

Original Research

Multidisciplinary Management of Psychogenic Non-Epileptic Seizures (Dissociative Seizures) in Children - Lessons Learnt From an Inpatient Service Experience

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Abstract

Introduction: Psychogenic non-epileptic seizures (PNES) present difficulties in diagnosis and management and facilities to manage these children vary greatly.

Objectives: This study aimed to evaluate the effect of a multi-disciplinary inpatient epilepsy/ neuropsychiatric service in improving outcomes of children with psychogenic non-epileptic seizures.

Methods: This retrospective study identifies lessons learnt from managing children with PNES in a specialist inpatient facility in Oxford, United Kingdom over a ten-year period. Forty-two children were identified and categorised into 3 groups: group A (n=21) with one or more epileptic seizures prior to the onset of PNES; group B (n=6) with no epileptic events but interictal EEG showing epileptiform discharge and; group C (n=15) with no prior epileptic events and normal interictal EEGs. All patients received inpatient input for 6-8 weeks from a multidisciplinary team (MDT) led by a neuropsychiatrist and neurophysiologist with special interest in paediatric epilepsy, supported by experienced nurses, psychologists, occupational therapists and hospital schoolteachers.

Results: Following initial investigations (including video-telemetry) to exclude organic pathology, a positive diagnosis of PNES was conveyed to the family, followed by several meetings to answer questions and explore non-drug interventions. Psychological therapies involved exploring areas of stress, introducing the 'idea of gain' and helping to develop alternative coping mechanisms. Anticonvulsants were gradually withdrawn in many cases. At discharge, episodes of PNES had stopped in the majority of children (20/21 (95%) in group A, 6/6 (100%) in group B and 12/15 (80%) in group C.

Conclusion: In our series, the facility of an inpatient epilepsy/neuropsychiatric service allowed for rapid thorough assessment and subsequent successful management of PNES. Early involvement of an MDT allowed children and their parents the space to accept the diagnosis and move forward.

Keywords: Psychogenic Non-Epileptic Seizures (PNES), Multidisciplinary, Inpatient, Management

INTRODUCTION

Psychogenic non-epileptic seizures (PNES) present difficulties in diagnosis and management. The diagnosis is often delayed, and the seizures can often be misdiagnosed as epilepsy¹. As a result, children are prescribed anticonvulsants for long periods, with delay in initiating appropriate intervention for the PNES¹. When PNES occur in children with co-existing epilepsy, the management can be particularly challenging². This article offers a model for managing these children, supported by our outcome data.

Psychogenic non-epileptic seizures (PNES) or dissociative seizures are non-epileptic events resembling epileptic fits, not associated with abnormal cortical electrical discharge³. Various terminologies have been used to describe PNES including pseudo seizures, non-epileptic seizures, and non-epileptic attack disorder.

The annual incidence of PNES was reported as 1.4 and 3.03 per 100 000 in studies from Iceland⁴ and USA⁵. A more recent study from Scotland⁶ reported an incidence of 4.9 per 100 000 per year based on a population of 366,567 over 3 years. The aetiology of PNES is psychological, often precipitated by psychosocial stress⁷. Video electroencephalography (Video EEG), reported by an experienced professional is valuable for a confident diagnosis of non-epileptic seizures and requires a normal EEG before, during and after the recorded event which has semiology discordant with epileptic seizures⁸.

METHODS

This retrospective study reviewed all patients referred over ten years with a final diagnosis of PNES to a specialist Unit at the Park Hospital (Child Psychiatric Hospital) in Oxford, United Kingdom (UK). The referrals were from General Paediatricians, Community Paediatricians, Child Psychiatrists and Child Psychologists from all over the UK.

The diagnosis of PNES was based on (1) the description of ictal behaviour not consistent with epileptic seizures and, (2) video-telemetry confirmation that the behaviours under investigation were non-epileptic seizures.

All patients in the study had been subjected to the standard management protocol that comprised of: (1) outpatient assessment and formulation, (2) multi-disciplinary inpatient assessment, (3) video-telemetry off medication when possible, (4) review of video-telemetry findings with child/parent, and (5) individualized therapeutic plan. The MDT at the Park Hospital was led by a dedicated neurophysiologist with special interest in paediatric epilepsy and a neuropsychiatrist, supported by experienced nurses, psychologists, occupational therapists and hospital schoolteachers. Following outpatient formulation, the children were admitted for a period of 6 to 8 weeks.

Case notes were reviewed for the onset and duration of PNES and semiology, the co-occurrence of epilepsy, inter-ictal and ictal EEG findings, treatment prior to admission, educational attainments, psycho-social difficulties at school and home, the outcome at discharge and follow up.

The children with 'learning difficulties' in this cohort were those who had poor scholastic abilities as determined on assessment by neuropsychologists and educational psychologists at Park Hospital. Children with disturbed family dynamics were identified through the multi-disciplinary assessment.

The main outcome measure was remission (cessation of PNES) at the time of discharge, after 6-8 weeks of inpatient management.

RESULTS

Forty-two children with the diagnosis of PNES were identified during the study period. All patients received inpatient MDT input. The cases were categorised into 3 groups (Table 1): Group A (n=21) with one or more epileptic seizures prior to the onset of PNES; Group B (n=6) with no epileptic events but interictal EEG showing epileptiform discharge and; Group C (n=15) with no prior epileptic events and **normal interictal EEG's**.

Thirty-six children (85.7%) were on one to three anticonvulsants at the time of referral for psychological interventions.

Table 1: Distribution of variables in group A, B and C

	Group A N=21	Group B N=6	Group C N=15
Sex (Male:Female)	9:12	2:4	7:8
Age of onset of PNES (Mean)	11 years (6-16)	11 years (8-15)	12 years (6-15)
Duration of PNES prior to referral (Mean)	18 months (1-36)	18 months (12-36)	17 months (4-48)
Learning difficulties (mild/moderate)	16	3	10
Disturbed family dynamics	11	4	7
Sexual/physical abuse uncovered	nil	1	2

Seizure (PNES) semiology was similar in the 3 groups and consisted of prolonged generalised jerking (including children who sustained minor injuries, were incontinent or had episodes occurring from apparent sleep), thrashing movements, sudden collapse with varying periods of unresponsiveness, fugue state and screaming and hallucinatory behaviours.

Among children who had prior epilepsy (Group A), 19% (4/21) had epileptic seizures in infancy only and were not taking anticonvulsants prior to the onset of PNES. Twenty-four per cent

(5/21) had the onset of epileptic seizures between the ages of 5-7 and were seizure-free for few years prior to the onset of PNES; 52% (11/21) had epileptic seizures between the age of 8-16 with PNES within a few months of epileptic seizure control; only 4.8% (1/21) had active epilepsy when PNES started.

A significant proportion of the children across the groups had learning difficulties and/ or disturbed family dynamics (Table 1).

The outcome at discharge following 6-8 weeks of psychological intervention was as follows (Table 2):

Table 2: The outcome at discharge following 6-8 weeks of psychological intervention

	Group A N=21	Group B N=6	Group C N=15
PNES stopped	20 (95%)	6 (100%)	12 (80%)
Drugs withdrawn	8 (38%)	5 (83%)	15 (100%)
Persistence of EEG abnormalities (n).	Gen spike wave ± photosensitivity (5) Photosensitivity (1) Focal discharge (7)	Gen spike wave ± photosensitivity (2) Photosensitivity (2) Focal discharge (2)	Not applicable
Psychiatric problems unmasked (n)	Conduct disorder (2), Depression (2)	Conduct disorder (1) Anxiety/depression (1)	Anorexia (1) Anxiety (1) Conduct disorder (2)

Follow-up data were available for 17 patients and the mean duration of follow-up was 2 years (1-3 years). There was no recurrence of PNES symptoms in 8 patients (47%) but four developed other psychiatric disorders, anorexia (n=1) and depression (n=3). PNES

gradually reduced during the follow-up period in 2 children (11.7%), who were still having episodes at discharge. There was recurrence in 4 patients (23.5%) and the attacks continued in 3 patients (17.6%). An observation was made of the fact that in this cohort,

the number of children in whom sexual abuse was uncovered was negligible.

DISCUSSION

PNES in children can be very disruptive and distressing for the child, extended family and professionals involved in their care. Their management is resource-heavy, requiring early intervention and the support of an MDT, and delay has significant long term educational and psychosocial implications⁹⁻¹¹.

Previous reviews on the management of PNES have emphasised the importance of a multidisciplinary approach in helping patients identify possible psychological triggers¹². We found that identifying a therapist who the child trusted was crucial in allowing them to explore possible triggers (including abuse).

Soon after admission, the episodes were recorded with video-telemetry, and additional investigations to exclude other causes of seizures or syncope were performed as required. EEG findings were conveyed positively, initially to the parents and then to the child (preferably with an advocate present). Often several meetings with the extended family were necessary to answer queries and acknowledge the emotional turmoil caused by the diagnosis while allowing professionals to explore non-drug interventions. This approach is supported by evidence that early diagnosis is associated with a better prognosis^{9,13,14}. Making a firm diagnosis allows appropriate use of anticonvulsant medications and timely psychological therapy^{1,8}.

Therapeutic interventions, in non-threatening environments such as hospital-school activities, play therapy and planned social outings were used to **explore areas of stress and gently introduce the 'idea of gain' (such as reliance on episodes for friendships or parental attention)**. Children and families were made to understand how emotional distress and physiological stresses could activate atypical defence responses in the body and brain – with PNES being an adverse by-product of this process. Similar studies¹⁵ have used neuro-biological frameworks to achieve the same goal.

Assessments were made of temperament, coping strategies, self-esteem, personal and parental expectations as well as educational difficulties.

In the next phase, the child and parents were helped to develop alternative coping mechanisms and

face-saving strategies for returning to school. For older teenagers, the possibility of being able to drive if the episodes stopped was a positive goal.

Whilst it was relatively easy to withdraw anticonvulsants in children with no clinical evidence of epileptic seizures and normal wake and sleep EEGs, drug reduction was harder in those with epileptic seizures or epileptiform discharges on EEG (despite many not having had a true epileptic seizure for several years) (Table 2). If the residual (group A) or incidental (group B) epileptiform discharge was suggestive of Rolandic epilepsy, and the child had never had a seizure, or not had a focal seizure for a year before the PNES started, anticonvulsants were withdrawn before discharge. However, if the EEG showed generalised spike-wave bursts, which increased as the drugs were reduced, these children were continued on a modest dose of single anticonvulsant at discharge. This was done to avoid the possibility of an epileptic seizure occurring, just when the child and the family had accepted the diagnosis of PNES, and the episodes had stopped or were reducing. We were aware that this strategy sent an ambiguous message to carers; this was managed by emphasising that the anticonvulsant dose should only be altered in future if a definite generalised tonic-clonic epileptic seizure occurred (and showed parents what this type of seizure looked like) with the option to return for further monitoring if there was any clinical uncertainty.

Some interesting facts observed in our cohort were that the clinical presentation was similar in all the three groups and only a very small proportion of those with a history of epileptic seizures in the past were having epileptic seizures at the time of presentation. Relatively few (10/42) had a comorbid psychiatric diagnosis (Table 2). We found a high rate of interictal EEG changes in those without epilepsy. This could be due to sampling error (small sample) and chance.

Our study had a few limitations. As this was a retrospective study, we do not have the precise percentage of children with mild and moderate learning difficulties respectively. We also could not ascertain with accuracy the time interval between the point of referral to acceptance by the service. We did not gather information on whether these children were prescribed antipsychotics but based on our clinical experience we can say that most would not be on treatment with psychotropic medication. We acknowledge that the short-term high success rates of psychological interventions used could be attributed

to the fact that the patients were separated from the stressful environment that was inducing the PNES.

CONCLUSIONS

In our series, the facility of an inpatient epilepsy/neuropsychiatric service allowed for rapid assessment and subsequent successful management of PNES. Early involvement of a multidisciplinary team allowed children and their parents the space to accept the diagnosis and move forward.

As inpatient neuropsychiatric services for children close, it is important to learn lessons from these services and adapt them to outpatient facilities which we acknowledge are already happening. We would like to suggest that each region should identify teams who can help these children and families, with further research needed on whether a team should be available for PNES only or include other dissociative behaviours in children. There is also a need for long term follow up of these young people, to see if other behaviours and psychiatric disorders develop and whether these can be anticipated and prevented.

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