



# Neurologist assessment of reactions to the diagnosis of psychogenic nonepileptic seizures: Relationship to short- and long-term outcomes



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## ABSTRACT

**Purpose:** To determine the relationship between neurologist assessment of reactions to the diagnosis of PNESs and outcomes at 6–12 months and at 5–10 years.

**Methods:** Two hundred thirty-eight patients with psychogenic nonepileptic seizures (PNES) were recruited into a long-term follow-up study. At diagnosis and 6–12 months post diagnosis, doctors recorded their assessments of patient and caregiver reactions to the diagnosis of PNESs.

**Results:** At baseline, 92/238 patients (38.7%) and 73/106 caregivers (68.9%) were assessed as having understood and accepted the diagnosis, while 6.7% of patients and 10.4% of caregivers reacted with anger. At 6–12 months, patient acceptance rose to 57.7%, with caregiver acceptance static at 70.8%. Attendance at follow-up was predicted by the presence of a caregiver at baseline: only one patient who came with a caregiver at baseline did not attend at 6–12 months (OR: 123.80,  $p < 0.001$ ). Outcome at 6–12 months was predicted by patient acceptance at baseline (OR: 2.85,  $p = 0.006$ ) and at 6–12 months (OR: 13.83,  $p < 0.001$ ) and by caregiver acceptance at 6–12 months (OR: 10.77,  $p < 0.001$ ). Presentation to primary or secondary care with attacks at 5–10 years was predicted by caregiver acceptance at 6–12 months (OR: 3.50,  $p = 0.007$ ).

**Conclusion:** Patient understanding and acceptance of the diagnosis of PNESs are linked to outcome at 6–12 months. The beliefs of caregivers may be important for outcome in the longer term, particularly with respect to health-care use.

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## 1. Introduction

Early outcomes in PNESs can be good, with up to 50% of patients becoming attack-free after communication of the diagnosis without psychological intervention [1–5]. Health-care utilization, which is high in this patient group, may also change favorably at diagnosis, and the effect can be impressive [5–7] even in patients whose PNESs continue [5,7].

This apparent therapeutic effect of the diagnostic conversation has focused attention on its content. Published protocols [8–10] provide some guidance as to what to say to patients, though their effectiveness is difficult to assess other than by observational study. One study [11] found that confusion and anger after explanation of the diagnosis were associated with poor outcome. The potential influence of the understanding and reaction of caregivers has not been studied.

In order to determine whether there is a link between patients' acceptance and caregivers' acceptance of a diagnosis of PNESs and outcome, we recorded neurologists' assessments of reactions to and acceptance of the diagnosis in 238 patients who attended a specialist

PNES clinic between 1999 and 2004 and in subsets of whom we had both short-term and long-term outcome data.

## 2. Methods and materials

Between March 1999 and August 2004, 260 consecutive patients seen at our PNES clinic were included in an outcome study [5,12,13]. For the purposes of the present study, we excluded 22/260 patients with a learning disability. The diagnosis was explained by author RD or MO according to a semistandardized protocol [10]. Outcomes at 6–12 months in patients who attended the clinic for follow-up at that time were recorded [5]. Outcomes at 5–10 years were obtained by contacting family doctors (presentation to a family doctor or hospital with seizures over a 6-month period, 188 family doctors responded [12]) and by postal survey of patients (patient report of whether they were free of attacks and time from the last attack (75 patients responded [13])).

At baseline, the interviewing doctor (RD or MO) assessed whether or not the patient had accepted the diagnosis of PNESs and whether a caregiver was present and accepted it. An attempt to come to a judgment was made in every case. The doctor also recorded whether or not the

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patient or caregiver reacted to the diagnosis with anger. The same exercise was repeated at the 6- to 12-month follow-up visit.

In the context of the present study, the word 'caregiver' can be a spouse, life partner, caregiver, relative, or friend who accompanied the patient to the baseline interview. The diagnosis was recorded as 'accepted' if the interviewing doctor was convinced that the patient or caregiver had understood the diagnosis of PNEs as a psychological condition, had accepted that it was related to past and present life circumstances, emotions, etc., and had understood that it would be treatable by psychological intervention but not by medicines. Therefore, for the purposes of the present study, the term 'accepted' also implies 'understood'. Patients and caregivers who appeared to accept the diagnosis but did not appear to understand it, and those who understood the diagnosis but did not accept it, were recorded in the negative.

### 2.1. Statistical analysis

Statistical analysis was carried out using SPSS 21. The Mann–Whitney U test was used to compare continuous variables and the chi-squared test for categorical variables. Simultaneous logistic regression models were used to evaluate the ability of patient and caregiver acceptance to predict baseline, 6- to 12-month, and 5- to 10-year outcome variables (Table 1). Exploratory bivariate analysis was carried out for each. Independent variables correlating with outcome at the 10% level or less ( $p \leq 0.1$ ) were considered for entry into the model. When screening for co-linearity identified two independent variables correlating at the 30% level ( $p \leq 0.3$ ) or less, the variable correlating less significantly with the dependent variable was eliminated. The remaining independent variables were entered into an initial model. Independent variables without significant predictive value at the 5% level ( $p \leq 0.05$ ) were then eliminated, and final analysis was carried out.

Patient and caregiver acceptance data at baseline and at 6–12 months were tested for predictive effect on presentation with attacks at 5–10 years, on whether patients reported that they were free of attacks at 5–10 years, and on whether they had been free of attacks for 6 months or more at 5–10 years. Baseline variables were tested for predictive effect on acceptance data. The study was approved by the Research Ethics Committee of the Southern General Hospital, Glasgow.

## 3. Results

Patient and caregiver reactions to the diagnosis of PNEs are shown in Table 2. Preliminary analysis showed that the data for the whole

**Table 1**  
Baseline variables tested as predictors of patient and caregiver acceptance of the diagnosis of PNEs.

Age at presentation of PNEs
Age at onset of PNEs
Interval between age at onset and diagnosis (delay to diagnosis)
Gender
Employed
Drawing social security benefits
Scottish index of multiple deprivation ( <a href="http://www.scotland.gov.uk/Topics/Statistics/SIMD">www.scotland.gov.uk/Topics/Statistics/SIMD</a> )
Diagnosis of epilepsy + PNEs
Learning disability
On anticonvulsant treatment
PNEs frequency
Emergency presentation with seizures
Medically unexplained symptoms other than PNEs
Contact with mental health services
Diagnosis of anxiety or depression
History of panic attacks
History of self-harm
Prescribed antidepressant
History of sexual abuse
History of physical abuse
History of other psychological trauma

group differed significantly from those for the subset who went on to attend the 6- to 12-month follow-up (and in whom we therefore had 'acceptance' data for both time points). We have therefore presented and compared baseline data relating both to the whole group ( $n = 238$ ) and to the subset who went on to attend the 6- to 12-month follow-up ( $n = 168$ ).

### 3.1. Reaction to diagnosis in patients and caregivers at baseline: the whole cohort ( $n = 238$ )

Of the 238 patients who attended at baseline, 92/238 (38.7%) were assessed by the doctor as having accepted the diagnosis and 51/238 (21.4%) were assessed as not having accepted the diagnosis. In the remaining 95 patients (39.9%), the doctor was unable to make a definite judgment. The ability to make a judgment was strongly linked to the presence of a caregiver (OR: 26.00 (6.06–111.60),  $p < 0.001$ ).

A caregiver attended 106/238 baseline interviews (44.5%). The doctor assessed 73/106 caregivers (68.9%) as having accepted the diagnosis and 33/106 (31.1%) as not having accepted the diagnosis. The difference between patient acceptance and caregiver acceptance was significant ( $p < 0.001$ ).

There was no significant difference between the proportions of patients (6.7%) and caregivers (10.4%) who were recorded as having reacted with anger ( $p = 0.245$ ).

### 3.2. Reaction to diagnosis of patients and caregivers at baseline: those who went on to attend follow-up at 6–12 months ( $n = 168$ )

Among the patients who went on to attend follow-up at 6–12 months, neurologists were able to make a judgment about acceptance in a higher proportion (141/168 (83.9%) vs. 143/238 (59.2%),  $p = 0.002$ ). A higher proportion of patients accepted the diagnosis at baseline among those who went on to attend follow-up at 6–12 months than in the whole cohort (54.2% vs. 38.7%,  $p = 0.002$ ). In contrast, caregiver acceptance was almost the same at 68.9% vs. 68.6% ( $p = 0.871$ ).

### 3.3. Reaction to diagnosis at 6–12 months

At 6–12 months, 168 patients attended follow-up. Those who had attended at baseline with a caregiver were much more likely to go on to attend follow-up at 6–12 months: a caregiver had been present at the baseline interview in 105/168 patients (68.6%) who attended follow-up in comparison with only 1/70 patients (1.4%) who did not attend ( $p < 0.001$ ).

Doctors were able to come to a judgment of acceptance in all 168 patients who attended follow-up at 6–12 months. Of those, 57.7% were assessed as having accepted the diagnosis and 42.3% were assessed as not having accepted it. Of the 113 caregivers who attended at the same time, 70.8% were assessed as having accepted the diagnosis of PNEs while 29.2% were assessed as not having accepted it. Comparing the same subset of patients at baseline and at 6–12 months, these proportions had improved slightly but the change was not statistically significant ( $p = 0.472$  and  $p = 0.319$ , respectively). There was a significant increase in the proportion of patients assessed as not accepting the diagnosis, however (42.3% vs. 29.2%,  $p = 0.017$ ), as more patients had converted from 'no judgment' to 'not accept' than to 'accept'. No patient or caregiver was assessed as angry at 6–12 months ( $p < 0.001$ ).

### 3.4. Relationships between reaction to diagnosis and outcomes at 6–12 months and 5–10 years

The results of binary logistic regression analysis are shown in Table 3. Having a caregiver present at baseline was highly predictive of attendance at 6–12 months (OR: 123.8, 95% CI: 16.8–910.7,  $p < 0.001$ ); that single factor accounting for 46.7% of variance.

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