Clinical Profile of Patients with Psychogenic Non-epileptic Seizures in Puerto Rico

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Objective: Specialized epilepsy clinics receive many cases (20%–30% of total cases) in which the patients are diagnosed with psychogenic non-epileptic seizures (PNES). In Puerto Rico, there has been a lack of research on and data about patients with PNES. This study examined the clinical profile of 34 patients with a confirmed diagnosis of PNES.

Methods: A secondary analysis of 34 clinical records of patients with PNES was conducted. The resulting profile was based on clinical interviews, the behavioral presentation of seizures, the history of traumatic experiences or abuse, and the relationship between PNES events and life stressors. Also, the Beck Depression Inventory-II was used to explore depressive symptoms.

Results: Seventy-six percent (n = 26) of the patients were female, with an average age of 34.32. All the patients in this sample experienced a PNES episode that was induced in the office through hypnotic imagery. In most cases, seizures consistently manifested PNES semiology: 82% presented unsynchronized and violent limb movements and featured vocalizations, pronounced ictal pelvic thrusting, and side-to-side head movements. Furthermore, 47% of the patients reported histories of trauma related to sexual, physical or emotional abuse. Moreover, 94% stated that most of their convulsions were triggered by stressful life events. Additionally, 50% of the patients presented symptoms of depression.

Conclusion: The clinical profile of patients with PNES reveals that a considerable number of them presented a history of multiple traumatic experiences and most seizures seemed to be induced by stressful events. It is recommended that additional clinical research be conducted on PNES, with the aim of achieving the effective detection and diagnosis of the disorder, as well as increasing the focus of the healthcare industry on developing evidence-based interventions. [*P R Health Sci J 2017;36:212-217*]

Key words: Psychogenic seizures, Psychological trauma, Depression

Psychogenic non-epileptic seizures (PNES) are described as time-limited episodes of alterations of consciousness and sensation and involuntary motor movements, which are associated with psychological conflicts instead of ictal epileptiform discharges (1,2). The behavioral manifestation of the phenomenon can be confused with epilepsy. However, there are some features that are more frequently reported in patients with PNES, such as, side-to-side head movement, prolonged duration, pelvic thrusting, ictal crying, atonic postures lasting more than a few minutes, and unusual unsynchronized movements (3).

PNES are recognized as being among the most common non-epileptic events (4). Many studies report that about 20% to 30% of patients attending specialized epilepsy centers are diagnosed with PNES (2, 5–7). The prevalence estimated by Benbadis and Hauser highlighted an annual incidence rate of 1.4 per 100,000 in the population studied (5). Consistently, around 75% to 80% of PNES sufferers are reported to be women (8). The usual onset is around the early 20s (4, 8), and it has been found that around 5% to 20% of patients diagnosed with epilepsy have comorbid PNES (4,9–10).

Usually, there are other psychiatric comorbidities associated with PNES, such as depressive, anxiety, somatoform, dissociative, personality, and post-traumatic stress disorders

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(11). Moreover, it has been documented that certain etiological factors are associated with PNES. These factors are history of trauma, significant interpersonal problems in both the family and the close social environment of the sufferer, unresolved bereavement, and deficient coping styles when dealing with stress (8, 12–13).

PNES is a phenomenon that affects not only the patient but also that individual's close relatives and friends. It has been documented that the presence of PNES usually is related to serious interpersonal, financial, or psychiatric problems (or to a combination of any two or all of the previous). Furthermore, longitudinal research has established that the estimated time of an accurate diagnosis is 7 years (9,14). Many PNES patients receive erroneous diagnoses, inappropriate antiepileptic drugs, harmful treatments, and ultimately unnecessary referrals for presurgical evaluations before finally receiving a correct diagnosis. Usually they are treated with antiepileptic drugs, which complicate the process of obtaining the correct diagnosis (9) and can harm the individual, bringing with them a greater risk of side effects (1). Moreover, several reports have indicated that diagnostic delay often causes a PNES sufferer to experience negative stereotypes and to mistakenly build his or her life around the erroneous epilepsy diagnosis (1, 15).

To date, intensive video-electroencephalographic (VEEG) monitoring is considered the gold standard for a proper diagnosis of PNES (1,16). However, other methods have been used in attempts to diagnose this clinical phenomenon (e.g., provocation techniques) (16). The outcome of an individual can improve if a correct diagnosis is made early and when the appropriate psychiatric medications and psychotherapies are administered (4).

In Puerto Rico, there has been a lack of research concerning investigations with PNES patients. The main purpose of this study was to develop an initial psychological profile of patients with PNES. Our aim was to document the specific semiology of Puerto Rican patients that were treated or evaluated by the second author. Also, we documented the lifetime number of stressful events and of traumatic experiences that the PNES patients reported having endured. We suggest that research into PNES in Puerto Rico is important, especially for mental health clinicians who possess little knowledge about the condition and its treatment. In a recent review conducted by Martínez-Taboas et al., it was documented that PNES has received little recent attention in Latin American journals. The last decade has seen such journals publishing only a few case discussions and some reports of case studies that were conducted with small numbers of participants (2).

Methods

Design

The research described in this manuscript was non-experimental and exploratory in nature (17). PNES is an understudied clinical phenomenon, and very few mental health professionals are well-versed in the differential diagnosis of this psychiatric disorder. The purpose of this exploratory study was to bring some relevant preliminary data to what has been a poorly researched topic in Puerto Rico. The intention of this analysis was to find the clinical psychiatric profile of PNES patients in Puerto Rico.

Procedure to guarantee the participant's rights in the investigation

The Institutional Review Board (IRB) of Carlos Albizu University approved this research. It was declared exempt because it would consist of a secondary analysis of data and wouldn't involve contact with patients. All the clinical files that were utilized in the current investigation had a confidentiality agreement document signed by the participant granting the use of the file for future research or publication purposes without releasing the participant's identity information. In the case of persons under the age of 21, the parents or guardians signed the agreement. These files were seen and examined only by AMT, who was the clinician who evaluated all the patients. Each file had a numeric identification code, which facilitated the matching process of the files with the socio-demographic and semiology document sheets. This information was stored safely under lock and key in AMT's office, where he has his private practice.

Clinical records

This study was based on the analysis of secondary data 34 clinical records obtained from the clinic of Dr. Alfonso Martínez-Taboas, who is the clinical psychologist of the Puerto Rican Society of Epilepsy and who has more than 25 years of experience with epilepsy. The patients whose clinical records we utilized were referred by different neurologists to Dr. Alfonso Martínez-Taboas's private clinic because each of these patients presented a clinical profile consistent with PNES.

The inclusion criteria for this study were being over 10 years old and presenting a positive diagnostic profile of PNES. In order to determine the presence of PNES, the following 4 criteria were applied in all cases: 1) There was clear and rapid induction of PNES in the presence of Dr. Martínez-Taboas, using the hypnotic induction protocol (see below) (18); 2) the semiology was consistent with PNES (e.g., pelvic thrusting, prolonged ictal atony, asynchronous limb movements); 3) the patient was not responding to the usual anti-seizure medications; 4) the referring neurologist has a strong suspicion that the clinical manifestation was congruent with PNES.

Procedure

After conducting the clinical assessment, the clinical psychologist carefully questioned the patient about his or her history of sexual, physical, or emotional abuse. In addition, the patient was questioned about any possible correlation between convulsive episodes and specific stressors. Additionally, the clinical psychologist collected data from the patient and his or her family on the semiology of the seizures.

After collecting the clinical data, the clinical psychologist explained to the patient and his/her family members that in many cases the diagnosis of PNES could be usefully explored by creating in the patient some imagery related to that patient's most recent episode. All the patients consented to the procedure.

The convulsions were induced by the clinician using a protocol of hypnotic imagery. In this protocol the patient is mentally regressed to the exact date and hour of his/her most recent seizure. Previous research with this technique reveals that many PNES patients begin rapidly to convulse in front of the clinician (18). In our study, when the patient convulsed, the clinical psychologist immediately recorded the event in the clinical notes. All the convulsions stopped abruptly after the psychologist firmly commanded that the ictal behavior cease. It should be noted that this procedure was conducted in a single assessment session that usually lasted from 3 to 4 hours per patient.

As all the patients convulsed during the hypnotic protocol, the psychologist documented the semiology of each one. It should be mentioned that in each case, a family member was present during the induction, and in all (100%) the cases, the family members corroborated that the seizures were exactly like the ones manifested in the patients' natural environments.

Measures

A template was created in order to obtain the patient's socio-demographic and psychiatric data, with the main purpose being to develop a profile of people suffering PNES. The socio-demographic data consisted of gender, age, residential area, marital status, and occupation.

Additionally, all the patients received a routine clinical interview. The focus of the clinical interview was on their seizures and other neurological manifestations. The information obtained was related to determining what type of neurological or psychiatric diagnosis the patient presented, whether he or she was taking anti-seizure medication, the time frame of the seizures, and whether there was a history of previous psychiatric and/or psychological treatment.

As part of the assessment (conducted by the clinical psychologist), the Beck Depression Inventory-II was administered; this is a 21-item self-report instrument designed to assess the possible presence and severity of depression (19). Good indices of internal reliability and construct validity have been reported for this instrument with Puerto Rican samples (20). Of the total sample, 24 of the patients filled out the Beck Depression Inventory-II. In addition, data (self-reported) were gathered regarding each patient's history of diverse types of trauma (when such trauma was present). To collect information about the possible presence of trauma and stressors, the clinical psychologist inquired about their presence and duly documented each type of trauma in the clinical notes.

Statistical analysis

The analysis consisted of descriptive statistics that presented the data found in the clinical files of the 34 patients. Frequencies were performed and central tendency measures and percentages were calculated. These data allowed us to better understand the profiles of the sample patients, Puerto Ricans suffering from PNES. These analyses were performed using the Statistical Package for the Social Sciences version 21 program (SPSS-21).

Results

For this study we examined the clinical records of 34 patients (26 females and 8 males) who, at the time of the evaluation, fell in the age range of 10 to 64 years (mean = 34.32 years). Most of them were married (50%), followed by those who were single (41%), separated (6%), or widowed (3%).

In reviewing the medical histories, 47% indicated that they had tentatively received a diagnosis of epilepsy prior to the study, with 41.2% indicating that they had previously been diagnosed as having the tonic–clonic type; 2.9%, the complex partial type; and 2.9%, both absence and tonic–clonic seizures; 53% had never received a formal diagnosis of epilepsy. Of the study participants, 70.6% had received a prior psychiatric diagnosis. Most reported a history of major depression (50%), followed by anxiety disorders (5.9%), combined depression and anxiety (5.9%), bipolar disorder, type 2 (2.9%), conversion disorders (2.9%), and a combination of conversion and depressive disorders (2.9%).

Table 1. Semiology and other characteristics of the convulsions

Variable	Total (N = 34)
Semiology of the convulsions, n (%)	
Desynchronized limb movements	28 (82.4)
Pelvic thrusting	15 (44.1)
Side-to-side head movement	13 (38.2)
Prolonged atonic behavior	12 (35.3)
Status epilepticus	10 (29.4)
Ictal crying or vocalizations	8 (23.5)
Urinary or fecal incontinence	0 (0)
Duration of seizures	
0–5 min.	10 (29.4)
6–10 min.	7 (20.6)
11–15 min.	2 (5.9)
16–20 min.	5 (14.7)
21–30 min.	5 (14.7)
31 min or more	4 (11.8)
Unknown	1 (2.9)
Recovery	
Quick	6 (17.6)
Moderate	16 (47.1)
Slow	8 (23.4)
Unknown	4 (11.9)

All the patients presented clearly defined PNES in front of the clinical psychologist and a family member. The semiology of each of the 34 patients was consistent with what other clinicians have recorded in the psychological/psychiatric literature about PNES. Most (82%) presented strong desynchronized limb movements, in many cases throwing fists in the air and experiencing thrashing behaviors. For example, 1 female patient

Table 2. History of abusive and/or traumatic experiences

Variable	Total (N = 34)
Any abusive experiences, n (%)	
Yes	16 (47)
No	16 (47)
Unknown	2 (6)
Type of abuse, n (%)	
Emotional	7 (20.6)
Sexual	7 (20.6)
Physical	6 (17.6)
Other traumatic experiences, n (%)	
Yes	9 (26)
No	18 (53)
Unknown	7 (21)
Stress in relation to the onset of seizures, n (%)	
Yes	32 (94)
No	2 (6)

fell to the floor and frenetically began to fight as with an invisible attacker. Her face showed terror and extreme fear. Interestingly, the convulsions of this patient began shortly after she was raped. It was also frequently recorded that nearly half of the PNES patients in the sample presented pelvic thrusting and side-to-side head movements, which are rare in epilepsy. Thirty-five percent presented a state of complete and prolonged atonic behavior, which also is rare in genuine epilepsy. Furthermore, 29% presented repetitive convulsions, as are seen in status epilepticus. Lastly, a few (23.5%) cried or uttered vocalizations. None of the participants reported experiencing urinary or fecal incontinence.

About a third of the PNES-related episodes lasted from 0 to 5 minutes (29.4%), followed by those lasting from 6 to 10 minutes (20.6%). Those that lasted from 11 to 15 minutes were the least reported in this study (5.9%). Of note, the above mentioned episodes of 42% of our patients lasted more than 16 minutes, which is highly unusual in epilepsy. Recoveries from PNES were reported as fast (17.6%), moderate (47.1%), or slow (23.4%) (see Table 2). By "fast," we mean a recovery with clear consciousness that was reached in less than 5 minutes. "Moderate" recovery was defined as reaching such consciousness in from 6 to15 minutes. And "slow" was the classification when a patient required more than 15 minutes to regain consciousness.

As part of the clinical evaluation, all the patients were carefully questioned about a variety of abusive or traumatic experiences. Nearly half (47%) reported a history of sexual, physical, or emotional abuse—of whom some reported having experienced a combination of any 2 or all 3 types of abuse. Additionally, 26% reported having suffered other types of traumatic experiences (e.g., a car accident, the death of a loved one, an assault). In total, 73% of the patients reported having suffered some type of traumatic experience (see Table 2).

Next, we examined whether PNES patients reported stressful events as part of the initiation of their convulsions. The great majority (94%) confidently stated that most of their convulsions were triggered by stressful events (e.g., family disputes, romantic breakups, acute problems in their employment).

Lastly, most of the patients filled out the Beck Depression Inventory-II (n = 24). Significantly, 50% of the patients scored above 21 points, which, according to the clinical norms, is indicative of having the clinical symptoms of a depressive disorder. At the time of evaluation, they presented a range of scores (from 3 to 40) (mean = 21.4).

Discussion

The current study comprises the first systematic presentation of a clinical profile of PNES in Puerto Rican patients. Consonant with those of previous, international studies, our results show that most of the patients in our study with a diagnosis of PNES were female (76.5%) (21). In addition, our results indicate that the semiology of the patients was similar to those reported in India, Turkey, and the USA (22). By this we mean that Puerto Rican patients with a diagnosis of PNES presented a behavioral repertoire (e.g., pelvic trusting, desynchronized limb movements, atonic behavior) that is comparable with that documented in other countries.

In an unpublished dissertation, Aviles (23) presented 10 cases of Puerto Rican children who manifested the clinical profile of PNES depicted here. The author argued that in his clinical cohort, he could detect many environmental precipitants such as stressful events, emotional abuse, and sexual abuse. These triggers are similar to what we found in the present study. Consistent with what has been observed in other studies, stressful events stand out as prominent triggers in patients with PNES (24). Ninety-four percent of our sample indicated that their convulsive episodes were related to stressful events (e.g., family disputes, romantic breakups, acute problems in their employment). Moreover, consistent with many other studies, we documented the presence of abusive experiences in 47% of the sample, and another 26% reported having experienced other traumatic events (7,11–12). It must be noted that such abusive experiences as they relate to PNES have been repeatedly reported by many other researchers in different parts of the world (3). Following van der Kolk (25) and Bowman (26), we suggest that the terror produced by such abusive experiences is converted to and manifests as a conversion or somatoform dissociative disorder.

A considerable number of the patients presented marked depressive symptoms. In fact, 50% of the patients scored more than 21 points in the Beck Depression Inventory-II, which score is indicative of prominent depressive symptoms. The systematic review of Bowman and Kanner (27) noted that depressive disorder was highly comorbid with PNES: in some studies more than 80% of PNES patients had a depressive disorder. This should be considered as an important factor to explore in the psychological treatment and management of PNES (28).

Our clinical experience is congruent with that described in the extensive literature, which literature points to the fact that most PNES patients receive an erroneous neurological diagnosis (e.g., epilepsy) and unhelpful treatments (e.g., polypharmacy).

We think that central to this unfortunate situation is a series of complex variables, such as inadequate education about PNES during graduate school and the tendency of some professionals to minimize psychogenic and traumatic factors in their clinical case-loads. To make the situation worse, even after a correct diagnosis of PNES is given to a patient, there is limited information about the proper way to treat the condition. Our experience with patients who have been diagnosed with PNES is that as soon as they are diagnosed, they are left in a clinical limbo about what type of treatment they should receive. This issue needs further research.

It is time that neurologists, mental health professionals, and other health providers recognize that PNES is a real and painful disorder that has enormous costs to the patient, his/her family, and to society at large. For example, Hamilton, Martin, Stone, and Worley (29) have estimated that persons with intractable PNES have lifetime direct costs of over 1 million dollars. That is so because these patients commonly exhibit seizures that are resistant to treatment and said patients often require intensive and expensive procedures, frequent emergency room admissions, unnecessary antiepileptic drugs, and specialized assessment with video-EEG monitoring units.

The results of the current study indicate that the presence of certain, well-identified high-risk variables justify a clinician's considering a diagnosis of PNES in a patient and further exploring that possibility. Thus, PNES should be contemplated when a patient is a female who has frequent seizures, the semiology of which features uncoordinated out-of-phase movements or prolonged atonic behavior; who has a history of abuse or other trauma; and whose seizures are unresponsive to a variety of anticonvulsants and are typically triggered by stressful interpersonal events. In such cases, the clinician has a reasonable clinical suspicion for exploring a possible diagnosis of PNES and should systematically assess his/her patient with that diagnosis in mind.

This study had several limitations. The first being that we did a secondary analysis of data from clinical records. The use of secondary analysis data limits the information that can be obtained as it depends on the notes made by the clinician. This generates the possibility of missing other variables of interest. Another limitation is that the diagnosis of PNES did not depend on what is considered the gold standard method for identifying this conversion disorder; instead, this method involves intensive video-electroencephalographic monitoring. This measure correlates the behavioral convulsive manifestations with the brain activity as recorded by an EEG unit. Although we recognize this shortcoming, it must be emphasized that our clinical diagnosis of PNES was rigorous. As detailed in the Methods section, the diagnosis was established using a plethora of important clinical data, such as psychiatric history, information about abusive experiences, details regarding the semiology of the seizures, and using, as well, a hypnotic protocol that induced a full-blown psychogenic seizure in front of the clinician in charge. Additionally, in all cases a family member was present during the aforesaid induction and confirmed that the seizure was exactly the same as what he or she had witnessed in the patient's natural environment. To further sustain the diagnosis of PNES, during the hypnotic induction, all the patients abruptly stopped convulsing when they received a firm command to stop (17).

Further research is needed to clarify the prevalence of PNES in Puerto Rican patients, especially in neurological and psychiatric clinics. Many individuals suffering from PNES postpone, often for many years, seeking professional help for their symptoms. Additionally, in Puerto Rico there is a lack of access to effective treatments for PNES, which speaks to the necessity for strategic services development. Patients with PNES usually present multiple psychiatric disorders, which provoke enduring and mounting problems, unless they receive the proper diagnosis, one that effectively addresses their underlying psychological problems. We hope that this research effort opens the door for the proper recognition of this serious psychiatric disorder.

In conclusion, the findings of this study demonstrate that patients with a clinical configuration of PNES present a complex somatoform psychiatric presentation, and that many of them endure a lifetime of traumatic experiences.

Resumen

Objetivo: En clínicas especializadas para el tratamiento de la epilepsia, se reciben numerosos casos (20%–30%) donde el diagnóstico correcto es convulsiones psicógenas no-epilépticas (CPNE). En Puerto Rico existen pocas investigaciones y datos sobre los pacientes con CPNE. En este estudio se estudió el perfil clínico de 34 pacientes con un diagnóstico confirmado de CPNE. Métodos: Se realizó un análisis secundario de 34 expedientes clínicos de pacientes que presentaron un cuadro clínico de CPNE. El perfil se basó en entrevistas clínicas, presentación conductual de la convulsión, historial de experiencias traumáticas y la relación entre CPNE y estresores de vida. Asimismo, se utilizó el Inventario de Depresión de Beck-II para auscultar sintomatología depresiva. Resultados: La edad promedio de los participantes fue 34.32 y el 76% (n=26) eran féminas. Todos los pacientes presentaron una convulsión psicógena inducida en la oficina a través de imaginería hipnótica. En la mayoría de los casos las convulsiones presentaban una configuración cónsona con CPNE: El 82% presentó movimientos de las extremidades desincronizados y violentos, además presentaron vocalizaciones, levantamiento pronunciado de la pelvis, atonías ictales prolongadas y movimientos constantes de la cabeza de lado a lado. El 47% reportó historiales de traumas relacionados a abuso sexual, físico y emocional. El 94% indicó que el inicio de sus CPNE se relacionaba a estresores agudos de vida. Conclusión: El perfil clínico de los pacientes con CPNE revela que un número considerable de estos pacientes presentan un historial de múltiples experiencias traumáticas y la mayoría de las convulsiones parecen detonarse con estresores de vida. Adicional, cerca de un 50% presenta síntomas marcados de depresión. Se recomienda realizar otras investigaciones clínicas

con pacientes con CPNE para lograr una detección, diagnóstico y enfoque efectivo fundamentado en intervenciones basadas en evidencia.

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