan)	Witnessing physical assault and threatened to remain silent. Fiancée's family judgemental. Abandoning grandparents to live with fiancée	Epilepsy	N/A	Nothing explicit. Combination of everything
CASE 2 (Beatrice)	Physical assault at work by large woman. Similar childhood assault. Difficulty getting insurance to cover treatment from attack	N/A	Anxiety Attacks	Assault at work, and relation to childhood assault
CASE 3 (Catherine)	"Gruesome" death of grandmother. Conflict with husband. Work stress. Violent roller coaster ride. New AED prescription. Recent death of other grandmother	Epilepsy	N/A	None. She will leave this to the medical professionals
CASE 4 (Dominique)	Losing court case to husband for rights to son. Not being able to locate or contact son on birthday. Father in ICU. Sister with breast cancer.	Epilepsy	N/A	Losing son in court case, and not being able to communicate with him
CASE 5 (Edward)	Esophogus cancer. Divorce from wife. Ulcer	Epilepsy	N/A	None

TABLE 2: Treatment Descriptions

CASE # (pseudonym)	**1st Treatment**	**Seizures**	**2nd Treatment**	**Seizures**	**3rd Treatment**	**Seizures**	**Delay**	**AED**
CASE 1 (Allan)	Observation. Discharged, told not epileptic	Ongoing	Ignored, referred to psychologist. Prescribed AED.	Ongoing	Observation. Definitive NES diagnosis	Ongoing	2.5 yrs	Lorazepam
CASE 2 (Beatrice)	Sought treatment 15 days after onset. Precautionary AED treatment	Ongoing	Follow-up. NES diagnosis. AED treatment ended.	Less frequent	N/A	N/A	6 mos	Levetiracetam
CASE 3 (Catherine)	Only sought treatment after long delay. AED treatment	Only 3 and then stopped	Recurred. Increased AED dosage. Treatment in emergency.	Ongoing	Observation. Definitive NES diagnosis. AED treatment stopped.	Ongoing	9 yrs	Carbamazepine others.
CASE 4 (Dominique)	Occasional seizures, no treatment. Sought diagnosis again when increased. Observation. No treatment	Rarely	Observation, one week each time. Told stress related, not epileptic.	Ongoing	Told stress and discharged. Demanded treatment, and has been hospitalized since	Ongoing	0 yrs	Gabapentin
CASE 5 (Edward)	Tests all negative. Conflicting diagnosis. No follow-up	Stopped a few months later	Precautionary AED treatment. Tests negative. After AEDs stopped, seizures returned	Ongoing	N/A	N/A	7 mos	Yes

TABLE 3: Emerging Themes

CASE # (pseudonym)	**Childhood**	**Head Injury**	**Witness Epilepsy**	**Co-Morbidities**	**Positive Experience**
CASE 1 (Allan)	Parents divorce, raised by grandparents	Yes, many concussions	Brother, friend	Migraine	Recent employment, happy relationship
CASE 2 (Beatrice)	Attacked by employer, did not report to parents	Not mentioned	NO. But had epilepsy as child	Anxiety, migraines	Not mentioned
CASE 3 (Catherine)	Only mentioned head trauma that caused severe migraines	Yes, resulted in severe migraines	Mother, uncle, cousins	Psoriasis, migraines	Promotion and raise at work, excitement to see brother and friends
CASE 4 (Dominique)	Not mentioned	Not mentioned	Ex-husband, neighbour	Anxiety, depression	Not mentioned, however hospitalization was seen as a positive event (freed from stress of being caregiver).
CASE 5 (Edward)	Self-described rough childhood, “horrible” events.	Yes, hit by car while on bike.	Mother	Psoriasis, cancer, ulcer	Fiancée pregnant, happy relationship, taking over family business, new beginning

TABLE 4: Seizure Descriptions

CASE #	**Sensations**						
(pseudonym)	**Preceding**	**During**	**Following**	**Conscious**	**Motor / Still**	**Duration**	**Environment**
CASE 1 (Allan)	Migraine, slurring, feeling overwhelmed	Hears everything at a distance, slurs	Fatigue, euphoria	Yes	Convulsions	5mins convulsions, ~24hrs not speaking	Home, presence of fiancée, family
CASE 2 (Beatrice)	Anxiety, fear of death, olfactory activation, dizzy, numbness, deja-vu	Crying, with no emotion	Tired, disoriented	Yes	Vacant stare, convulsions	30sec - 3min	Home, once at physiotherapists, warning signs at hypnotism show
CASE 3 (Catherine)	Severe fatigue, extreme nervousness, or no warning	When conscious unable to communicate	Intense fatigue, migraine, peacefulness.	Sometimes	Both	Short to 1hr	Home, or when travelling, but with husband
CASE 4 (Dominique)	Overwhelming stress	Not mentioned	Tired, confused, needs to sleep	Not during major seizures. Yes, during minor ones	Convulsions	1 - 30min	Alone at home, in public places, or hospital
CASE 5 (Edward)	Dizzy and confused	Unable to communicate	Very tired, confused, memory loss	Not during major seizures (seconds). Yes, during minor ones	Generally convulsions, some absence staring	20sec for major, 3-4min for minor	Mixed, but with sister, fiancée, mother present

TABLE 5: Quality of Life

CASE # (pseudonym)	**Relationships**	**Work**	**Socializing**	**Driving**	**Memory**	**Spiritual**	**Other**
CASE 1 (Allan)	Fiancée good, family stressful, but supportive	Yes, but taking many days off	No, considered himself social before	No, fiancée drives him	Not mentioned	No impact	Loss of independence
CASE 2 (Beatrice)	Conjoint good, supportive	On leave for last 8 months.	Yes, with girlfriends, very positive	No	Not mentioned	Not directly from illness, but adversity has given her a stronger connection	Loss of independence, feeling isolated
CASE 3 (Catherine)	Husband and family supportive	On leave for 2 months, has good job.	No, home with husband, before yes.	No	Yes, blames loss of memory on AEDs	Lost faith after "gruesome" death of grandmother, slowly returning	Loss of independence, feels cooped up and treated to cautiously
CASE 4 (Dominique)	Caregiver for ill father and sister, stressful	On leave for 3 months, since hospitalized	No, afraid to go out on street	No	Only briefly mentioned.	No impact	Loss of independence, afraid to go outside alone.
CASE 5 (Edward)	Fiancée good, family good, all supportive	No, planning to take over family business	No, only with family	No, fiancée drives him	Yes, blames loss of memory on AEDs	Not related to illness, but positive events in life has made him believe more.	Loss of independence, relies on fiancée

APPENDIX A: McGill Illness Narrative Interview (Adapted for Non-Epileptic Seizures)

Section 1. INITIAL ILLNESS NARRATIVE

1. When did you experience your health *seizures* for the first time?
    a. We would like to know more about your experience. Could you tell us when you realized you had *seizures*?
    b. Can you tell us what happened when you had your *seizures*?
    c. Did something else happen?

2. If you went to see a helper or healer of any kind, tell us about your visit and what happened afterwards.
    a. If you went to see a doctor, tell us about your visit to the doctor/hospitalization and about what happened afterwards.
    b. Did you have any tests or treatments for your *seizures*?

Section 2. PROTOTYPE NARRATIVE

3. In the past, have you ever had a health problem that you consider similar to your current *seizures*?
    a. In what way is that past health problem similar to or different from your current *seizures*?

4. Did a person in your family ever experience a health problem similar to yours?
    a. In what ways do you consider your *seizures* to be similar to or different from this other person's health problem?

5. Did a person in your social environment (friends or work) experience a health problem similar to yours?

a. In what ways do you consider your *seizures* to be similar to or different from this other person’s health problem?

6. Have you ever seen, read or heard on television, radio, in a magazine, a book or on the Internet of a person who had the same health problem as you?

a. In what ways is that person’s problem similar to or different from yours?

Section 3. EXPLANATORY MODEL NARRATIVE

7. Do you have another term or expression that describes your *seizures*?

8. According to you, what caused your *seizures*?

a. Are there any other causes that you think played a role?
b. Why did your *seizures* start when they did?
c. What happened inside your body that could explain your *seizures*?
d. Is there something happening in your family/work/social/personal life that could explain your *seizures*?
e. Can you tell me how that explains your *seizures*?

9. Have you considered that you might have [INTRODUCE POPULAR ILLNESS LABEL-PL]?

a. What does [PL] mean to you?
b. What usually happens to people who have [PL]?
c. What is the best treatment for people who have [PL]?
d. How do other people react to someone who has [PL]?
e. Who do you know who has had [PL]?
f. In what ways is your *seizures* similar to or different from that person’s health problem?

g. Is your *seizures* somehow linked or related to specific events that occurred in your life?

h. Can you tell me more about those events and how they are linked to your *seizures*?

Section 4. SERVICES AND RESPONSE TO TREATMENT

10. During your visit to the doctor (healer) for your *seizures*, what did your doctor (healer) tell you that your problem was?

a. Did your doctor (healer) give you any treatment, medicine or recommendations to follow?

b. How are you dealing with each of these recommendations?

c. Are you able to follow that treatment (or recommendation or medicine)?

d. What made that treatment work well?

e. What made that treatment difficult to follow or work poorly?

f. What treatments did you expect to receive for your *seizures* that you did not receive?

g. What other therapy, treatment, help or care have you sought out?

h. What advice and suggestions are you getting from family, friends and laypeople that you may have discussed your *seizures* with (either directly, or indirectly)?

i. What other sources of information have you received, or been provided in regards to your *seizures*? (eg pamphlets, groups, classes)

j. What other sources of information have you explored, sought out, utilized in regards to your *seizures*? (eg. internet, library, books, journals)

k. What other therapy, treatment, help or care would you like to receive?

Section 5. IMPACT ON LIFE

11. How has your *seizures* changed the way you live?
    - a. How have your *seizures* changed the way you feel or think about yourself?
    - b. How have your *seizures* changed the way you look at life in general?
    - c. How have your *seizures* changed the way that others look at you?
    - d. How have your *seizures* influenced your spiritual life, faith or religious practice?
    - e. What has helped you through this period in your life?
    - f. How have your family or friends helped you through this difficult period of your life?
    - g. How has your spiritual life, faith or religious practice helped you go through this difficult period of your life?
    - h. Is there any thing else you would like to add?