

Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome

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Rationale: The study aim was to assess patients' understanding of and reaction to a diagnosis of non-epileptic attack disorder and to explore whether these factors contribute to outcome.

Method: Eighty-four patients diagnosed with non-epileptic attack disorder participated in the study. Participants answered questions about their seizures and understanding and reaction to the diagnosis. Data were collected by semi-structured telephone interview. Questionnaires were sent to the patients' general practitioners (GPs) to gather information regarding the patient's seizure status, prescription of anti-epileptic drugs and opinion regarding the diagnosis.

Results: At the time of follow-up, a third of participants reported being seizure free. A total of 63% did not have a good understanding of the diagnosis, most were unclear about the precipitating factors and the most common reaction to the diagnosis was confusion. Many reported a negative impact of NES on everyday life. Sixty-five percent reported receiving psychological follow-up but the number of sessions attended was few (median 2). There was evidence that the reaction to the diagnosis contributed to the outcome in particular an angry outcome was associated with a poor prognosis. Ten GPs did not agree with the diagnosis.

Conclusion: Patients understanding and reactions to a diagnosis of non-epileptic attacks are important factors that should contribute to the development of more tailored treatment approaches.

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Key words: non-epileptic attack disorder; non-epileptic seizures; outcome; diagnosis.

INTRODUCTION

Non-epileptic attack disorder (NEAD) has been defined as a condition in which non-epileptic seizures (NES) occur. The latter have been defined as a sudden, usually disruptive change in a person's behaviour, perception, thinking or feeling which is usually time limited and which resembles, or is mistaken for, an epileptic seizure but which does not have the characteristic electrophysiological changes which accompany a true epileptic seizure¹. A distinction is made between attacks that have a physical cause such as syncopal episodes and those that are considered to have a psychological origin. NES represents a significant clinical problem. Reported rates of misdiagnosis are high particularly in those attending tertiary referral centres^{2–7}. In patients presenting with status epilepticus at hospital up to 50% turn out not to have

epilepsy⁸. Misdiagnosis has also been highlighted as a potential problem at the primary care level⁹.

NES are psychologically driven, although the psychological mechanisms remain unclear and available evidence suggests these are likely to be variable. For some, the attacks appear to represent the manifestation of a conversion disorder or a dissociative reaction in response to some past or ongoing psychological threat^{10–15}. Sexual abuse has been identified as a major psychological precipitant^{16–18}. NES have been proposed by some as a means of exerting control over the family and the wider social environment^{19,20}. In other cases, the seizures are the physical expression of a more generalised anxiety disorder²¹. NES may also be deliberate and form part of a fictitious disorder or a means of financial gain²².

Much research has focused on diagnosis and clearly such studies are important. If methods of

diagnosis can be improved then this will reduce the chances of individuals being incorrectly diagnosed with epilepsy. Several studies have highlighted the clinical characteristics of the seizures although most have demonstrated considerable overlap in features between epileptic and non-epileptic attacks. Many studies have demonstrated the value of ambulatory and video-EEG monitoring^{23–30}. A number of studies have advocated the use of provocative methods such as placebo activation as an aid to diagnosis and as a means of maximising the yield of intensive electrophysiological monitoring techniques^{31–34}.

In contrast to investigations on diagnosis and clinical characteristics there is limited data on the long-term outcome of NES and factors associated with favourable prognosis. Previous outcome studies have found that at least a quarter of patients with NES remained event free during follow-up periods of up to 14 years^{23,35–40}.

Guberman²³ proposed that patients with a good outcome were less likely to show signs of psychiatric dysfunction and more likely to have a shorter history of NES and an acute emotional trauma preceding the onset of the seizures. Meierkord *et al.*³⁷ followed 110 patients with a diagnosis of NES made up to 14 years earlier. A total of 40% of the patients reported they had stopped having NES. A good outcome was associated with being female, living an independent lifestyle, no co-existing epilepsy and having a specific psychological approach to management with emphasis on supportive counselling and explanation. They did not find that the presence of a psychiatric disorder, the clinical features of the attack or previous episodes of pseudo-status were predictors of prognosis. Walczak *et al.*³⁸ interviewed 51 patients diagnosed with NES, using a structured telephone questionnaire with the aim of identifying what factors determined prognosis. Of their sample, a third were no longer having NES at least 12 months after diagnosis. A total of 41% experienced a decrease in frequency of NES by more than 80% and many had discontinued taking AEDs. Overall the sample judged themselves as functioning better following the diagnosis than before. The authors stressed that major changes in lifestyle were small and few gained employment despite self-reported improvements in lifestyle. Psychotherapy was recommended in all cases and 41 attended for at least one session. Twenty-three individuals were still receiving regular therapy at the time of follow-up. No correlation was found between psychotherapeutic input and outcome. The authors argued that the most important obstacles to a good prognosis were co-existing psychiatric disorder and social factors arising from living with a disabling chronic condition and if these were not addressed and resolved then psychotherapy would be of limited benefit.

Jongsma *et al.*³⁹ did find some support for the positive impact of psychotherapy. They followed up 33 patients with NES 23–67 months following diagnosis. One quarter of the sample was seizure free and these were more likely to include those who had received psychotherapy. Gudmundsson *et al.*⁴⁰ followed up children and adolescents diagnosed with NES. Of the 17 individuals available for study 14 had ceased to have attacks and had returned to school. Better outcome was associated with being female, younger age at presentation, having multiple seizure types and not having received both inpatient and outpatient treatment.

Data available to date from outcome studies is limited and at times contradictory. Furthermore, a number of potentially important areas have not been included. In the current study we followed up patients after a change in diagnosis to NES. In addition to assessing previously explored variables such as age of onset, duration of the disorder, psychiatric history and exposure to psychological therapy, we also examined patients' understanding and reaction to the diagnosis and the possible impact of this on outcome.

METHODS

All patients had a prior diagnosis of epilepsy changed to NEAD after a detailed evaluation at the Assessment Centre of the National Society of epilepsy (NSE), including direct observation of seizures and EEG recordings. Patients who had had a clear diagnosis of NEAD, and no epileptic seizures, were contacted 1–7 years following the diagnosis. Prospective participants were sent a letter explaining to them the purpose of the study and requesting their consent to take part. Within 1-week of posting the letter, participants were contacted by telephone. Any queries were clarified and agreement to be included in the study was sought. If it was convenient, the interview was undertaken at this time, or a more suitable time and date were arranged. The aim of the interview was to assess participant's perception and understanding of the diagnosis and also to obtain information regarding the course of their disorder. The average length of the interview was 20 minutes. The patients' general practitioners were also sent a questionnaire regarding their patient. Demographic information was obtained from the patients' medical notes.

Sample

Eighty-four patients were included in the study. The participants with NEAD were drawn from a cohort of 115 patients who had been given an unequivocal

diagnosis between 1988 and 1996 following a period of inpatient assessment. Seven patients were excluded due to their likely inability to cope with the cognitive demands of the study. Six had a learning disability and the seventh had developed a pre-senile dementia. In addition, 19 patients were lost to follow-up and five patients refused to participate, all on the grounds that they did not believe they had NEAD.

General practitioners

The general practitioners of 78 of the 84 (92%) participants who were contacted responded to the postal questionnaire.

Materials

Patient questionnaire

A questionnaire was devised specifically for the purposes of this study. It included both closed questions regarding the patient's current and past seizure status, in addition to open-ended questions designed to elicit information about their understanding of NEADS, acceptance and reaction to the diagnosis.

Open-ended questions from the interview were assessed using content analysis⁴¹. The participant's answers were extensively read by one of the researchers (SC) and put into categories. An independent judge, being blind as to the original ratings, also rated and assigned individual responses into the categories. A contingency table was devised for each question. The degree of agreement and the inter-rater reliability was assessed by calculating Cohen's Kappa coefficient (k range ≈ 73 to ≈ 95).

GP questionnaire

This was briefer and asked questions relating to the GP's endorsement of the diagnosis of NEAD and current drug use.

RESULTS

Demographic details at the time of the interview together with clinical information derived at the time of the inpatient assessment are given in Table 1. The majority of the sample was female and single. One third were employed. Almost two thirds had a psychiatric history, with depression the most common diagnosis represented. Twenty-one individuals were diagnosed as having a current psychiatric problem and this included seven diagnosed with an anxiety disorder and

Table 1: Demographic and clinical details.

Sex	
Females	77%
Age (at interview)	35.2 years (range 16–64)
Marital status	
Single	47 (56%)
Married	33 (39%)
Divorced/separated	4 (5%)
Occupational status	
Employed	30 (36%)
Unemployed	12 (14%)
Housewife	17 (20%)
Student	12 (14%)
Other	13 (15%)
Psychiatric history on assessment	
Present	57 (68%)
Depression	29
Anxiety	10
Psychiatric diagnosis on assessment	
Present	21
Depression	7
Anxiety	7
Personality disorder	4
Eating disorder	2
Briquet's syndrome	1

seven with depression. A third of the sample reported evidence of past sexual abuse.

Seizures

The mean age of seizure onset was 23 years with a range of from 3 to 50 years. The mean duration of the attacks before the re-diagnosis was 10 years, ranging from 1 month to 41 years. The reported seizure frequency on admission was high, with a mean of 26 episodes per month. Three quarters of the sample reported they sustained significant physical injury as a consequence of their seizures; bruises, burns and fractures being the most frequently cited. A quarter of the sample reported the seizures had resulted in at least one hospital admission. Nine individuals reported multiple hospital admissions (maximum 10).

At follow-up 6 months to 7 years post diagnosis 28% of the participants reported the seizures had stopped and a further 48% reported at least a 50% reduction in attacks. The remainder reported no change (13%) or an increased frequency of seizures (11%). Twenty-seven (32%) of the participants continued to be prescribed AEDs by their GPs despite the diagnosis of NES.

Understanding of the diagnosis

Understanding of NES was categorised as the participant offering some indication that the episodes

were not due to epileptic activity but rather were mediated by psychological factors. Only a third of the participants interviewed had some understanding of the diagnosis of NES. Some described how they saw NES as a build up and subsequent release of emotions 'a seizure triggered by emotion rather than an electrical discharge'. One respondent described NES thus 'they are not organic but psychologically based and are more likely to happen when you are in conflict or under stress'. Others described attacks as a means of responding to stress. One participant explained the attacks 'can be caused by past experiences, but I am not sure of the connection. Some people handle stress by eating, others by non-epileptic seizures'. One woman with a history of sexual abuse described NES as her 'screaming inside' when she would remember events surrounding her abuse. Even for those with some understanding of NES there was still considerable confusion about the nature of the NES. This confusion appeared to be in part as a result of the frequently reported absence of a temporal relationship between the experience of a stressful event and the occurrence of NES. Most respondents demonstrated no clear grasp of the diagnosis and five participants continued to firmly believe they had epilepsy. One woman said "How could it not have been epilepsy. I had previously been taking five AEDs".

Precipitating and contributing factors

This question was addressed to those who reported that seizures had continued ($N = 61$). Twenty-five (40%) could not identify any pattern or specific stimuli that would precede NES. A range of problems frequently associated with an increase in stress were identified by 60% and these included pre-menstrual tension (13), relationship difficulties (6), pain (5), being alone (4), fear about the future (4), work problems (1) and a desire to conceive (1).

Feelings of anxiety and panic and/or a specific stressful event were cited as contributing to the development of NES in a third of the sample. Among the specific factors were a pending divorce and financial problems, flashbacks to past sexual abuse, death of a brother, post-traumatic stress following an assault. A total of 14% (20) of the statements made were categorised in terms of heightened awareness and over-vigilance to bodily sensations. These participants tended to misinterpret benign sensations as a precursor to an attack. One person described her 'supersensitivity to physical twitches' and a corresponding 'sense of doom and dread'. Twenty-four individuals stated they could not identify any contributing factors.

Reaction to the diagnosis

All the participants in this study had been previously diagnosed with epilepsy. Almost two thirds of the participants stated they agreed with the revised diagnosis.

The most frequently reported reaction was confusion (38%). This appeared to stem from a lack of clarity in their understanding of the diagnosis and the confusion associated with a contradictory diagnosis. Eighteen percent of responses were classified as an angry reaction. This appeared to have contributed to a reduced confidence in the diagnosis. This anger appeared fuelled by the restrictions imposed by the previous 'wrong' diagnosis for example taking AEDs and not being permitted to drive. One woman upon learning the diagnosis said she 'felt suicidal and unprepared for this diagnosis. All at once a lot of significant information that had affected my career prospects and decisions not to have children was given to me. I felt I had been cheated and wanted my life back again'.

Twenty-one percent of the responses indicated some relief at not having epilepsy and reported being free of living with the burden of epilepsy and being able to get on with their lives. One man said 'I came off the tablets after 13 years. I would now start afresh as a normal person without tablets and the stigma of epilepsy'.

Negative impact of NES on everyday life

The participants' responses to these questions were divided into four categories and many participants cited more than one category. Fifty-eight responses were categorised in terms of increased anxiety engaging in everyday activities and social situations and many were deemed socially isolated. Reduced self-confidence was indicated by 53 responses as a negative consequence. 'Attacks make me more subdued because I am scared people will laugh at me, consequently my social world had diminished'. Fifty individuals cited the seizures as obstacles to employment.

Psychological follow-up

Psychological follow-up was recommended for 72 (86%) of the 84 participants. Fifty-five participants reported receiving follow-up by a mental health professional. Everyone who was offered psychological follow-up reported attending for at least one session. The median number of follow-up sessions, however, was only 2 (range 1–36).

Participants' response to psychological follow-up was varied. The opportunity to discuss problems was

given most frequently as the benefit of psychological input. In this group were individuals who reported that this was the first opportunity to really discuss their problems. One participant described therapy as an opportunity to 'learn to be more in control of my life and accept the diagnosis'. Sixteen participants' responses perceived relaxation training as one benefit of input. Thirteen individuals' responses to psychological follow-up were categorised as no benefit. The limited number of sessions, a poor relationship with their allotted mental health professional and a resistance as one woman put it to opening up a 'can of worms' contributed to reports of disappointment with follow-up therapy. One participant expressed confusion about what her therapist was doing and how it had any relevance to the episodes she was experiencing. Eighteen statements indicated other benefits. These included learning practical problem solving strategies, availability of the therapist on the telephone and journaling techniques.

General practitioners

The majority of the GPs agreed with the diagnosis. Ten GPs, however, reported that they did not and continued to prescribe AEDs. All of their patients continued to have NES and this group included the five patients who did not accept the diagnosis.

Variables associated with NES outcome

Those participants who continued to have seizures at follow-up were more likely to be taking AEDs ($\chi^2 = 7.9$; $P < 0.0001$). They were more likely to describe reactions to the diagnosis that were classified as confused ($\chi^2 = 0.6$; $P < 0.001$) and angry ($\chi^2 = 9.1$; $P < 0.002$). Those patients who reported no longer having seizures were more likely to have described 'a relieved not to have epilepsy' reaction on receiving the diagnosis ($\chi^2 = 19.1$; $P < 0.0001$) and were more likely to be employed ($\chi^2 = 12.3$; $P < 0.009$).

The participants' understanding of NEAD, the disruptive impact on daily life, age of onset of the episodes, psychiatric history and occurrence of psychological follow-up were not associated with outcome.

DISCUSSION

The characteristics of our patient sample had much in common with those reported in the research literature. Our participants were predominantly young at seizure onset, single and female^{26,36-39,42,43}. There

was a considerable length of time from the onset of the attacks to the diagnosis of NEAD; 41 years in one case. Attacks were occurring frequently and the rate of reported injuries was high with more than a quarter of the sample requiring hospital treatment and admission. Past and current psychiatric morbidity was common with depression being the most frequent diagnosis^{15,17,44}. There was evidence of sexual abuse in a third of cases^{1,2,11,17,19,24,43}. In keeping with other outcome studies almost a third of participants reported being event free at the time of follow-up^{4,28,36-38}.

One of the main objectives of the study was to explore participants' understanding of the diagnosis of NES. An explanation of the diagnosis was provided at the time of re-diagnosis and all patients had at least one session with a psychologist. Feedback was given to family members in a number of cases. Information about the diagnosis did not appear to have been clearly remembered by two thirds of the sample. The reported poor understanding about NES may suggest that the information imparted at the time of diagnosis was inadequate or inappropriately delivered. The provision of detailed explanations of NES once the diagnosis has been established has been a recommendation in past studies³⁷ but this study suggests the patients' understanding and retention of such information needs to be checked, reiterated and reinforced perhaps at a later less emotionally charged time. Although not specifically recorded it is our clinical experience that patients diagnosed as having NES are less likely to receive follow-up from epilepsy clinical and support services and perhaps this is a practice that needs to be reviewed. Follow-up may enable understanding of the diagnosis to be reviewed with the patient and their family⁴⁴. Further explanations could be given at this stage a role that could possibly come under the remit of clinical psychologists, epilepsy nurse specialists or epilepsy counsellors.

Participants' accounts of the factors contributing to NES primarily refer to reports of anxiety and stresses that had occurred or were currently occurring in their lives. The NES also appeared for some to be a way of disengaging from stressful situations as reported by Minter⁴⁵ and Moore *et al.*²⁰. Two thirds of the group however could identify no specific stressors and this appeared to contribute further to their lack of understanding about NES. This apparent lack of any perceived association between emotional antecedents and seizures may also make it more difficult for the subject to appreciate the psychological basis of their disorder and this may reduce motivation for psychological intervention.

It is maybe surprising that more than two thirds of the group reported that they accepted the diagnosis of NES, despite an apparently poor understanding about

the condition. It was anticipated that there might have been more resistance to this revision of diagnosis. The participants' reaction to the diagnosis was characterised mostly by confusion (one third) and relief at not having epilepsy (one fifth). The later response was made on the basis of a perceived positive outcome and this included no longer having to experience the stigma of living with epilepsy, the disadvantages of not being permitted to drive and having to tolerate the side effects of antiepileptic medication. This positive reaction was associated with a reduction or cessation of attacks. An angry response was reported by about a fifth of those followed up and this reaction was associated with a longer history of a diagnosis of epilepsy and a poorer outcome. Mokely *et al.*⁴⁶ have recently highlighted hostility as a characteristic or coping style in some patients with NES and that this would be expected to be associated with poor compliance and a more negative outcome.

The accounts of the sample indicated a negative psychosocial impact of NES that has much in common with intractable epilepsy. Many participants' everyday lives were characterised by social isolation, difficulties obtaining employment and a reduction in self-confidence and self-esteem. For many individuals these psychosocial problems are likely to be overlooked and to become entrenched over the years of misdiagnosis. Other researchers have proposed that where the psychosocial burden of NES is great psychotherapeutic interventions will be of little benefit unless these are addressed³⁸. Moore *et al.*²⁰, however, found no difference in the self-esteem scores between their NES group and normal controls. They concluded that for the NES group, self-perception was not affected and that NES may even enhance self-esteem. We however found no evidence to support this although in some individual cases NES may have secondary gain and may make the patient feel powerful and important.

The lack of psychological follow-up for many of those for whom it was recommended was disappointing although this confirms clinical experience. It was unclear from our data whether this represented a lack of availability of appropriate mental health professionals, a failure on the part of the referrer (the GP in most cases) or the patient. Of those patients who reported receiving psychological input the number of sessions attended was small with most of this group reporting only a single appointment. The account of the participants also suggested that the expertise of the therapist was variable and psychological input often non-directive. In many instances the input offered seemed insufficient to bring about positive change and too short to establish a trusting therapeutic relationship to focus on issues of a personal and potentially distressing nature. The lack of a relationship between

psychological input and outcome was not expected but for reasons given above the current study cannot be considered an adequate trial of the efficacy of psychological therapy. Increases in therapy provision may be indicated but this may be of limited benefit without improved education and training about NES to psychologists and other deliverers of psychological therapies. Identifying patients' perceptions and understanding of NES and factors associated with outcome is the material that is needed for effective tailoring of treatment and to better target treatment to those who are most likely to benefit from psychological input.

For many of the participants in this study, it was the GP who recommended that they undergo further inpatient investigations and it is reassuring that the majority agreed with the diagnosis. It was a significant and previously uninvestigated finding that 10 GPs did not agree with the diagnosis and continued to prescribe AEDs despite the evidence and recommendations to the contrary. It is not clear whether these GPs had other evidence to refute the diagnosis or whether this was due in some instances to an inadequate understanding of the condition.

There was an association between high frequency of NES prior to the diagnosis, chronicity of the condition, continued use of AEDs and a poorer outcome. It seems likely that those who experience more frequent, long-standing NES, together with the ongoing use of AEDs are less able to change their cognitions and behaviour. It has been a consistent finding that length of misdiagnosis relates to outcome and most researchers have stressed the need for accurate early diagnosis^{23,36,37,40}. This study would seem to reinforce this conclusion.

The current study is one of the few to include patients' perceptions and reaction to a change in diagnosis from epilepsy to NES. It indicates that current level of education and psychological support is far from adequate and that patients' response to a diagnosis of NES may predict outcome and may possibly be helpful in tailoring the therapeutic approach. Conclusions drawn from this study however must be guarded as much of the data was subjective and likely to be influenced by recall bias and selectivity. Employing a telephone interview rather than a face-to-face interview may also have influenced the findings. In retrospect more detailed information regarding the reasons for limited follow-up and the nature of the psychological input would have been useful. Questions addressed to the GPs were purposefully limited to increase participation rates. More work on the outcome of patients with NES and the potential benefit of psychological therapy is needed that will help target those individuals who are most likely to derive benefit from treatment.

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