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SPECIAL REPORT

PNES around the world: Where we are now and how we can close the diagnosis and treatment gaps—an ILAE PNES Task Force report

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Summary

An international consensus clinical practice statement issued in 2011 ranked psychogenic nonepileptic seizures (PNES) among the top three neuropsychiatric problems. An ILAE PNES Task Force was founded and initially charged with summarizing the current state of the art in terms of diagnosis and treatment, resulting in two publications. The first described different levels of diagnostic certainty. The second summarized current knowledge of management approaches. The present paper summarizes an international workshop of the ILAE PNES Task Force that focused on the current understanding and management of PNES around the world. We initially provide a knowledge update about the etiology, epidemiology, and prognosis of PNES—in adults and in special patient groups, such as children, older adults, and those with intellectual disability. We then explore clinical management pathways and obstacles to optimal care for this disorder around the world by focusing on a number of countries with different cultural backgrounds and at very different stages of social and economic development (United Kingdom, U.S.A., Zambia, Georgia, China, and Japan). Although evidence-based methods for the diagnosis and treatment of PNES have now been described, and much is known about the biopsychosocial underpinnings of this disorder, this paper describes gaps in care (not only in less developed countries) that result in patients with PNES not having adequate access to healthcare provisions. A range of challenges requiring solutions tailored to different healthcare systems emerges. Continued attention to PNES by the ILAE and other national and international neurologic, psychiatric, and health organizations, along with ongoing international collaboration, should ensure that patients with PNES do not lose out as healthcare services evolve around the world.

KEY WORDS: Psychogenic nonepileptic seizures, Diagnosis, Treatment, Gap, International.

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Key Points

- This paper summarizes the discussions focusing on the current understanding and management of PNES around the world
- We initially provide a knowledge update about the etiology, epidemiology, and subgroup of PNES
- We then demonstrate clinical management and obstacles for this disorder in six countries (United Kingdom, U.S.A., Zambia, Georgia, China, and Japan)

In 2011, a consensus clinical practice statement based on an international survey of experts carried out by the Commission on Neuropsychiatric Aspects of Epilepsy of the International League Against Epilepsy (ILAE) ranked psychogenic nonepileptic seizures (PNES) among the top three neuropsychiatric problems with anxiety/depression and psychotic disorder.[1] PNES are clinically defined as events resembling epileptic seizures but caused by psychological processes. Most are classified in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) as a conversion disorder.[2] On the basis of results of the survey mentioned above, an ILAE PNES task force was founded and initially charged with summarizing the state of the art in terms of diagnosis and treatment. Two consensus publications resulted from this assignment. One established different levels of diagnostic certainty, depending on the data available to clinicians at the point of diagnosis.[3] The other summarized management approaches described in the literature.[4] Having completed these projects, the ILAE task force turned its attention to the topic of PNES around the world. Prior studies have described treatment practices for PNES in the U.S.A., United Kingdom, Chile, and Brazil.[5–8] The present paper summarizes presentations at a joint meeting of the ILAE PNES Task Force and the Japan Epilepsy Society in Nagasaki, Japan, in October 2015. After providing a brief knowledge update about PNES, we discuss some particular patient subgroups before exploring the challenges associated with the provision of care around the world for patients with PNES by focusing on six countries that represent different cultures and stages of socioeconomic development. Finally, we consider approaches that may help close gaps in diagnostic and treatment services for PNES in different countries.

Knowledge Update

In the absence of well-resourced, formal epidemiological studies, the prevalence of PNES is very difficult to determine. Long delays from seizure onset to accurate diagnosis and a tendency for patients with PNES to disengage from medical services after diagnosis mean that a substantial subpopulation of patients with PNES disorders will not be easy to identify, even in developed countries. Epidemiological data from poorer countries are virtually lacking altogether. One estimate based on the number of patients referred to epilepsy centers who are thought to have severe epilepsy but who turn out to have PNES yielded a possible prevalence range of 2–33/100,000 (0.002–0.033%).[9] Alternatively, one could generate an estimate based on the assumption of a similar long-term course as for epilepsy and an extrapolation from incidence figures. Following this approach, an incidence figure of 5/100,000/year would yield an estimated prevalence of approximately 1/10 that of epilepsy, or 5/100,000.

The incidence of PNES is somewhat easier to study and has recently been determined to be 4.09/100,000 in a study based in the United Kingdom.[10] To date, comparative differences in the incidence and prevalence of PNES around the world have not been studied. However, research from many countries documents that PNES is not a disorder that only exists in the developed world. In addition to presentations closely resembling those in Western and other highly industrialized societies, PNES-like states are also recognized in some cultures around the world as a cultural phenomenon.[11]

A "gold standard" diagnosis of PNES is based on a history consistent with PNES and the recording of a typical event with semiological features of PNES but no epileptiform activity in the electroencephalogram (EEG) before, during, or after the ictus. The combination of a history, semiology, and video EEG findings consistent with PNES provides the level "documented" PNES. However, the recognition of PNES diagnoses with lower levels of certainty is important, because not all sites (or patients) around the world have access to video EEG and clinicians and patients may have to make treatment choices (for instance, about stopping inappropriate antiepileptic drugs or commencing psychological treatment) when the diagnosis is not completely certain. These levels include in descending order "clinically established," "probable," and "possible."[3]

Our understanding of the etiology of PNES has improved significantly over the last two decades.[12] PNES are a multifactorial biopsychosocial disorder. No single mechanism or contributing factor has been identified as necessary and sufficient to explain the disorder in all cases.[13,14] Traditionally conversion disorder, dissociative mechanisms, and stress-related factors have been considered in psychopathological models of PNES.[12,15] However, more comprehensive, integrative models of PNES have been developed that take into account a wider range of possible pathopsychological mechanisms, including abnormal arousal and inhibition (see Fig. 1).[16,17] Although patients do not universally report trauma or neglect in early life, studies using different self-report and experimental methodologies have identified adverse childhood experiences as a factor predisposing to the development of PNES in later life.[18,19] Many (but not

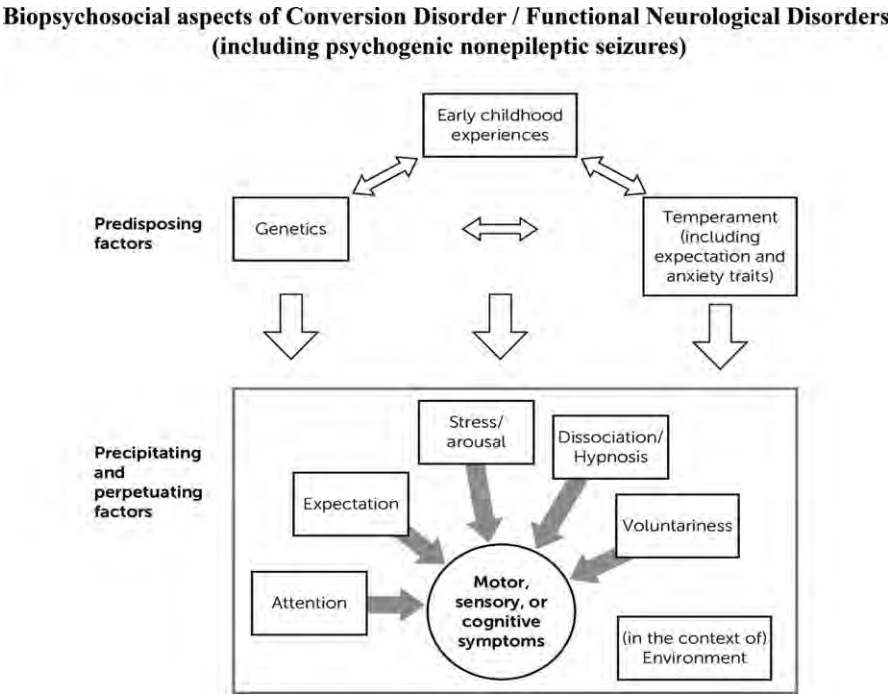

Figure 1.

Biopsychosical aspects of conversion disorder/functional neurological disorders (including psychogenic nonepileptic seizures). From Voon V, et al. Functional neuroanatomy and neurophysiology of functional neurological disorders (conversion disorder). J Neuropsychiatry Clin Neurosci 2016; 28(3):168–190. With permission from Copyright ©2016 American Psychiatric Association. All rights reserved.
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all) patients with PNES also report trauma in adult life, potentially leaving them with symptoms of posttraumatic stress disorder (PTSD), such as hypo- or hyperarousal and flashbacks.[20] To date, no research has explored differences in the psychiatric comorbidity or the psychopathological underpinnings of PNES comparing different cultures or countries around the world, although studies have reported differing rates of previous sexual abuse in women with PNES in Eastern and Western countries.[20–23]

The burden associated with PNES is considerable for healthcare systems and societies at large, as well as for affected individuals and their families.[24] It is estimated that 20–30% of patients referred to epilepsy centers with intractable seizures have been misdiagnosed with epilepsy—the vast majority of these patients are eventually diagnosed with PNES.[25] In addition to the direct healthcare costs associated with PNES, indirect costs to patients and caregivers caused by loss of employment and reduced availability for household work have great societal impact.[26] Several studies have found that direct healthcare costs decline following the diagnosis of PNES because of substantial reductions in healthcare resource utilization.[27,28] The early reduction in healthcare use is often sustained over the longer term, although long-term employment outcomes do not seem favorable.[29,30] Randomized clinical trials (RCTs) now provide an evidence base for different psychological treatment approaches for PNES (although it is not certain to what extent the findings of these studies can be generalized to poorer countries).[31] Although the health economic effects of psychological treatments have not been studied in randomized trials, observational studies suggest that psychological interventions can reduce healthcare costs associated with PNES.[32]

PNES in Different Subpopulations

PNES is well documented in children;[33,34] however, there is a lack of population-based data on the prevalence or incidence of PNES in the pediatric population. Studies reveal better outcomes for children than for adults with PNES.[35] Studies of children up to 12 years of age have identified the following patient characteristics: PNES have been reported from the age of 3 years;[32] unlike in adults, there is no female predominance; motor inhibition (dialeptic attacks) was more common than hyper-motor-type events;[34,36] a history of physical or sexual abuse is reported less commonly by pediatric than by adult patients.[33] School phobia or difficulties in school (including bullying, specific learning difficulties, or unrealistic expectations) have been reported as the most common precipitating or perpetuating factors.[33] A number of neurologic, psychiatric, and psychosocial risk factors have been reported for children and adolescents with PNES.[37,38]

PNES are usually thought of as a disorder of younger adults. They are likely to be underrecognized in older adults. A number of studies have identified older patients who have had PNES long term[39–41] and patients whose PNES have started in later life.[42] One study showed that in patients with a PNES onset in later life, seizures often seemed to be precipitated by health-related traumatic experiences.[43] In the same study, patients with late-onset PNES had better baseline psychological health and reported a lower rate of sexual abuse than younger adults with PNES. Unlike in younger adults (but similar to in children), the gender ratio was even. There may be a tendency for older adults to have PNES with convulsive movements in the form of low-amplitude, high-frequency tremors with partially preserved responsiveness.[41,42] Physiological nonepileptic events such as postural and cardiac syncope occur more commonly in elderly patients[41] and need to be considered carefully in the differential diagnosis of seizures.[43]

Patients with intellectual disability (ID) make up another important PNES subgroup, and studies reveal that the proportion of patients with PNES and comorbid ID is similar to that of patients with PNES and additional epilepsy (i.e., about 10%).[44,45] One study focusing on patients with PNES and ID suggested that this particular subgroup of patients differed from those with PNES but no ID in a number of ways. In the group with ID, there was a trend toward a male preponderance, relative paucity of antecedent sexual abuse, frequent episodes of psychogenic nonepileptic status, as well as a greater proportion of patients in whom situational or emotional triggers immediately preceding individual PNES were reported.[46] Gates and Erdahl[47]proposed "a reinforced behavior pattern" as a particularly important pathogenetic factor leading to PNES in patients with comorbid ID,[47] an idea reemphasized in the study by Magaudda et al.[48] In view of the somewhat different etiology of PNES in this patient subgroup, treatment may need to be different as well. A therapeutic approach combining the modification of the patient's environment and mind-set may be particularly useful.[49]

Unfortunately, no data are available about PNES in these specific subgroups from less highly developed regions of the world. However, awareness of these patient subgroups needs to be promoted around the world to ensure that PNES are not overlooked or mistreated in these subpopulations.

PNES around the World

This section describes services for PNES in six countries with different sociocultural backgrounds and at different stages of economic development. These examples provide an impression of the range of difficulties patients with PNES are likely to encounter when they try to access diagnostic or treatment services (see Table 1 for an overview).

Table 1. PNES around the world

	HDI	Access to epilepsy specialists	Access to video-EEG monitoring	Who diagnoses PNES?	Who treats PNES?	Access to psychotherapy, including CBT or CB-informed psychotherapy	National guidelines for the treatment of PNES
Zambia	0.587	Highly limited	Highly limited	Psychiatrist Neurologist	Clinical officers	Inaccessible	No
China	0.727	Limited	Limited	Psychiatrist Neurologist	Psychiatrist Neurologist	Almost inaccessible	No
Georgia	0.754	Limited	Limited	Neurologist	Neurologist Psychologist	Highly limited	No
Japan	0.891	Easily accessible	Easily accessible	Neurologist Psychiatrist Neurosurgeon	Neurologist Psychiatrist Neurosurgeon Psychologist	Limited	Yes, but not evidence based
United Kingdom	0.907	Easily accessible	Easily accessible	Neurologist	Psychiatrist Psychologist	Limited	No
United States	0.915	Easily accessible	Easily accessible	Neurologist	Psychiatrist Psychologist Neurologist	Limited but increasing in the Veterans Administration program	No

HDI: The Human Developmental Index (HDI) is a composite statistic of life expectancy, education, and income per capita indicators. Psychologists here include cognitive behavioral therapists.CB, cognitive behavioral; CBT, cognitive behavioral therapy; EEG, electroencephalogram; PNES, psychogenic nonepileptic seizures.

Zambia

Background

Epilepsy is the most common neurological condition, affecting 14.5/1,000 of the population.[50] Epilepsy is not considered a "normal medical condition" by the population but a mental disorder or form of "insanity." The situation is not better for patients with PNES.

Services

Most regional health care is provided by clinical officers in psychiatry or general medicine with limited training. These are not trained physicians. Expert care is centralized in the capital, Lusaka. This makes it very difficult for patients to access diagnostic facilities or benefit from the advice of medical specialists.

Diagnosis

Regional health centers have no access to EEG, video-EEG monitoring, 24-h EEG, or high-quality MRI/CT. PNES diagnoses are mainly made by psychiatrists, neurologists (only present in very small numbers and usually found centrally in tertiary hospitals), or clinical officers in psychiatry and general medicine.

Treatment

An estimated 80% of people with epilepsy receive treatment from traditional healers who do not refer the patients to health professionals even if they fail to improve with their treatment.[50,51] It is unknown how many patients with PNES access traditional healers.

Service gaps

The referral chain from primary care via provincial healthcare institutes to the final tertiary medical centers does not work well. As a result, patients may not be referred, or referrals come directly to tertiary centers without prior screening, consequently overloading tertiary care centers with patients. No support groups or education and information materials are available.

Proposed solutions

There is a strong need to increase awareness about PNES, develop the infrastructure for the diagnosis and management of patients with PNES, develop proper teaching and training modules for clinical officers and nonspecialists, increase the number of health professionals trained in the management of PNES, and develop a strong referral system.

China

Background

In this large Asian country, population 1.4 billion, GDP per capita 7,590 USD, over 90% of the population are Han Chinese, but there are many smaller cultural and ethnic groups. There are highly variable levels of population density and urbanization. Physical or sexual abuse is less often reported by PNES patients than in Western studies.[21]

Services

Almost all municipal hospitals have routine EEG and MRI/CT, and many have video-EEG monitoring units, but these tests are not available in township hospitals. PNES may be diagnosed by doctors in different clinical specialties. PNES are still widely called "pseudoseizures" or "hysteria." More comprehensive diagnostic assessments and treatments involving video-EEG monitoring and cognitive behavioral therapy (CBT) are only available in larger centers with psychiatry departments.

Diagnosis

About 18% of patients with intractable seizures admitted for video EEG to the Epilepsy Unit in the West China Hospital are actually found to have PNES. About one-third of these were initially misdiagnosed as epilepsy.[21,52] Misdiagnosis rates of two-thirds have been found in patients with more chronic seizure disorders.[53]

Treatment

At present, most patients with PNES in China do not have access to CBT or other forms of psychotherapy. The most common treatment for PNES in China involves the prescription of psychotropic drugs. Some patients do not receive any treatment at all.[21]

Service gaps

The referral system in China is not well developed. Many patients from rural areas and with poor educational or economic conditions choose to visit local clinics, in which PNES are often misdiagnosed and mistreated, whereas better placed or informed patients come to tertiary centers directly, where they may receive a better level of medical service.

Proposed solutions

There is an urgent need for the development of standard referral, diagnostic, and treatment processes for PNES in urban and rural areas of China.

Georgia

Background

This is a predominantly Christian country at the boundary of Eastern Europe and Asia, with a population 3.7 million and GDP per capita of 4,435 USD. The mixed cultural background has produced a historically high level of tolerance toward minority religions and ethnic groups. Minority groups have maintained distinct and separate sociocultural development, and PNES are observed more commonly in these groups than in the rest of the population.[54]

Services

Specialist medical services were established in 1974 when an epilepsy center was founded at the Tbilisi Sarajishvili Institute of Neurology. A standard diagnostic and treatment protocol has been formulated. From the end of the 1990s, neuropsychiatrists providing therapeutic support for patients with PNES admitted to the institute have initiated nonpharmacological treatment.

Diagnosis

All diagnostic techniques are available, but high-resolution MRI and video-EEG monitoring are only offered in Tbilisi (the capital), and investigations usually have to be paid for by patients. Staff at the epilepsy center in Tbilisi have developed a positive diagnostic approach to PNES aiming to identify psychopathological processes that account for PNES. The diagnostic process is generally managed by a neurologist or epileptologist.[55,56]

Treatment

The provision of nonpharmacological services (i.e., psychotherapy) is a major problem resulting from a shortage of trained specialists, especially cognitive behavioral therapists. Both health professionals and patients tend to prefer combined pharmacological and psychotherapeutic intervention (non-CBT), where it is available.

Service gaps

Despite the early introduction of a specialized epilepsy service in Georgia, currently, because of a fundamental reorganization of the healthcare system, the treatment of chronic neurological disorders is not a government health priority. Private insurance companies cover strictly diagnostic laboratory investigations; however, not all citizens (especially not all elderly and socially vulnerable persons) have private medical insurance. The low-income environment and economically limited healthcare system pose particular challenges for patients with PNES.

Proposed solutions

Efforts of health policymakers and experts in the field should be directed to establish more socially oriented policies for patients with PNES. Intensive training of care providers, introduction of CBT, and knowledge exchange with international medical centers could raise diagnostic and treatment standards while maintaining a culture-specific management approach.

Japan

Background

This country is a highly industrialized, culturally and ethnically uniform East Asian country, with a population of 126 million and GDP per capita of 36,194 USD. PNES have been studied in Japan since the early 1950s.[57]

Services

From the early 1900s, psychiatrists familiar with epilepsy have played a central role in the diagnosis and treatment of PNES. Although this situation is changing, a substantial number of psychiatrists still treat PNES patients using a long-term therapeutic approach.[58]

Diagnosis

All diagnostic techniques are widely available. High-resolution MRI and video-EEG monitoring are offered in every municipal epilepsy center. Investigations are mostly covered by public health insurance but have to be paid partially by patients (with an upper limit on patient contributions). In 2009, the Japan Epilepsy Society published a guideline for the diagnosis and management of PNES.[59] Along with video-EEG monitoring, the guideline emphasized the significance of longitudinal observation with therapeutic intervention.

Treatment

Along with psychotherapy inclusive of CBT, the PNES treatment guideline of the Japan Epilepsy Society emphasized the significance of environmental adjustment, especially in patients with ID, aiming to reduce precipitating and perpetuating factors. Most patients with intractable PNES are eventually referred to psychiatrists.

Service gaps

Although experts at epilepsy centers effectively differentiate between PNES and epilepsy, the number of psychiatrists involved in the management of patients with PNES has gradually decreased.[58] As a result, the gap between the diagnosis of PNES and their treatment is increasing in Japan (as it may be in other countries where there is a divide between psychiatry and neurology).

Proposed solutions

It will be crucial to educate not only physicians/neurologists interested in epilepsy about PNES but also nurses, psychologists, and occupational therapists. In addition, young psychiatrists need to be educated about epilepsy and PNES to prevent further retreat of psychiatrists from epilepsy care.

United Kingdom

Background

In this highly industrialized, culturally and ethnically diverse Western European country, with a population 65 million and GDP per capita of 46,297 USD, the National Health Service provides universal health care for all, based on clinical need and free at the point of delivery. The National Institute of Clinical Excellence (NICE) recommends diagnostic and treatment pathways on the basis of evidence.

Services

PNES are usually diagnosed by general neurologists. All neurologists have access to routine EEG, most, to video EEG. Access to epilepsy/PNES experts is limited. Treatment is provided by clinical psychology/psychotherapy services, typically in community or mental health settings. Although some psychotherapy provision exists almost everywhere, access to psychotherapy with expertise in the treatment of PNES is very limited. Most psychiatrists have a limited understanding of PNES (or epilepsy).

Diagnosis

Despite widespread access to video EEG, 30% of PNES diagnoses are made on clinical grounds.[6] There are no national guidelines for the diagnosis of PNES. The diagnosis is communicated by neurologists. Many use leaflets or websites to support the explanation. Most patients are referred to psychologists or psychiatrists for further exploration.

Treatment

There are no national treatment guidelines for PNES in the United Kingdom. Most patients are referred for psychological treatment but receive only a small number of sessions from therapists unfamiliar with PNES. Exceptions exist in centers of excellence. A large multicenter RCT of a CBT approach for PNES is under way.[60]

Service gaps

Despite improving knowledge about PNES, most patients are initially misdiagnosed as having epilepsy, and the mean delay between PNES manifestation and diagnosis is around 5 years. Psychiatrists, psychologists, and psychotherapists not working in epilepsy centers have a very limited understanding of PNES, and access to longer psychotherapy programs (more than six sessions) is limited.

Proposed solutions

The completion of the multicenter CBT RCT may generate the evidence required to persuade the National Institute for Clinical Excellence (NICE) to issue guidance for the diagnosis and treatment of PNES.[60] The integration of training modules about PNES in neurological and psychiatric specialist education may improve understanding of the disorder in the future.

United States

Background

This is a highly industrialized country with an ethnically, culturally, and religiously diverse native-born and immigrant population of 322 million, with GDP per capita of 55,805 USD. Urban and rural settings have a wide array of healthcare services. The Affordable Care Act of 2010 expanded provisions covered by public and private insurance to those formerly uninsured.

Services

Routine EEG, ambulatory EEG, and video EEG are available in tertiary care epilepsy referral centers across the country. Treatment is provided at a handful of epilepsy centers where outpatient individual and group therapy is offered for adults with PNES. The majority of psychiatrists and psychologists in the U.S.A., however, do not follow up or treat patients with PNES or other conversion disorders.

Diagnosis

Video EEG is available at all Level 3 and Level 4 Epilepsy Centers and at Veteran Administration (VA) Epilepsy Centers of Excellence (ECoE). There are no national guidelines for the diagnosis of PNES; however, video EEG is accepted as the diagnostic gold standard. The diagnosis is communicated by neurologists, with some epilepsy unit teams incorporating mental health providers. Patients are referred to mental health providers, but not all engage.[5]

Treatment

There are no national treatment guidelines for patients with PNES. A pilot multicenter RCT using a manualized cognitive behavioral–informed psychotherapy revealed decreased seizures, comorbid psychiatric symptoms, and improved quality of life in the therapy arms.[31] The seizure therapy treatment workbook is being used by patients and providers in the VA ECoEs and in some Level 4 Epilepsy Centers.

Service gaps

Despite diagnosing many patients with PNES, most civilian Level 4 Epilepsy Centers still do not provide treatment for patients with PNES. A growing number of VA ECoEs provide treatment for veterans with PNES using trained providers on site and via computer video telehealth.[61,62]

Proposed solutions

As more civilian and VA hospitals develop clinics that are successfully treating patients with PNES and with epilepsy using the Seizure Workbook,[63,64] more sites will be trained to deliver evidence-based interventions.

Addressing Gaps in Diagnostic and Treatment Services for PNES

The reduction in quality of life experienced by people with PNES is well documented and is a major global public health issue.[65] Our understanding of the management of this condition has improved significantly over the past decade. Unfortunately, clinical studies showing what is

possible in terms of treatment and strong evidence of personal and public health need are unlikely in themselves to alter care. We suggest that six key themes can be addressed. These combine to offer a route map nationally and globally to build the care of people with PNES over the next decade.

Access to diagnostic process

We have established criteria for diagnosis, with minimum standards to allow their use in global healthcare settings. There is a need to develop country-specific resources, at least to provide minimum diagnostic services to ensure that all people can have a diagnosis made and communicated to an appropriate standard.[3]

Development of treatment pathways

The development of evidence-based treatments for PNES has advanced significantly in the last 10 years.[4] However, interventions have not as yet been universally adopted, specifically by psychological and psychiatric service providers. Treatment pathways need to be developed either within epilepsy services or generic psychiatric services. Such pathways must be adapted to local service structures but must be inclusive to ensure people with PNES are not excluded because they fall outside the range of treatments routinely addressed by psychological service providers (e.g., for mood or anxiety disorders).

Providing services for patients with chronic PNES disorders

Although some patients with PNES remit simply after a decent explanation of the diagnosis with or without ensuing short-term CBT programs,[10,16,31] a substantial number of patients need longer-term psychotherapeutic or mental health interventions either because of continuing PNES or background psychosocial problems that remain unchanged even after the cessation of PNES.[29,66] Although most recent research efforts on PNES have been directed at the communication of the diagnosis or short-term treatments, the latter group of patients have been largely neglected, even in well-resourced Western countries.[29,65]

Closing the gap between neurology and psychiatry

The ongoing and increasing process of subspecialization across all fields of medicine has contributed to a widening gap between neurology and psychiatry in many countries around the world. For many patients with PNES, this gap means that different medical specialties are responsible for the diagnosis and treatment of their disorder. This discontinuity of the diagnosis-treatment pathway causes many patients not to access treatment after a diagnosis of PNES has been made. Better education of neurologists about the management of the mental health problems they commonly encounter (including PNES) and of psychiatrists about seizures (epileptic and nonepileptic) and closer working relationships between health professionals could help to close this gap.

The individualization of care—a blueprint for conversion/dissociative disorders

The dominant theme of health care is toward a more individualized approach. The approach is underpinned by a credo that all conditions will be understandable on an individual genetic level. In the field of PNES this goal currently seems beyond reach, but recent progress in the neurobiological and psychological underpinnings of PNES will hopefully allow us to better tailor treatments to individual patients in this heterogeneous patient population.[14,67] Our deepening understanding of this condition hopefully also means that agencies that fund research and service developments will recognize the importance of this disabling disorder and that stigma will be reduced.[68]

Ensuring that patients are well informed and empowered

This is possibly the largest challenge, but one that must be achieved for change to occur. In many branches of medicine patients are being empowered as their own advocates to navigate their health journey. The same process needs to be developed for people with PNES. PNES patient groups in the U.S.A. and the United Kingdom demonstrate that it is possible to develop patient advocates who can support professionals in the drive to improve access to diagnostic and treatment services.

Conclusion

The Japan PNES conference built on prior workshops and identified gaps in care for patients with PNES, not only in poor countries but around the world. Apart from highlighting that, just like epilepsy, PNES is a global problem, this article demonstrates how patients with this disorder and professionals keen to help them face different problems around the world. This article hints at some of the possible solutions. Although many of the recent scientific findings about the etiology and treatment of PNES summarized here are likely to be universally true, optimal solutions or improvements will have to be specific to individual countries, reflecting the different cultural traditions of each.

Disclaimer

This report was written by experts selected by the International League Against Epilepsy (ILAE) and was approved for publication by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.

Disclosure

Dr. LaFrance serves on the Epilepsy Foundation Professional Advisory Board; has served as a clinic development consultant for the Cleveland

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