

Difficulties in treating psychogenic non-epileptic seizures (PNES)

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Abstract

Psychogenic non-epileptic seizures (PNES) are such pseudo-neurological condition which has puzzled professional to great extent and still proper protocol to treat PNES is lacking. Although PNES is classified under conversion or dissociation disorder but its paroxysmal nature differentiates it from them, posing challenge in its categorization. PNES etiology is psychological but its somatic manifestation purely mimics epilepsy which complicates its diagnosis, though video-encephalography (V-EEG) is the gold standard but its cost and availability restricts its wide use. Till date none of the discipline whether it is neurology or psychology or psychiatric claims PNES in its realm which drew concern during its management attempt. PNES diagnosis is carried by neurologist, its psychological mechanism is better explained by psychologist and its medication better dealt with psychiatrist but its hard to find all these three professional under one roof thus pirouette between these three professionals which costs them financially and put them vulnerable to faulty medication. The present overview briefs the underlying issue and challenges in PNES categorization and diagnosis. Also, it discusses the trivial issues which are significant but mostly ignored.

Key words: PNES, etiology, diagnosis, treatment

Psychogenic non-epileptic seizures (PNES) are the episodes of altered movements, sensations or experiences which are similar to epilepsy but not associated with abnormal discharges in the brain and have psychological bases. PNES resembles epilepsy in its somatic manifestation but the underlying pathology seems emotional turmoil and does not accompany electrophysiological changes as occurring in epilepsy (Bodde et al., 2009). Due to the emotional disturbances, PNES patients seem unable to integrate their cognitive, emotional and sensorimotor information (Ogden, Minton & Pain, 2009). Thus vulnerable to a disturbed, faulty, and inflexible cognitive-affective system.

Categorization limitations

PNES seems to be still in its infancy stage and till now it has not received an independent label as a disorder and is classified under somatization disorder in DSM 5 and dissociation disorder under ICD-10 (Asadi-Pooya & Sperling, 2015). The multifaceted etiology of PNES poses challenge for health professionals making its diagnosis and management difficult. Despite encouraging advancements in this field the diagnosis and management of PNES pirouettes between neurology, psychology and psychiatry (Francis & Baker, 1999). This is because the semiology of PNES seizure is close to epilepsy and it is observed by neurologist because PNES case is firstly reported in neurologist clinic. But its basic etiology is better understood and explained by psychological principles and here psychologists are more apt in explaining PNES underpinned emotional unrest. However, whether emotional distress is the solely reason behind PNES is now debatable because recent researches has too claimed the organic bases of PNES (Labate et al,2012; Ding et al,2013, Ding et al, 2014 & Xue et al,2013). So presently the exact etiology of PNES is still under elucidation though majority of professional since the time Freud still agree the root cause is emotional problem and, if one tries to unfold psychogenic episode of

behind seizures then primarily psychological explanation is sought to get first hand information to figure out the problem of patient. Further, PNES is associated with multiple co-morbidities such as anxiety, depression, Borderline personality disorder (BPD), and mistakenly sometime it is understood as similar to dissociation or conversion disorders though it is classified under the same category but paroxysmal nature of PNES makes it different from that of dissociation/conversion. Since PNES is associated with various psychiatric co-morbidities therefore sometimes the medication part is dealt by psychiatrist.

Ideally management and treatment of PNES requires combined effort of neurologist, psychiatrist and psychologist. But it is very rare and hard to find all these three professionals under one roof and therefore, such eclectic consideration is seldom practiced in most cases. Also, patient rarely visit all these professionals mainly due to social and financial constraints. The situation worsens due to the prejudice and stereotype laden understanding for the clients especially for the females, if encountered with seizures. As none of the departments (i.e. neurology, psychiatry or psychology) claims PNES independently in their realm so it necessitates an eclectic consideration towards PNES, then only one can be conclusive about PNES. In addition, one more problem which increase the vulnerability towards exact categorisation is less informed and unprofessional attitude to label PNES as only attention seeking tendency, which may be disastrous and sometimes leads to off-loading practices by the practitioners.

Issues during diagnosis

Generally, PNES cases are first observed in neurology department because it mimics epileptic seizures and 40 percent of intractable epilepsy and 25 percent of epileptic seizures are actual case of PNES (Baslet, 2011). Therefore, an inappropriate diagnosis of PNES as epilepsy is possible because the clinician has to rule out several overlapping neurological and psychological

disorders. Practically, it is hard for the clinicians to be conclusive during patient's first visit. This occurs as apart from semiological details; patient has to undergo through several neuro-radiological examinations like video-encephalography (V-EEG), magnetic resonance imaging (MRI), CT-scan electroencephalography(EEG) and other routine check-ups to get a clear picture of his/her problem. During problem identification phase patient is called several time where clinician tries to find probable causative factor behind seizure episodes and figure out several predisposing, preceptitative, perpetuating, aggravating and triggering factors. Sometimes it is lengthy, time-taking and troublesome for patients to sustain and cooperate throughout this process which results unrest among the patient and become more vulnerable to psychological dstress. The expectation of immediate treatment by PNES patients mostly results in a consoling or faulty treatment by clinician which lack promise of quality and adequacy. This might not be acceptable, but may be justifiable from the side of clinician because they have to manage patient's expectations to be get cured and built up anxiety to get medicine because it lowers patient's apprehensiveness. Though it benefit patient but in long run it costs physical, psychological and financial burden. (van der Kruijs et al. 2014; Sharpe, & Faye, 2006). The psychopathology associated with PNES is commonly accepted (Reuber, 2009) but a proper diagnosis is warranted, for example, dissociation/conversion disorders need to be differentiated during diagnosing of PNES (Barry & Sanborn, 2001) by a clinical psychologist. However, such arrangement lack majority of the time which poses challenge to correct diagnosis. Moreover, there are multiple psychological and neurological disorders to name a few, mix-PNES (PNES+ epilepsy) and frontal lobe epilepsy may overlap with PNES, thus complicating the diagnostic procedure further. All these issues cast significant impact on correct diagnosis. Also, it is usually observable that it takes too late to ascertain that PNES existed therewith epidemiological evidence of 7.2 years (Reuber, Fernández, Bauer, Helmstaedter, & Elger, 2002) a considerable

time lapse considering the pathological condition during which the patients must have already gone through much turmoil, thus, a worry some condition for the PNES patients.

Only when the seizures becomes intractable, leading to poor prognosis, ultimately get referred to psychiatrists where the diagnosis of dissociation and conversion is very much possible because these disorders are co-morbid in 60 to 90 percent of PNES cases (Bowen & Markand, 1996) and here the patients again reach the primary stage of diagnosis and investigation. Further, PNES patients hardly gets psychological assistance, because drug assistance possibility is maximum if a patient is observed through neurology or psychiatry, though PNES mechanism owes to the psychological principles as well. In addition, medical community too, accepts that PNES occurs due to faulty cognitive-affective system which can be better managed if a trained psychologist intervenes the process, but sadly the role of psychologists in managing PNES is not encouraging, the main reason being lack of acknowledgement and coordination among concerned department. Also on the part of the patients themselves, it is a hard fact that very limited people can afford such costly treatment on the one hand while on the other, the lack of patience, appropriate infrastructure and highly trained professional also has to be a major concern.

Overcrowding of patients

Though there are certain well established diagnostic techniques to evaluate PNES but the question is that how correctly it is being practiced and to what extent it is useful in treating or managing PNES patients, and also who can afford it is still under research. The ground reality regarding diagnosis of PNES is discouraging. Generally, neurology OPDs are full of seizures patients. In such situation, clinicians ask certain major thumb questions to differentiate PNES from epilepsy. In addition a large number of patient's population in their OPDs are to dealt with which may makes provisional diagnosis erroneous. Because there is high possibility that patients

might be suffering from other pseudo-neurological and psychological disorders which the neurologist might have discounted not due to lack of expertise but due to the practice prevailing). The stereotype regarding psychogenic seizure that it happens to those females who annihilate their depraved conduct, particularly sexual desires, complicates the matter. The stigma and prejudice associated with such awful instances prevents appropriate reporting of seizures or PNES. In addition, the patients with psychiatric and psychopathological symptoms such as anxiety, depression, somatization disorder: conversion or dissociation, also visit neurology ward. So educating the patients and their keens is necessary. A major factor creating the crowd in neurology department in India can be accorded to the grave concern that if any one goes to psychiatric ward or for psychological assistance then that person develops a fear of being labelled as "*pagal*" (due to social stigma). It is a crude reality on the ground level which is humiliating and, thus discourages the assistance from such professionals, which must have been benefitting rather. In addition, the prevalence of PNES among females is 75% (Benbadis & Allen-Hauser, 2000) creates a pathetic condition because if she goes to psychiatric ward or for any other similar assistance, it can be embarrassing for her and to her family and casts negatively for future. This may lead to problem in marriage or the marriage life further, if or when any one comes to know. Thus, a prevalence of negative labelling of the medical or psychological assistance in such cases prevents appropriate reporting and treatment both. This highlights the significance of psychosocial components of PNES as well. Only to worsen the situation further, the patients visit the neurology department directly on the one hand, and are adamant to be there only than considering the assistance of a psychiatrist or psychologist, at times even when suggested leading to overcrowding and thus compromising the quality of treatment.

What can be offered?

The existing inconclusiveness regarding a relative incurability of PNES among the practitioners themselves and implicit acceptance to the deteriorated self on the part of the client, owes much to the fact that the patients are considered a natural client of neurology only, implicates the way PNES needs to be addressed. At the onset, discounting the familial, personal and social underpinnings at the very crucial level of diagnosis is sure to emerge into certain implications. And here comes the wide array of matrices entangled at the core and disallowing the specificity to settle down, i.e. the most significant information. The contention of placing the human being as a social construct by its own derivatives puts forth the fact that when a physical or physiological diagnosis discounts the scope for proper etiology, addressing the associated psychological and social indices must be rather warranted. Extending the scope of treatment and its effectiveness must find place in the eclectic approach assimilating a coordinated treatment schedule between neurologists, psychiatrists and a psychologist. While neurologists may deal with the organic pathology and neurologists and psychiatrists taken together may start the diagnosis and study and treat the case simultaneously and a proper counselling offered to the client by a trained psychologist in parallel, and more importantly towards the terminal end, would certainly improve the client's perspectives. Bringing psychiatry and psychology closer to the neurology owes much to the advent of social psychiatry which deals with a mental disorder within its interpersonal and cultural context. Bringing the cultural context means favouring the emic and etic considerations and creating a broader thus complete picture which is sure to improve one's understanding regarding PNES in general and in particular both which must adhere to the merits of cross-cultural psychiatry as well. The austerity of survivor-caregiver metaphor must be apt in such cases. In general, the word 'survivor' is used for the clients with terminal illness with the least possibility to survive after a certain limit e.g. cancer. On the other

hand, the insidious trauma the caregivers are going through in particular, is paid no consideration but a complete treatment package must consider it, as the caregivers have more significant observations and sufferings too. Further there is possibility that clients or their families may not be able to bear the escalating expenses of treatment over time. If the role of social psychiatry and psychological treatment within the ambit of community psychology is made a success, it may lead to rationalized cost of treatment and an improved success rate for sure. To deal with it, placing PNES within the ambit of aided funds from the government schemes or improving an awareness regarding it may help the clients and their keens up to a certain extent at least. The acceptance of reality by the one with PNES and the caregiver must propagate the wider range of social acceptance of a specific condition with the required intensity. Acceptance, motivation, understanding, control and consolidation are the key to treatment to PNES (Lesser, 2003).

It seems considerably fair to allow the principles of community psychology to educate those living with PNES and their keens, as the development of a sensitive prudence within the masses as well is much warranted. Propagating awareness following the principles of community psychology may also help in deinstitutionalizing the stigma associated with PNES. It's significance lies in the fact that during course of the treatment or otherwise as well the PNES clients remain with their keens, family and society as well. It is also noticeable that neurology does not address the behavioural issues associated with PNES which are an integral though and the stigma associated with it. Even the address of stigma in psychiatry or psychology is hardly a decade older. Considering the faulty behavioural manifestations and responses, it is suggestible that the key to social acceptance of PNES lies in the propagating waves of community psychology and social-psychiatric interventions guided by the physical treatment by a neurologist. For example, treatment of PNES including cognitive behaviour therapy (CBT) (Tuft, 2015) and mindfulness based therapy from a psychiatrist or psychologist along with the proper

medications guided by a neurologist must certainly improve the treatment outcome. Extending the domain of faulty cognitive-affective dispositions and interpretations thereof may also attract the enterprise of rational emotive behaviour therapy (REBT) to improve the quality of life of people surviving with PNES. CBT, REBT (Alsaadi & Shahrour, 2014) or the guild of two seems more appropriate and imperative as PNES is often the result of traumatic psychological experiences. Devising an appropriate filter must also be an imperative to ensure appropriate treatments at appropriate stages. Such moderations may also be helpful in delimiting the requirements of the patients and the practitioners both, thus sure to improve the impact of treatment on the one hand and downsize the undue crowding on the other.

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