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Is patient acceptance of the diagnosis of psychogenic non-epileptic seizures linked to symptomatology?

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Abstract

Introduction

Assessment of general symptoms in patients with psychogenic non-epileptic seizures (PNES) comparing those who do versus do not accept the diagnosis.

Methods

Questionnaire pilot study of newly diagnosed psychogenic non-epileptic seizure patients confirmed by video-EEG, using a 59 item general symptom questionnaire, with frequency (score) ranging from never (0) to every day (5). Subsequent blinded assessment of patient's acceptance of diagnosis was made.

Results

Of 13 patients studied, over a 5 month period, 8 accepted the diagnosis and 5 did not. Acceptance of diagnosis was associated with a lower total symptom score (p <0 .001) and significantly lower symptom scores in 7 of the 10 symptom subscales.

Conclusion

The underlying symptomatology of psychogenic non-epileptic seizure patients differs between those who do versus do not accept the diagnosis. The complexity of additional symptoms may contribute to poorer outcomes in those that do not accept the psychogenic non-epileptic seizure diagnosis.

Introduction

Psychogenic non-epileptic seizures (PNES) clinically resemble epileptic seizure but are not due to abnormal brain electrical discharges and have an estimated prevalence of 2-33 per 100,000[1]. Multiple medically unexplained symptoms (MUS) have been reported, in addition to seizures, in the PNES population[2]. Patients vary in terms of their acceptance of a diagnosis and research shows that better outcomes are associated in those that accept the PNES diagnosis[3]. The better outcome could be due to several factors such as difference in illness management or underlying pathophysiolog. The aim of this study was to determine whether symptom frequency differs between the patients who accept versus those who do not accept the diagnosis.

Method

In this pilot study, participants were diagnosed during admission with video Electroencephalography (EEG) negative for epileptiform discharges and completed a newly developed questionnaire that was constructed as part of service development. The 59-item questionnaire was intended to be as broad as possible and was based on the combination of two existing questionnaires[4-6]. The response format was based on one of the parent scales[4]: The categories for symptom frequency are (with corresponding values for scoring): Never/almost never (0), Less than 3 or 4 times per year (1), Monthly (2), Weekly (3), More than once per week (4) and Every day (5). The 59 item questionnaire was divided by content into 10 subscales based on groups of symptoms (see Table 1). Subscale and total scale scores were calculated for each patient by taking the mean of the values of the items in the subscale and scale. Diagnostic acceptance was assessed by whether the patient was willing to accept the non-epileptic seizure diagnosis after explanation. The doctor assessing acceptance was blinded to the questionnaire's results.

Statistics

Patients were assigned to two groups according to the perceived acceptance of the 'non-epileptic seizure' diagnosis whilst an inpatient. The unpaired t-test was used to compare subscale and total scale scores of the accepting and non-accepting groups of PNES patients. The mean of the mean scores were used to calculate the average scores in order to limit the effect of person-person variability.

Ethics

The local Research Design Service advised that this study did not require ethical approval and was a service evaluation with the purpose of allowing patients to raise general symptoms that may be overlooked about during a traditional seizure clerking.

Results

15 patients took part in this study of whom 2 were excluded due to their readmission in the study timeframe of 5 months. The mean age was 34 years (range 17-49) with a median age of 38 years, and female: male ratio of 11:2. Both males were in the not accepting group. A previous epilepsy diagnosis had been made in 5 patients, depression in 3, anxiety in 2 and previous emotional trauma in 2 people. There is no statistical difference in these demographics between acceptance groups.

Table 1 summaries the data based on the mean frequency score (0-5) in 10 symptom subscales. The general symptom burden was significantly less in those patients who were accepting of the diagnosis (mean 1.9 v 3.3, $p < 0.001$).

Discussion

The underlying symptomatology of psychogenic non-epileptic seizure (PNES) patients is lower in patients who accept the diagnosis compared to those who do not. The greater symptom burden in non-accepting patients may be an additional factor contributing to their failure to accept the diagnosis. This study suggests that there may be a benefit to addressing the more general symptoms during admission and diagnosis to improve outcomes as better outcomes have also been reported in PNES patients with fewer somatoform complaints[7].

The small sample size could have caused Type 1 error, but the significance of the data shows an underlying trend in this population which needs further examination. Of the 13 patients studied, the only two males were in the non-accepting group. While gender differences may have affected the results, males in the general population report fewer symptoms than females, suggesting that the results cannot be explained by gender imbalance.

The symptoms reported by patients include high levels of both psychological and somatic symptoms. Although there are several possible explanations for these findings, these data are consistent with a recent hypothesis that the cause of functional disorders is a distributed pathophysiology[8,9]. That is, the underlying pathology consists of numerous, small errors in systems throughout the body in contrast to a specific pathophysiology where a large error is located in one system or part of the body. If the whole body, rather than only the brain, is a complex parallel distributed processing system[8], then any dysregulation within this network system will tend to become distributed over the whole network and therefore have widespread biological, behavioural and psychological consequences. Although yet to be established, this hypothesis is consistent with evidence of covariation between all symptoms of functional disorders[10.11] as well as the evidence of covariation amongst disparate biomarkers[9]. If this hypothesis of distributed pathophysiology is correct, then non-accepting patients should differ in (aggregated) inflammatory or metabolic biomarkers compared to accepting patients, have less effective behavioural coping styles, consistent with evidence of poorer outcome in non-accepting patients[3] and, consistent with data observed here, have more somatic and psychological symptoms.

Conclusion

The patients who are less accepting of the diagnosis of non-epileptic seizures have significantly more multi-system non-specific symptoms and this might explain the management difficulties often experienced in such cases. The poorer outcome previously reported in non-accepting patients [3] may be due to *both* differences in pathophysiology and disease management.

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