

Clinical manifestations and cultural correlates of psychogenic nonepileptic seizure symptoms: An Indian perspective

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ABSTRACT

Introduction: Patients with psychogenic nonepileptic seizures (PNES) tend to have more frequent and disabling seizures than those which true epilepsy and are often misdiagnosed as epilepsy due to lack of clear diagnostic criteria and variations in clinical semiology. This study was an attempt to improve the understanding and type of clinical manifestations seen in patients of PNES and the cultural beliefs regarding their symptoms. **Materials and Methods:** In this cross-sectional observational study, 71 patients diagnosed with PNES by neurologists on the basis of their clinical presentation and a two hours normal VEEG recording were enrolled in the study after ethics approval. The clinical manifestations of PNES were recorded in detail along with details of various cultural attributions of the patients to the symptoms which were recorded in open- and closed-ended questions. **Results:** Clinical manifestations included verbal unresponsiveness (74%), whole body rigidity (72%), upper limb (55%) and lower limb movements (39%), vocalizations and head movements in less than 25%, and automatisms in only 6 patients. Pelvic thrusting as a manifestation was seen in only one patient. Thirty-eight patients attributed their symptoms to being possessed by God/ghost/evil spirit; nine to black magic being done on them; twenty-four patients did not relate symptoms to religious beliefs. Sixty-two patients had visited faith healers. **Conclusions:** This study is the first of its kind which looks at various clinical presentations of PNES patients in order to assess if there is any cultural basis for the symptoms.

Keywords: Clinical manifestations, cultural factors, PNES, pseudo seizures, Psychogenic seizures

Introduction

Patients with psychogenic nonepileptic seizures (PNES) tend to have more frequent and disabling seizures than those which true epilepsy and often receive inappropriate, ineffective and costly treatment as they are often misdiagnosed as epilepsy. One of the major limiting factors in its diagnosis is the lack of clear diagnostic criteria.^[1] The presentation of nonepileptic attacks

is usually to family physicians, neurologists, neurosurgeons, and emergency rooms. It is therefore important that family physicians are aware of the various clinical manifestations of PNES as patients may first present dramatically with injuries, which often result in hazardous procedures and treatment given for drug-resistant epilepsy.^[2-4] Early diagnosis and referral to the psychiatrist are vital as a longer duration of the disorder is associated with poorer outcome.^[5]

The onset of the nonepileptic attacks is often gradual and heralded by stress or with auditory or visual stimuli,^[6] though some authors suggest an abrupt onset.^[7] These episodes usually occur when the individual is awake and may present with aura,

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viz. palpitations, malaise, choking, numbness, paraesthesia, pain, odours, tastes, visual hallucinations or distortions.^[6] Researchers have reported frustration in healthcare providers over the understanding of the symptoms, providing the right treatment and a proper liaison or referral system.^[8,9] Recently Magaouda *et al.*^[10] proposed a clinical classification of PNES as: (1) hypermotor, (2) akinetic, (3) focal motor, and (4) subjective symptoms.

Another difficulty the physicians in India face is the lack of awareness among people and cultural beliefs associated with PNES due to which the patients are brought late for treatment. India follows several religions and has God fearing citizens. Apart from idol worship, people believe in spiritual teachings and maybe followers of certain sects. There are also a lot of cultural beliefs in society about black magic, possession states with beliefs related to wrongdoing and getting relief from it by making sacrifices for atonement of sin. Several religions follow their own core beliefs and so people visit temples, mosques, churches, etc., to get relief from their problems. It is commonly seen that for psychiatric symptoms, patients and relatives visit religious leaders, faith healers like a 'guru, baba, fakir, maulana, priest' etc., to get relief from their symptoms. Many cases of conversion disorders or PNES are considered to be related to black magic done on that person and possession by 'atma/soul, satan, genie' etc., as per the religion followed. These people are treated by magico-religious methods due to which symptoms may improve for a few days leading to reinforcement in the belief system. Sometimes these patients may also be taken to family physicians for advice and so it is important that the family physicians refer them to a psychiatrist.

This study was therefore an attempt to improve the understanding and type of clinical manifestation of PNES and study the cultural correlates associated with the symptoms in the Indian subcontinent.

Materials and Methods

Study setting: The study was conducted in the outpatient department of psychiatry of a general municipal hospital.

Study duration: The study was done over a period of 15 months from June 2004 to August 2005 after ethics approval. Data collection was done over 12 months followed by data analysis over 3 months.

Study design: The study was a cross-sectional, observational study utilizing a semi-structured proforma which included all demographic data, the details of the psychogenic seizure, viz. clinical manifestation, duration of the episode, loss of consciousness, incontinence and injuries, if any. The patient's social history was also taken in detail with specific questions to understand the areas of conflicts, interpersonal problems, discord or any other stressors which included stressors with spouse, in-laws, children, interpersonal, workplace, financial

etc., To understand the cultural correlates, the proforma had specific open- and closed-ended questions to know the beliefs of the patient regarding the seizure, going to faith healers, beliefs about seizure being caused by black magic or curse of God and patient's attitude towards his/her own religion.

Sample size and sampling: All patients referred from the specialized epilepsy OPD of neurology for PNES were screened as per universal sampling and only those who satisfied the criteria for dissociative seizures as per ICD 10 criteria were included in the study.^[11] A total of 89 patients referred were screened and 71 patients were enrolled after satisfying inclusion and exclusion criteria.

Data collection: All patients were referred by the neurologist to psychiatry OPD only after they were diagnosed to be having psychogenic seizures on the basis of their clinical presentation and a two hours VEEG recording which was normal. Data collection was done over a period of 12 months from June 2004 to May 2005. Each interview lasted for about 45 min where all the details of clinical manifestations and cultural beliefs of patients were recorded on the proforma.

Data analysis: Frequency distribution was used to denote the gender, religion, clinical manifestations of PNES and the cultural beliefs held by the patients.

Ethical issues: The study was initiated after institutional ethics committee approval and informed consent of the patient.

Results

Characteristics of PNES

Type of physical manifestations

The analysis of the physical manifestations of PNES in our sample revealed a higher clinical presentation of verbal unresponsiveness in 53 (74%) patients, followed by whole body rigidity in 51 (72%) patients, upper limb movements in 39 (55%) patients and lower limb movements in 28 (39%) patients. Vocalizations and head movements were seen in less than 25% of patients. Automatism were seen in only six patients. Pelvic thrusting as a manifestation was seen in only one patient. Many patients also showed more than one physical manifestation [Table 1].

Gender and PNES

Our sample had a female preponderance with 55 females and 16 males and all the physical manifestations were seen nearly equally in both genders except for pelvic thrusting which was seen in only a single male patient. Also eye and head manifestations were seen in 19 and 10 male patients, respectively as compared to the females.

Duration of PNES

The duration of the psychogenic seizures varied from 1 min to 45 min with no patient having any injury, tongue bite or incontinence during the episode. Sixty-one patients were

responsive to commands only after the episode and would suddenly get up and claim to be unaware of what had happened. About nine patients claimed to be aware of what was happening around them during the episode. Only one patient claimed unconsciousness and remained unresponsive in that state for 45 min after which she would wake up without having any memory of the episode.

Frequency of PNES

The frequency of the psychogenic seizures varied from occurring for the first time in 38 patients, once a year for 12 patients, once in 30–45 days for about 14 patients, to about twice/thrice a week in 8 patients and daily episodes in about 3 patients. Forty-three patients did not give any immediate stressor or precipitating event prior to the psychogenic seizure though 28 patients gave stressors like interpersonal problems, fighting with in-laws or husband, not being able to do things her/his way immediately preceding or about a couple of days prior to the onset of the symptoms.

Cultural beliefs associated with symptoms of PNES

Our sample had 62 patients who were Hindus whereas 9 patients included Muslims and Christians. All patients and their families expressed they were religious by nature. Hindus reported following the rituals of fasting, praying, visiting temples, idol worship, attending spiritual talks/religious discourses. Muslims followed namaz and fasting during Ramzan. All Hindu patients gave the cultural beliefs of the existence of black magic. Sixty-three patients were taken by friends/family or had gone by themselves to faith healers like priests/baba/fakirs/maulana etc., to get relief from their symptoms. Patients gave multiple responses about their beliefs regarding the symptoms of PNES [Table 2].

Table 1: Physical manifestations of PNES

Physical manifestations	Number of patients (n=71)	
	Present	Absent
Upper limb movements	39 (54.9%)	32 (45%)
Lower limb movements	28 (39.4%)	43 (60.5%)
Vocalization	18 (25.3%)	53 (74.6%)
Verbal unresponsiveness	53 (74.6%)	18 (25.3%)
Pelvic thrusting	1 (1.4%)	70 (98.6%)
Whole body rigidity	51 (71.8%)	20 (28.1%)
Whole body flaccidity	9 (12.6%)	62 (87.3%)
Eye manifestations	28 (39.4%)	43 (60.5%)
Head manifestations	16 (22.5%)	55 (77.5%)
Automatism	6 (8.4%)	65 (91.5%)

Table 2: Cultural beliefs associated with PNES

Cultural beliefs for PNES	Number of patients (n=71) (Multiple responses)
Beliefs of existence of black magic	62 (87%)
Beliefs that black magic was done on them	9 (12%)
Curse of Goddess	38 (53%)
Possession by soul/ghost/evil spirit	38 (53%)
No religious/spiritual beliefs	24 (33%)

Discussion

This crosssectional study aimed to look at the clinical manifestations of PNES and the cultural correlates associated with the PNES symptoms in India. Our study highlights the clinical manifestations which are a little different from the western literature. The cultural beliefs associated with the symptoms are studied for the first time as there is no literature available.

Clinical characteristics of PNES

Patients of PNES present with varying motor phenomena of upper or lower body movements, rigidity, verbal unresponsiveness or vocalizations which often confuse the physician.^[1-7,12] Varying frequencies of upper limb movements in the range of 55%–85% have been studied by researchers which are in keeping with our findings.^[1,7] Lower limb movements were documented in 39% of our patients which is also similar to the findings of other researchers.^[7] Motor phenomena can include muscle tone increase, opisthotonos, ‘arc de cercle’ phenomenon, occasional jerking and features resembling myoclonic epilepsy, tonic posturing, tonic movements, repetitive motor movements and loss of tone.^[7]

Vocalization during the attacks was marked by its absence in our sample, which was also reported by some researchers.^[7] Eighteen (25%) of our patients had responded to verbal commands during the attack, whereas 75% of them did not. Our findings are in keeping with those of several researchers where 75%–85% of patients had verbal unresponsiveness.^[13-15] Culturally, media depiction of the same is seen in various movies and serials due to which identification of the symptom can be seen in the Indians.

Pelvic thrusting is classically associated with nonepileptic attacks with a variable incidence of 0%–50%^[3,7,13] and may also occur in frontal lobe seizures and temporal lobe seizures.^[16,17]

We had only one patient which is a much-lowered prevalence than the western studies where pelvic thrusting was seen in around 17%–44% of patients.^[18] This could be due to cultural variation seen in the Indian subcontinent where pelvic thrusting symbolizes sexual activity and sex being a taboo subject; patients may not symbolically use pelvic thrusting movements. Another study from India had similar findings.^[19] Seventy-one per cent of our patients demonstrated tonic posturing. Patidar *et al.*^[14] found clinical manifestations as motor attacks in 24 patients and limp attacks in 39 of their 63 patients. They attributed more of limp attacks due to cultural variation and poor emotional support in their patients as compared to the findings of other Indian researchers.^[19,20] Stiffening of the body with clenching of teeth and verbal unresponsiveness in response to stressors is commonly seen in various Indian cultures and is often accepted. There is also a high portrayal of the same in most Indian films and TV serials where a lot of attention is given to the person. It therefore acts as a source of identification for patients who present with PNES.

The presence of eye manifestations, i.e., flutter, staring, uprolling of eyes^[3,7,9,13] was documented by 39% of our patients. Uprolling

and blinking of eyes are again commonly depicted in films/TV serials for seizure-like activity and are also commonly asked by every physician which could account for its prevalence in our sample of patients. On assessing for the presence of head movements, only 22% of the patients documented its presence as compared to 77% who did not exhibit the same. A wide range (20%–60%) of the absence of head movements has been seen in the previous studies, which more or less corroborates with our findings.^[7,13] Symbolically it would reflect turning away from an adverse event or wanting to say ‘no’. We had a low prevalence (12%) of automatisms as compared to other studies.^[1,7] This could be due to the fact that majority of PNES patients manifest symptoms like generalized seizures rather than complex partial seizures where automatisms are supposed to be common. This would therefore account for the low prevalence in Indian culture where seizure is more equated to bilateral motor manifestations than unilateral or focal phenomena.

Not a single patient in our study had any incontinence or injury during the nonepileptiform attack. However, dramatic presentations have been reported.^[13] It is often difficult to differentiate epilepsy from nonepileptic attacks only on the basis of clinical presentation^[20] and especially nonepileptic attacks without motor activity. These patients often get diagnosed with seizure disorder. It is extremely important to understand that patients are not feigning their symptoms but there is a psychological cause, where the underlying anxiety associated with the stressful condition is converted into a physical symptom.^[21] The frequency of episodes seen in our patients was comparatively less than in other studies where daily and weekly attacks were predominant.^[22] This could also be due to underlying psychopathology and conflict. Conflict resolution is not possible for every patient as it is difficult to understand the primary gain which is unconscious.^[23] Sometimes the presence of a stressor or precipitating factor can aid in understanding the conflict which may then be used in a therapeutic alliance to allay the anxiety. But more important is to establish symptom resolution where the family and patient have to be educated regarding the nature of the psychological symptoms and allaying their anxiety about the symptom being life-threatening or detrimental to the patient.

It is important to reduce the amount of attention given to the patient during the attack which is the ‘secondary gain’.^[23,24] Hence relatives have to be counselled regarding the same which then results in the reduction of the symptoms. This is a difficult task in India where there are strong social networks and family ties with cultural, spiritual and religious correlates which may often increase the secondary gain.

Cultural beliefs associated with symptoms of PNES

Our finding of majority of the sample being Hindus is in keeping with the religious background of the country where Hindus are in majority as compared to the minority groups. The Indian culture is rich in religious beliefs of ‘being possessed by Gods or demons’, ‘trance states’, ‘spiritual enlightenment’, ‘fainting

spells’ and ‘teeth clenching’ which are the various dissociative phenomena which have received a revered status in most of the religions followed in India. Eighty-eight per cent (62) of the patients had sought cure from faith healers and fakirs by visiting temples, mosques, dargahs etc., and had followed the preachings of priests and fakirs by spending a lot of money to get rid of the possessed spirits or the wrath of Gods and Goddesses. Even though some of the patients did not feel so, the families accepted the beliefs of friends and relatives to find a cure for the symptoms by magico-religious methods. Most of the symptoms like fainting, clenching of teeth and upper and lower limb movements were considered akin to possession states. Possession states are seen in various cultures and are an accepted phenomenon among the general public. Myths and misconceptions along with feelings of insecurity trigger this response. Some of the difficult cases were also sent to the hospital for evaluation by these faith healers and fakirs. The reason why the faith healers become the first contact is due to the superstitious beliefs present in society, though education of the masses is definitely helping people to understand that it is a mental illness.

However psychological theories may not explain all the symptoms which have led researchers trying to find out structural and functional changes in the brains of those with conversion disorders and establish the neural correlates with improving our understanding of PNES.^[23]

Till then, all those who deal with PNES patients should work towards helping the patients achieve symptom control and improve their prognosis. The focus should be to understand these manifestations as PNES and not true seizures so as to avoid unnecessary investigations and treatment with seizure medications. Many physicians dealing with PNES often feel ill-equipped due to the nature of the symptoms and difficulty in establishing the diagnosis.

Our study had a few limitations. It was done in a tertiary care hospital with patients following up in a specialized OPD and hence may not reflect the findings in general population. It did not assess the underlying psychiatric comorbidities and personality factors which would have helped in the better understanding of the psychogenic seizures. We also did not analyse the association between stressors and the clinical presentation of the patients.

Conclusions

We found PNES with more verbal unresponsiveness as compared to motor symptoms and other clinical manifestations. All Hindu patients gave the cultural beliefs of the existence of black magic and had gone to faith healers for relief of their symptoms. Large-scale prospective studies looking into these nuances with consultation liaison between family physicians as the first doctor of contact and physician and psychiatrists would not only help in improving the awareness but also the prognosis for the PNES patients.

Ethics committee/Institutional review board's permission

We also declare that the study was assessed and approved by the institutional ethics committee/institutional review board and that the letter of approval is available with us for examination. The ethical aspects of the study were conforming to the Declaration of Helsinki.

Declaration of patient consent

Patient consent statement was taken from each patient as per institutional ethics committee approval along with consent taken for participation in the study and publication of the scientific results/clinical information/image without revealing their identity, name or initials. The patient is aware that though confidentiality would be maintained anonymity cannot be guaranteed

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Conflicts of interest

There are no conflicts of interest.

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