The Royal Wolverhampton NHS Trust

A NEADed Approach

Phil Tittensor, Consultant Nurse for the Epilepsies, Jacqui Rowe, Clinical Nurse Specialist for the Epilepsies, Carla Youssef, Clinical Nurse Specialist for the Epilepsies, Francesco Manfredonia, Consultant Neurologist. Royal Wolverhampton NHS Trust.

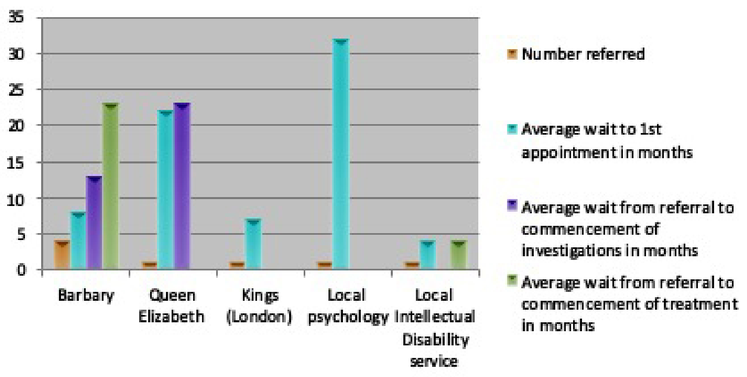
Introduction

Non-epileptic Seizures superficially resemble those caused by epilepsy, but do not happen as a result of abnormal electrical discharges in the brain. The seizure burden for people with Non Epileptic Attack Disorder (NEAD) is very high. Seizures are often frequent and prolonged, causing a significant social impact, injuries and hospital admissions. The overall incidence is thought to be between 2 – 33 per 100,000, making it a significant neurological condition (Benbadis et al 2000).

The problem

More readily available video telemetry and video capture on mobile telephones, have made it much easier for experienced clinicians to diagnose NEAD. However, its treatment has proven more challenging, with very limited services available. Approaches based on Cognitive Behavioural Therapy (CBT) have the best evidence, but there is a paucity of good quality trials to investigate alternative treatments. In addition, there is very limited access to appropriate psychology services in many areas. Management pathways often involve referral to a tertiary centre. This can lead to very long waiting times for either the diagnostic confirmation or treatment (see graph 1). Attempts have been made to provide short interventions that could be delivered locally (NEST 2008). Some patients will be rendered seizure free simply by having the condition carefully explained and some very simple avoidance techniques taught (Hall-Patch et al 2010). However, the majority of these patients end up being seen in epilepsy services, often for many years, with little improvement in their seizures.

Graph 1 - waiting times for tertiary and local assessment and treatment



Royal Wolverhampton NHS Trust NEAD audit

Method

An audit of 35 consecutive NEAD patients, attending appointments with the epilepsy nursing team, was undertaken in April 2019, with seizure outcomes measured. Data was recorded using the Partners in Epilepsy Database (PIE) and the RWT Portal system, and captured using an Excel spreadsheet. Data was compiled on level of diagnostic certainty (La France et al 2013), seizure semiology, time to diagnosis and seizure outcomes.

Results - Diagnosis

Thirty-five patients were reviewed in that time, twelve male (34%) and twenty-three female. Over half (57%) were referred for long-term management of their condition. Nine patients (26%) had a diagnosis of epilepsy when referred to the nursing team which was later changed to either NEAD or a combination of the two conditions. Six were referred for either a second opinion from a consultant neurologist or for primary diagnosis of NEAD.

Over half of our cohort (57%) had been diagnosed within 3 years of presentation. The nationally accepted average is 7 years to diagnosis. Over a quarter of our cohort (26%) was waiting for longer than 7 years for a diagnosis to be made (see graph 2).

The majority of our cohort had convulsive non-epileptic attacks (80%). 17 of these (49%) had a mixed semiology, with catatonic collapsing events and or dialeptic (staring) events in addition to their convulsive episodes. Very few patients had purely catatonic (6%), dialeptic (3%) or mixed, non-convulsive (9%) events. One patient had a semiology that was not possible to classify.

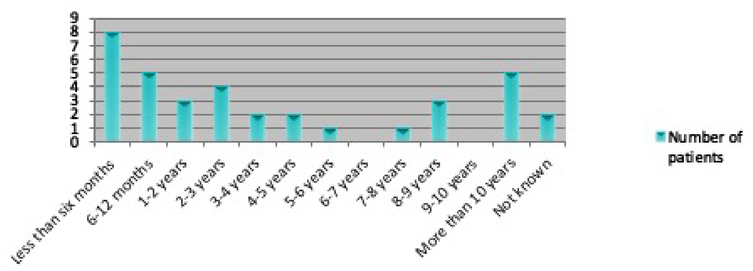
57% of our patients had a diagnosis made following a review of an ictal event by an experienced clinician, with concordant EEG findings (see graph 3). For 19 patients (54%) the diagnosis was made by a consultant neurologist. 11 (31%) were diagnosed by an experienced epilepsy nurse, with the remaining 5 having been diagnosed by a consultant in behavioural neurology (2), a consultant neuropsychiatrist, a consultant psychiatrist or at the tertiary centre but not clear about the clinician's specialism (1 each).

Results - Outcomes

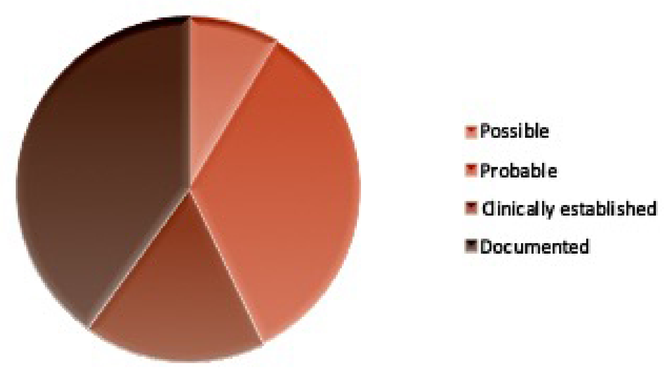
The majority of patients showed symptom improvement following the involvement of the epilepsy nursing service. The average seizure frequency of our cohort reduced from 708 per month (20 per patient) to 347 per month (10 per patient). 11 patients achieved seizure freedom for more than 3 months, which is significant as this is the driving threshold for NEAD (see Graph 4). The 35 patients were seen 141 times from referral to the time of the audit. The average visits per patient was 4 (range 1 - 11).

The majority of patients are continuing under the review of the epilepsy nursing team (83%). 6 (17%) have been referred to the tertiary centre for treatment (with 2 of these remaining under epilepsy nursing review as well). One has been referred to the tertiary centre for further diagnostic evaluation and one discharged to the GP.

Graph 2 - Length of time to NEAD diagnosis



Graph 3 - Level of diagnostic certainty



Levels of diagnostic certainty of NEAD

This was measured using the International League Against Epilepsy (ILAE) scheme (La France et al 2013).

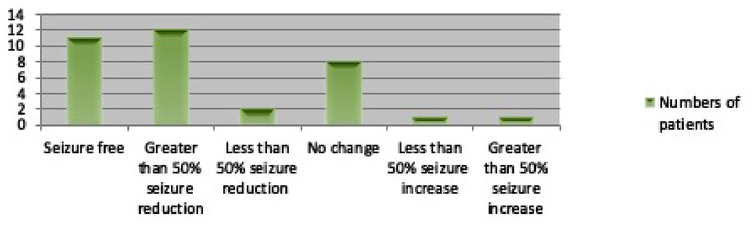
Possible indicates consistent history, event described by witnesses or patient with no epileptiform activity in routine or sleep deprived inter ictal EEG.

Probable is consistent history, event reviewed by clinician in person or on video showing semiology typical of NEAD with no epileptiform activity in routine or sleep deprived inter-ictal EEG.

Clinically established is consistent history, with the event reviewed by a clinician experienced in the diagnosis of seizure disorders, either in person or on video, while not on EEG with no epileptiform activity in routine or ambulatory ictal EEG during a typical event, the semiology of which, would make ictal epileptiform EEG activity expectable during equivalent epileptic seizures.

Documented is a consistent history, an event reviewed by clinician experienced in the diagnosis of seizure disorders showing semiology typical of NEAD whilst on video EEG. No epileptiform activity immediately before, during or after the event captured on ictal video EEG with typical NEAD semiology.

Graph 4 - Change in seizures from referral to audit



A Proposal

The success of psychological approaches often depends on the patient's acceptance of the type of therapy on offer and the therapist themselves. We have begun to pilot a short, nurse led intervention within the epilepsy service in Wolverhampton. Patients are given the choice of three intervention pathways; A CBT approach (NEST 2008) an approach using relaxation techniques, originally tried for people with epilepsy (Tittensor 2007), and an approach developed by Broten (2013) for people with depression, using acceptance and commitment therapy (ACT). Patients first receive a 2 hour group educational session explaining NEAD, using the approach described by Hall-Patch et al (2010) and describing the three treatment options. The patients are given copies of the presentation and have a week to choose their preferred pathway. They then receive four, hour long one to one sessions delivered by a Consultant Nurse for the epilepsies at two weekly intervals. Finally, there is a group evaluation and feedback session a few weeks later. Following the intervention, patients are followed up as usual by the epilepsy nursing team.

If seizures remain problematic, further referral to the tertiary neuropsychiatry service or local psychology can be made. There is urgent local psychology support in place for patients or therapists in case of psychological crisis that the epilepsy nursing team are unable to resolve. The epilepsy nursing team meet weekly to provide psychological peer support.

Outcomes of feasibility pilot

At the time of preparation, 6 patients had completed the pilot, with a further cohort of 4 patients undertaking it in October/November 2019. Initial results were:

- All patients chose the ACT pathway
- All patients felt that the therapy was useful to them – all had previously tried CBT type therapy
- Although direct seizure reduction was not a primary aim of ACT, two patients have been seizure free following the course and one is applying for the return of her driving licence
- There were insufficient feedback forms returned at the time of poster preparation for formal evaluation to be presented
- Further dissemination via a peer reviewed journal is planned following the completion of the pilot phase

Conclusions

The audit results confirm that some people with NEAD will see their seizures improved significantly, around a third to the point of seizure freedom, with basic psycho-educational intervention, delivered in a clear and consistent manner by knowledgeable professionals. However, two thirds of people will continue to have frequent non-epileptic attacks. The impact of these can be significant from a psychological viewpoint. While long sessions of CBT have been shown to be helpful, our audit has demonstrated the enormous waiting lists for tertiary treatment, and such programmes may be beyond the ability of most local services to deliver. We believe that a short intervention would be deliverable more widely in the NHS. If our pilot results look promising, we would look to develop a multicentre trial for the intervention.

References

Benbadis SR, Hauser WA (2000). An estimate of the prevalence of psychogenic non-epileptic seizures. Seizure Vol 9:280–1.

Broten L (2013). A brief Acceptance and Commitment Therapy protocol for depression in an inpatient setting: an effectiveness study. Western Michigan State University. Dissertations 189. https://scholarworks.wmich.edu/dissertations/189

Hall-Patch L, Brown R, House A, Howlett S, Kemp S, Lawton G, Mayor R, Smith P, Reuber M for the NEST collaborators (2010). Acceptability and effectiveness of a strategy for the communication of the diagnosis of non-epileptic attacks. Epilepsia Vol 51, issue 1

La France WC, Baker GA, Duncan R, Goldstein LH, Reuber M (2013). Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach. A report from the International League Against Epilepsy Nonepileptic Seizures Task Force. Epilepsia. 54 (11): 2005-2018.

NEST Group (2008). Non-epileptic seizures-a brief educational intervention. Nest@sheffield.ac.uk

Reuber M, Quirishi A Bauer J, Helmstaedter C, Fernandez G, Widman G, Elger CE (2003). Are there physical risk factors for psychogenic nonepileptic seizures in patients with epilepsy? Seizure. 12:561-567.

Designed and produced by The Department of Clinical Illustration and Graphic Design, New Cross Hospital, Wolverhampton, WV10 0QP - Tel: 01902695377

MI_6058114 25.09.19_V_1