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Clinical Study

Communicating the diagnosis of psychogenic nonepileptic seizures: The patient perspective

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ABSTRACT

Psychogenic nonepileptic seizures (PNES) are a common cause of refractory seizures. Video-electroencephalographic (EEG) monitoring has allowed PNES to be effectively distinguished from epileptic seizures. Once the diagnosis of PNES is established, neurologists face the challenge of explaining it to patients. Patients may not always receive the diagnosis well. The aim of this study is to evaluate how effectively patients receive and perceive the diagnosis of PNES. This prospective study was conducted in an eight-bed epilepsy monitoring unit (EMU). Adult patients with newly confirmed PNES were included. After receiving written consent, a self-administered questionnaire was given to patients after the attending physician had communicated the diagnosis of PNES. A total of 75 patients were recruited. All patients had their typical seizures recorded on video-EEG (range 1–12, mean 2.18). Seventy patients were satisfied with the diagnosis of PNES. Nine patients did not agree that PNES has a psychological cause. Nineteen patients thought that the EMU doctors had no clue as to the cause of their seizures and 20 thought that there was no hope for a cure of their seizures. A significant number of patients with PNES feel that there is no hope for cure of their seizures. Thorough education about PNES, properly preparing patients before discussing the diagnosis of PNES, and preferably earlier diagnosis may prevent this miscommunication and result in better outcomes. A comprehensive approach including psychological counseling and psychiatric input, evaluation and treatment, in order to bring the illness from the subconscious to the conscious level, and effective follow-up may be helpful.

1. Introduction

Psychogenic nonepileptic seizures (PNES) are a common cause of refractory seizures. PNES are seen in 10–58% of adult patients with intractable seizures. PNES account for 10–40% of all patients referred to epilepsy centers [1,2]. These seizures are often misdiagnosed and patients are at risk of receiving inappropriate medications for prolonged treatment periods or invasive interventions such as intubation and vagus nerve stimulator implants [3]. Simultaneous video-electroencephalographic (EEG) monitoring has allowed PNES to be effectively diagnosed. Once the diagnosis is established, epileptologists explain to the patients that they do not have epilepsy, but that their seizures are a manifestation of psychological distress. This can be difficult, as patients may be reluctant to accept the diagnosis. Communicating the diagnosis to the patient is very important as it may have therapeutic implications. A substantial number of patients with PNES become seizure-free shortly after being informed of the diagnosis [4–6]. However if this diagnosis is not accurately perceived by the patients, long term outcome and follow-up in these patients may be compromised. We aimed to evaluate how well we are communicating the diagnosis in our comprehensive epilepsy center.

2. Methods

This prospective study was conducted in an eight-bed epilepsy monitoring unit (EMU) where patients were referred for a second opinion for their intractable seizures. We collected basic demographics of the patients in this study (Table 1). Satisfaction with the EMU experience and understanding of the PNES diagnosis were assessed with a self-administered 41 item questionnaire. The first

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Table 1
Demographics of patients diagnosed with psychogenic nonepileptic seizures

Age, mean (standard deviation)	40.5 (12.6)
Female/Male	52/23
Ethnicity	
Caucasian	72
African American	2
American Indian	1
Marital status	
Single	9
Married	49
Divorced	17
Educational status	
Some schooling	3
High school graduate	39
College	31
Unknown	2
Occupational status	
Unemployed	27
Employed	26
Home maker	3
Retired	3
Disabled	16

27 questions developed by the EMU staff used a Likert scale to analyze the patient's experience in the EMU. The remaining 14 items evaluated the patient's understanding of the PNES diagnosis (Table 2) in a yes/no format. Patients were included in the study if their typical seizures were recorded during the video-EEG monitoring, and their seizures were determined to be PNES.

The diagnosis of PNES was established when a typical seizure was recorded on video-EEG, found not to be associated with any EEG changes, and was not clinically consistent with epileptic seizures that may occur without scalp EEG changes (such as simple partial seizures, frontal lobe complex partial seizures, or other seizures from a deep source). We excluded patients with coexisting epilepsy, patients with interictal epileptiform discharges and patients in whom the PNES diagnosis was uncertain. All patients who were on antiepileptic drugs had their medications withdrawn when they were admitted to the EMU. Since PNES may coexist with epilepsy in some patients, we performed 3–5 days of video-EEG monitoring after withdrawal of antiepileptic drugs before confirming the absence of coexistent epilepsy.

Table 2
The 14 questionnaire items regarding perception of psychogenic nonepileptic seizures and patient answers

Questionnaire item	Patient responses, n		
	Yes	No	Abstained
I am satisfied with the diagnosis of nonepileptic spells. (Q28)	70	4	1
Nonepileptic seizures may cause brain damage. (Q29)	9	51	15
PNES means psychological cause of seizures. (Q30)	61	8	6
Diagnosis will change the outcome of my condition. (Q31)	58	12	5
I will follow up with my neurologist. (Q32)	70	4	1
I will follow up with neuropsychological testing. (Q33)	71	3	1
I will follow up with psychiatrist if referred. (Q34)	71	3	1
Doctors have no clue what causes my seizures. (Q35)	19	51	5
There is a physical cause for my seizures. (Q36)	32	36	7
There is help available to treat my seizures. (Q37)	68	4	3
My seizures may improve if underlying stressors are addressed. (Q38)	63	5	7
People think that I fake my seizures. (Q39)	36	38	1
PNES means being crazy. (Q40)	25	49	1
There is no hope for me to get rid of seizures. (Q41)	20	52	3

During the EMU admission, patients were asked whether they would be interested in evaluating the communication of their PNES diagnosis. All patients included in the study signed a written consent form. The study questionnaires were given to the patient by an epilepsy fellow shortly after the attending epileptologist had communicated the final diagnosis of PNES. In our institution, eight attending epileptologists rotated on the EMU. Even though there was no scripted discussion with the patients or their family members, these attendings presented the diagnosis of PNES in a similar way as "good news" and explained the nature of the condition, its possible causes and the treatment plan. The attending epileptologists also discussed with the patient that discontinuation of antiepileptic drugs avoids unnecessary medication adverse effects and is a key positive aspect of the diagnosis. The treatment plan typically includes neuropsychological testing and counseling in addition to psychiatric evaluation. All patients with the diagnosis of PNES were given a 3 month follow-up appointment in the epilepsy clinic. All patients were also scheduled for neuropsychological testing and referred to a psychiatrist to follow-up as outpatient.

All patients with PNES captured during the EMU evaluation were approached for this study. Four patients refused to be enrolled in the study; they did not differ in demographics from other patients. We analyzed 75 consecutive consenting patients diagnosed with PNES on video-EEG monitoring. We also reviewed if patients followed-up in the neurology clinic and if they had neuropsychological testing after discharge from the EMU. In patients who returned for follow-up (33 patients, 44%) we reviewed seizure control at follow-up. The study was approved by the Vanderbilt University Institutional Review Board.

3. Results

There were 52 females and 23 males. Their mean age was 40.6 years (range 16–80). The mean age of onset of these seizures was 34.1 years (range 4–76). Patients were monitored for a mean of 3.2 days (range 1–8) in the EMU to capture their typical seizures. The mean duration of PNES before the final diagnosis was 71.5 months (range 1–564 months, median 24 months, standard deviation 123.8 months). The mean duration of PNES in women was 76.1 months (range 1–564 months, median of 24 months and standard deviation 127.2 months) while mean duration of PNES in men was 61 months (range 1–540 months, median 13 months and standard deviation 118.1 months). Males were significantly older than females when they started to have PNES ($p = 0.01$, Wilcoxon rank sum test) and at the time of video-EEG monitoring ($p = 0.02$, Wilcoxon rank sum test) (Table 3). Forty-two patients (56%) had a high school degree and 31 patients (41.3%) had college education while other patients did not finish

Table 3
Demographic and clinical variables stratified by sex in patients with psychogenic nonepileptic seizures

Variables	Sex	Patients	Mean	SD	Median	*p* value (Wilcoxon rank sum)
Age	F	52	38.69	12.69	35.5	0.03
	M	23	44.74	11.72	49	
Age at seizure onset	F	52	31.69	14.22	31	0.01
	M	23	39.83	13.68	41	
Motionless seizures	F	52	1.35	2.21	1	0.48
	M	23	1.48	1.88	1	
Motor seizures	F	52	2.17	2.56	0	0.97
	M	23	2.13	2.67	1	
Duration of seizures (months)	F	52	76.1	127.2	24	0.06
	M	23	61.2	118.1	13	

F = female, M = male, SD = standard deviation.