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Diagnostic and Treatment Services for patients with Psychogenic Nonepileptic Seizures (PNES): A Survey of Health Professionals in Urban China

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Abstract

Purpose: ~~Aim of t~~This study is intended ~~was ~~to provide an overview of diagnostic and treatment services across China.

Methods: Using a~~the~~ questionnaire devised by the Psychogenic Nonepileptic Seizures (PNES) Task Force of Neuropsychiatry Commission of the International League Against Epilepsy (ILAE)~~ neuropsychiatric committee devised~~, we conducted a survey among Chinese health professionals at the Sixth Advanced International Course: Clinical Epileptology. Descriptive analyse~~i~~s were~~as~~ performed.

Results: ~~102 r~~Responses from 102 eligible clinicians were analysed. Responses were received from urban areas in 20 provinces / municipalities around China. Most respondents were neurologists. The results showed that hospitals in urban China were mostly well-equipped, and that health professionals' understanding of PNES largely~~mostly~~ reflected current international expert opinion. However, many of the participants would not actually make the diagnosis, and most provided neither follow-up nor treatment (especially psychotherapy) for patients with PNES. Only about one third of the patients diagnosed with PNES were estimated to receive ~~have ~~at least one appointment for psychological treatment. In the opinion of the respondents, tacit trauma (neglect and stress) play an important role in the development of PNES. The main obstacles to patients with PNES accessing health services for their condition were thought~~considered~~ to be lack of knowledge or awareness among health professionals, patients and society.

Conclusion: Despite good access to equipment, diagnostic and treatment services for patients with PNES in China are currently deficient. Education programs about PNES with different target groups, and more effective referral and social security systems emerge as particular development needs from this survey.

Keywords: Psychogenic Nonepileptic Seizures; neurologist; survey; health service; diagnosis; treatment; China.

1. Introduction

Psychogenic Nonepileptic Seizures (PNES), also known as Dissociative or Conversion Seizures, are one of the commonest differential diagnoses of epilepsy. Although there has been an increasing number of studies on the aetiology [1], diagnosis [2, 3] and treatment [4, 5] of PNES, relatively little is known about the actual provision of services~~ provisions~~ for patients with this diagnosis around the world. In order to address this question, the PNES Task Force of Neuropsychiatry Commission of the International League Against Epilepsy (ILAE) carried out an international survey~~neuropsychiatric committee~~ among health ~~devised a questionnaire for health~~ professionals intended to investigate how patients are diagnosed and treated in different countries [6]. In the present study, we have used the ILAE ~~Using this~~ questionnaire ~~, we conducted a survey~~ among Chinese health professionals~~, aiming~~ to provide an overview of diagnostic and treatment services across China.

2. Materials and Methods

2.1. Participants

The survey was conducted at the Sixth Advanced International Course: Clinical Epileptology, which was held at Chengdu City, Sichuan Province, China, from August 21st to August 26th 2016. Hosted by the China Association Against Epilepsy (CAAE), Sichuan Association Against Epilepsy (SAAE) and West China Hospital, the course focused on the diagnosis, treatment and rehabilitation of people with epilepsy (PWE). The h~~H~~ealth professionals attending the course were mostly neurologists routinely involved in the treatment of ~~who usually saw~~ PWE, but ~~who were~~ also likely to come across patients with PNES in their daily work. They therefore represented a similar group of professionals to those who have completed equivalent surveys in other countries [6].

We distributed the questionnaires to the health professionals attending the course when they were registering, and reclaimed the questionnaires at the end of each meeting day.

2.2. Questionnaire

The questionnaire includes multiple-choice question and some open questions and was expected to take ten to 20 minutes to complete. It comprised of five sections with a total of 35 questions：

A. About yourself: general information of the respondents (16 questions).

B. About PNES in your area: gender distribution of patients and possible aetiological factors of PNES (two questions).

C. About your diagnostic service for patients with PNES: availability of several diagnostic tests (four questions).
D. About your management of PNES: communicating the diagnosis, following patients up, and treatment of PNES (ten questions).
E. About the health service you work in: medical payment methods, and reasons why some patients with PNES have difficulties to access medical services (three questions).

The questionnaire was translated from English into Chinese by two independent native-speaking authors who were also fluent in English. Then the two Chinese versions were reconciled into one by discussion and agreement between the two authors, producing a final version which was used in this survey.

2.3. Statistical analysis

Descriptive d~~D~~ata analyse~~i~~s were~~as~~ performed using SPSS version 19.0 (SPSS Inc., Chicago, IL, USA). ~~Descriptive analysis was performed. Quantitative data were expressed as the mean ± standard deviation (SD), and qualitative data were summarized as proportions.~~ Additionally, for question 11-16, which described the participants' work with patients with PNES, we compared the answers of fully-trained~~the~~ participants with those of participants still in f~~ully-trained and~~ in training using ~~by~~ chi-square tests or Fisher's exact tests.

3. Results

One hundred and forty-seven questionnaires were distributed and 121 were returned~~claimed~~. Nineteen of the 121 reclaimed questionnaires were excluded because fewer ~~for less~~ than 90% of the questions had been answered. Ultimately, 102 questionnaires were included in the data analysis. We presented the results respectively in Table 1-7, and the key points were summarized in Table 8 for clarification and salience.

3.1. About yourself (Table 1 & 2)

All of our participants were from urban areas. Respondents practiced in different parts~~regions~~ of China, including 20 provinces / municipalities, covering all of the six geographical regions of the country [7]. Most respondents (71.6%) were neurologists with a special interest in epilepsy (epileptologists). Other specialties included general neurologists, neuropsychologists and neurosurgeons. Some participants practiced in more than one medical speciality. Fifty-five percent of respondents were fully trained, and the rest were still in training.

Amongst the participants, 27.5% stated that they personally diagnose PNES; 21.6% that they arrange treatment for PNES; and 38.2% that they provide follow-up for patients with PNES. With regard to their level of confidence about diagnosing and treating PNES, 61.7% of the participants stated that they were familiar with the typical appearance of PNES; while only 16.6% knew how to arrange or provide treatment for patients with PNES. Only 8.8% replied that they were sufficiently familiar with psychotherapy to know how this treatment might help patients with PNES. The fully trained participants were significantly more confident in diagnosis and treatment of PNES and reported being more practiced in these activities than those still in training~~as well~~. However, senior respondents were not more familiar with psychotherapy than ~~th~~trainees~~ose still in training~~.

3.2. About PNES in your area (Table 3)

~~As Table 3 shows, o~~Of the participants who stated that they made at least made one diagnosis of PNES per year (n=94, according to question 12), 74.5% saw PNES more often in women than in men (see table 3). The three most commonly endorsed ~~Among the~~ potential aetiological ~~listed~~ factors were~~,~~ childhood emotional / physical neglect (considered relevant in a mean estimate of 30.4% of cases), school pressures (29.8%), and Family conflict / pressures (27.6%) ~~were the three most commonly endorsed aetiological factors for PNES~~. Other major aetiological factors (endorsed by~~in~~ more than a quarter of the respondents~~patients~~) included accumulated life stress and anxiety.

3.3. About your diagnostic service for patients with PNES (Table 4 & 5)

Most of our respondents had access to inpatient video-EEG (83.3%) and magnetic resonance imaging (MRI) of the head (82.4%). They estimated that MRI of the head would be available for 66.1% and routine EEG for 65.4% of their patients with PNES. The mean estimate of the proportion of patients with PNES whose diagnosis was supported by the~~a~~ video-EEG recording of a typical attack (the diagnostic “gold standard” [3]) was 54.5%.

3.4. About your management of PNES (Table 6)

The vast majority of respondents (81.4%) said that it was typically the neurologists who first communicated the diagnosis of PNES to the patient. Face-to-face explanation was the most frequently used mode of communication. When discussing the diagnosis with patients, most ~~(69.6%)~~ of the participants~~-~~ (69.6%) would say something like “the causes of PNES are complicated. T~~and that t~~here may be predisposing factors, factors which first started attacks and factors which maintain the problem”. Respondents stated a preference for following up the following subgroups of patients with PNES: those with additional epilepsy (74.5%), patients in whom there continues to be doubt the diagnosis (58.8%), and patients undergoing antiepileptic drug (AED) reduction and withdrawal (51.0%). The respondents most commonly endorsed individual psychological treatment as most effective for PNES (73.5%). Although psychotherapy was described as available for most private patients (75.5%) and publicly insured patients (72.5%), it was estimated that only 40.5% of the patients diagnosed with PNES would gain access to individual psychological treatment in reality, and even fewer were estimated to be offered at least one appointment for psychotherapy (35.5%). The most commonly available treatment for patients with PNES was education – i.e. explaining the diagnosis to the patients -- which about 56.7% of the patients were thought to have access to.

3.5. About the health service you work in (Table 7)

It was estimated that 45.8% of the medical expenses related to PNES care were self-pay, and 42.4% covered by insurance or government health care. Other means of payment were rarely used. Nearly all (97.1%) of respondents said that patients would not receive disability benefits because of PNES. The most common hurdles to accessing diagnostic or treatment services for PNES were thought to be: lack of popular awareness of PNES (51%), illiteracy (44.0%)~~,~~ and lack of accessible healthcare practitioners who know about PNES (40.5%).

4. Discussion

This was the first survey of Chinese health professionals on health services for and attitudes towards PNES. The ILAE PNES Task Force has previously~~d~~ conducted a worldwide survey capturing responses from ~~overing~~ 63 countries ~~previously~~ and explored differences in the level of service provision in relation to ~~interpreted the results by categorizing countries based on 2014~~ per capita gross national income (GNI) calculated using the World Bank Atlas method [8]. According to these criteria, China, whose GNI in 2014 was \$7,380, is a ~~belonged to~~ middle income countries (MICs, \$4,126–12,735).

Our findings suggest that hospitals in urban China are mostly well-equipped with diagnostic machinery. The respondents to our survey had access to the most important medical devices used in the diagnosis of patients presenting with seizures (question 19). Overall, the~~is~~ level of accessibility of investigations was on a par with that reported ~~in~~ by healthcare practitioners in other MICs [6]. However, health professionals in China had greater access to inpatient video-EEG (83.3%) and MRI (82.4%) than respondents from other MICs in the previous study [6]. In keeping with this, it was estimated that video-EEG was used in the diagnostic process in 57.7% of patients with PNES (question 20), and that the diagnosis of PNES was supported by the “gold standard” of recording a typical attack with simultaneous video-EEG in 54.5% of cases (question 21) – a considerably higher proportion than the mean estimate from other MICs (30%) [6]. So, in terms of access and use of “hardware”, China excelled among MICs.

Despite the good provision of “hardware”, however, the “software” relating to PNES was less impressive. Although 61.7% of the participants answered that they knew how to diagnose PNES (question 14), only 27.5% of them would make the diagnoses personally (question 11), and even fewer (16.6%) were confident about the treatment of PNES (question 15). However, our participants were relatively young with half still in training (see further discussion under the limitation section). Focusing exclusively on the ~~If our~~ fully-trained participants ~~were separately observed~~, the confidence-gaps between China and other MICs (73.3% versus 88% in diagnosis; 30.3% versus 55% in treatment) was still apparent~~existed~~, albeit ~~nevertheless,~~ significantly smaller~~narrowed~~. Whereas fully-trained participants in this study were much more confident in the diagnosis and treatment of PNES (question 14 & 15), and were more likely to report being actively involved in making the diagnosis and arranging treatments, respondents who were still in training reported personally communicating the diagnosis more often than the senior respondents (question 11). It is a common practice in urban hospitals of China that senior doctors make diagnostic and therapeutic decisions, while junior doctors do more “front-line” work including communicating diagnoses. This may a~~at a~~lso explain~~s~~ why the number of patients diagnosed per year or under current care did not differ between participants who were fully-trained and those in training (question 12 & 13) – despite the fact that senior doctors were considered in charge of diagnostic and treatment decisions, junior ones also participated in the discussions of the diagnosis and the care processes, so they might consider patients diagnosed or treated by their medical teams as “their own”. Despite these considerations, the fact that many of our participants would not make the diagnosis of PNES at all also raises the possibility that many patients with PNES carry erroneous diagnostic labels (such as a misdiagnosis of ~~are misdiagnosed as having~~ epilepsy) and~~or~~ never receive the diagnosis of

PNES: this problem was also highlighted by a previous study based on a cohort of 64 Chinese patients with PNES, which showed that 20 (31.3%) had initially been misdiagnosed with epilepsy [9].

Once the diagnosis is made, it is typically communicated by neurologists (question 23) – however, given that most of the respondents were neurologists, it is possible that this result reflects respondent~~selection~~ bias. In their explanation of the condition, the respondents most frequently used statements reflecting their knowledge and understanding of PNES - casting PNES as a mental health problem, which had complicated causes and could improve with psychotherapy (question 25). Debatable as it might be, this account of PNES essentially concurs with recent international expert statements about PNES [4, 10].

The treatment most likely to be accessible to patients was education, which meant telling the patients or their family about the diagnosis (question 29). Although previous studies have emphasized how important a good explanation of the diagnosis is as a first intervention, and that such explanations can be effective in some cases without more elaborate additional treatment [11], in urban China only about half of the patients diagnosed with PNES were thought to receive such an explanation. The concept of PNES is not easy to explain clearly, and some doctors may not fully understand this condition themselves (question 14). What is more, many patients, especially those of low socioeconomic status and those with a poor educational background, may struggle to understand complex explanations. So, as responses to question 25 revealed, some of our participants did not discuss the diagnosis of PNES, or did not offer detailed explanations. It is possible that illiterate patients were particularly likely not to receive an explanation. Other treatments were even less accessible (question 29).

In line with recent evidence [12, 13], nearly three quarters of respondents considered individual psychological treatment (including CBT) as most effective (question 28). However, the overwhelming majority neither provided psychological treatment, nor were they able to describe how psychotherapy might help patients with PNES. Only about one tenth of the respondents described themselves as able to do this (question 16). Meanwhile, over two thirds would refer patients to others when PNES were suspected or diagnosed (question 11). “Others” is likely to include psychologists, psychiatrists or other health~~expert~~ professionals in this context. It seems~~ed~~ that psychotherapy services are widely developed in urban China. Three quarters of our participants answered that, in their areas, psychological treatments were available for private or publicly insured patients (question 30). However, they also estimated that only 40.5% of the patients with a diagnosis of PNES would in reality have access to individual outpatient psychological treatment (question 29), and even fewer (35.5%) would be offered at least one appointment (question 31). This suggests that most patients with PNES diagnosed in China would currently not receive any psychotherapy. Possible explanations might include the poor understanding of psychotherapy by diagnosticians of PNES, insufficient importance attached to psychotherapy, the inefficient referral system, and the economic burdens as we will discuss later.

Most respondents would not follow-up patients with PNES as a matter of principle, but they would follow up patients with PNES when they had additional epilepsy, when the diagnosis of PNES was in doubt, or when they were reducing AEDs (question 36). In other words, follow-up was usually considered important as long as there was some more specifically “epileptological” work to do. It seemed that most respondent considered the on-going treatment of patients with PNES as beyond the scope of their service.

The medical expenses relating to PNES were estimated to be shared in equal measure by patients themselves and by insurance / government health care (question 33). However, hardly any respondents thought that patients would receive any disability benefits because of PNES (question 34), compared to 23% in other MICs and 50% in high income countries [6]. Two major reasons might be responsible for this~~e barely received disability benefits~~. First, PNES often fail~~ed~~ to attract the recognition ~~get deserved awareness~~ and concern they deserve as an important cause of disability in China. ~~The d~~Doctors will~~ould~~ rarely recommend disability assessments to patients with PNES~~ to disability appraisal~~. And when appraising an individual’s disabilities associated with PNES, ~~the~~ assessors may ~~were likely to~~ make misdiagnoses (as discussed above), or suspect malingering~~ dealing with PNES patients~~. Another reason for the low rate of disability benefits reported may be that ~~On the other hand, the majority of~~ individuals with PNES are unwilling ~~experienced some degree of perceived stigma [14], so it might be undesirable for PNES patients~~ to go to ~~the~~ a disability appraisal institution~~s~~ or receive a label of disability because of the stigma associated with the disorder [14]. In any case~~Anyway~~, this result suggests that many patients with PNES in China face significant economic problems, which will further limiting access to potentially costly psychotherapy.

The survey provided some interesting insights into the opinions or attitudes of Chinese health professionals towards PNES. The vast majority (74.5%) reported seeing PNES more often in women than in men, some only saw it in women (question 17). This finding remains unexplained but is consistent with the gender ratio described in the international literature [15, 16]. Responses to the question about aetiological factors (question 18) were very variable suggesting that there was a lot of uncertainty about the aetiology of PNES. No single factor suggested on the questionnaire attracted endorsement from the majority of respondents, even the most commonly recognized factor (childhood emotional / physical neglect) was only identified in ~~a mean of ~~under one third of patients with PNES. Childhood emotional / physical neglect was considered a relevant factor more frequently than abuse. Other noteworthy factors included school pressures, family conflict / pressure, and accumulated life stress etc., all relating to pressure or stress. It seems~~ed~~ that tacit traumas (neglect and stress) were considered more harmful. Similarly, it has been previously revealed that the most common precipitating factors for PNES in children would appear to be school-related difficulties and interpersonal conflicts within the family [17]. Childhood sexual abuse, a factor recognized often in western countries [15, 18], was only estimated to be relevant in a mean of 11.0% of Chinese patients. Other studies on the possible link between sexual abuse and PNES have yielded contrasting results between Eastern and Western cultures. Like our survey, former studies also found that a history of abuse (sexual and physical) was rarely reported~~seen~~ in China [9], as well as other Asian countries, such as Iran [15] and India [19]. It may be that other psychopathological mechanisms explain development of PNES in Eastern cultures. H~~, h~~owever, it is also possible that the difference in the reported prevalence of sexual abuse is the result of underreporting by Eastern respondents. Chinese patients and doctors may be more uncomfortable to talk about sexual issues than their Western counterparts. Lastly, when asked why it may be ~~was ~~difficult for patients with PNES to receive health services, our respondents identified a number of different reasons, the top three being a lack of popular awareness of PNES, illiteracy, and lack of accessible healthcare practitioners sufficiently knowledgeable about PNES (question 35). Importantly, these hurdles to accessing diagnostic or treatment services for PNES were all about awareness and education. This ~~result ~~suggests that improved education at different levels (society, health professionals, patients themselves) could be of great benefit~~help~~ to patients with PNES in China.

5. Limitations

When considering these findings, one should bear in mind that they were subjective answers reflecting the personal experience of respondents. While they may reflect current reality in China, they should be interpreted as a definitive, accurate reflection of the current state of provisions for people with PNES. And there are several limitations we must clarify.

First, we distributed the questionnaires at the Sixth Advanced International Course: Clinical Epileptology, as a result, the participants were mostly neurologists who usually dealt with PWE and patients with PNES. However, some of the participants were relatively young (79.5% of them were 21-40 years old, and 45.1% were in training), and inexperienced. When considering the comparisons between respondents from China and those from other MICs in the previous study , readers would notice that fewer health care professionals from China stated that they have personally diagnosed PNES (27.5%) than those from other countries (88%). It is possible that this reflects differences in professional hierarchies or how different medical subspecialities (such as neurology and psychiatry) collaborate in China and other countries, but it may have had an effect on the respondents' answers. We note that the proportion of respondents fully trained was lower in this study about China than in the previous study about services for PNES in other MICs [6].

Second, although respondents came from all six areas of China, they all worked in urban areas, suggesting that the results may not reflect the situation in rural China very well. In the last few decades, the urban population of China has been increasing with a quick pace. In 2011, China's urban population exceeded rural population for the first time, and by the end of 2015, the urban population reached 0.77 billion (versus 0.60 billion of rural population) [20]. Still, there is nearly half the population living in rural China, where the situation of PNES caring is poorly known.

Third, the ILAE questionnaire was generated by an international panel and developed in English for use around the world. It was~~,~~ not specifically aimed to explore the situation in China. In order to facilitate comparisons with other countries, we did not make adjustments for the Chinese language, cultural beliefs or styles of medical practice. The medical system in China is differently organized and faces unique challenges, such as the limited time for the care of each patient and designated roles of personnel and resource. These factors would limit the interventions available for PNES patients. Therefore, the unadjusted questionnaire design might have effects biasing the results of the survey. And questions, which might have been of particular interest in the Chinese context, for instance the role of Traditional Chinese Medicine in the treatment of PNES, were not included. Furthermore, the translation was not performed following the Brislin technique [21], which involves the backward translation into the original language and the approval of the authors of the original version. The nonstandard translation (and the reporting of the findings in English) may have introduced additional biases, as the process of translation inevitable introduces changes in meaning. In the future a revised version to reflect such adjustments may be necessary for more accurate assessment to help advance the diagnosis and management of PNES in China.

6. Conclusion

In summary, this survey revealed a number of deficiencies of current diagnostic and treatment services for patients with PNES in China, especially in terms of the understanding and provision of psychotherapy. On the positive side, as an effect of the accelerated economic development of the last few decades, hospitals in urban China are mostly well-equipped, and the understanding of PNES reflected by the responses from health professionals mostly concurred with international expert opinion about the nature and best management of PNES. On the other hand, although more than half of our participants knew how to diagnose PNES, many stated that they would not actually make this diagnosis. In most cases, they provided neither follow-up nor treatment (especially psychotherapy) for patients with PNES. Only about one third of their patients with PNES were estimated to receive at least one appointment for psychological treatment. According to the respondents, tacit trauma (neglect and stress) could play a more important role in the development of PNES than abuse (especially sexual abuse). The main obstacles stopping patients with PNES from receiving health services were considered to be lack of knowledge or awareness in society, among health professionals, and patients themselves. To achieve better diagnostic and treatment services for patients with PNES, education targeting different recipients, and more effective referral and social security systems emerge as particular priorities from this survey.

Disclosure

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Figure legends

Table 1. General information of the participants (n = 102)

Questions[a] and options / answers	Responses[b]
1. What is your age?	
21-30 years	28 (27.5)
31-40 years	53 (52.0)
41-50 years	15 (14.7)
51-60 years	6 (5.9)
2. What is your gender?	
Female	62 (60.8)
Male	40 (39.2)
3. Where do you practice?[c]	
East China	
Shanghai	9 (8.8)
Jiangsu	5 (4.9)
Zhejiang	4 (3.9)
Fujian	2 (2.0)
Shandong	2 (2.0)
Jiangxi	1 (1.0)
South Central China	
Guangdong	10 (9.8)
Guangxi	1 (1.0)
Hunan	4 (3.9)
Hubei	3 (2.9)
North China	
Beijing	14 (13.7)
Tianjin	2 (2.0)
Northeast China	
Heilongjiang	2 (2.0)
Jilin	1 (1.0)
Southwest China	
Sichuan	23 (22.5)
Chongqing	8 (7.8)
Yunna	3 (2.9)
Guizhou	2 (2.0)
Northwest China	
Shaanxi	5 (4.9)
Gansu	1 (1.0)
4. In which setting do you work?[d]	
I work with hospital inpatients	92 (90.2)
I work with hospital outpatients	60 (58.8)
5. Roughly what is the percentage of publicly funded patients you see?	57.9 ± 25.3 (0-100)
6. Roughly what is the percentage of private patients (self-	39.1 ± 23.6 (1-90)

funding/covered by private health insurance) do you see?	
7. What patient groups do you see?[e]	
Children (aged 0-18)	74 (72.5)
Adults (aged 19-74)	75 (73.5)
Elderly patients (75 and older)	55 (53.9)
Patients with intellectual disability	41 (40.2)
8. What is your speciality?	
Neurologist with special interest in epilepsy / Epileptologist	73 (71.6)
General neurologist	29 (28.4)
Neuropsychology	6 (5.9)
Psychiatry	3 (2.9)
Psychology	2 (2.0)
General / Internal Medicine	2 (2.0)
General Practice	1 (1.0)
Counselling	1 (1.0)
Other	14 (13.7)
Neurosurgery	6 (5.9)
Neuropathology	5 (4.9)
Electroencephalography	1 (1.0)
Neuroimaging	1 (1.0)
Sleep	1 (1.0)
9. What is your level of training in your health profession?	
Fully trained	56 (54.9)
In training	46 (45.1)
10. On average, roughly how many hours do most of your patients have to travel to see you?	
Up to 1 hour	4 (3.9)
1-2 hours	28 (27.5)
3-4 hours	29 (28.4)
5-6 hours	22 (21.6)
7-8 hours	5 (4.9)
12-24 hours	3 (2.9)
>24 hours	11 (10.8)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

[c] All the participants come from urban areas, so we do not expound respectively the urban and rural areas. Here we present the province / municipality the participants work in.

[d] No participant in our survey works in community-based settings or sees private patients.

[e] All the participants see both female and male patients (nobody is specialised for one gender).

Table 2. Situation about the participants' work with patients with PNES

Questions[a] and options	Responses[b]			
	All (n=102)	Fully trained (n=56)	In training (n=46)	P value
11. Tell us about your work with patients with PNES.				
I refer patients to others for diagnosis when I suspect PNES.	30 (29.4)	18 (32.1)	12 (26.2)	0.522[#]
I personally diagnose PNES.	28 (27.5)	24 (42.9)	4 (8.7)	**<0.001[#]**
I communicate the diagnosis of PNES.	59 (57.8)	26 (46.4)	33 (71.7)	**0.008[#]**
I refer patients with PNES to others once I have made the diagnosis and explained it to the patient.	41 (40.2)	22 (39.3)	19 (41.3)	0.842[#]
I recommend treatments for PNES.	46 (45.1)	26 (46.4)	20 (43.5)	0.842[#]
I arrange treatments for PNES.	22 (21.6)	19 (33.9)	3 (6.5)	**0.001[#]**
I provide psychological treatment for PNES (beyond explaining the diagnosis).	11 (10.8)	6 (10.7)	5 (10.9)	1.000*
I provide psychiatric treatment for patients with PNES.	4 (3.9)	3 (5.4)	1 (2.2)	0.625*
I prescribe medicines for patients with PNES.	19 (18.6)	14 (25.0)	5 (10.9)	0.079[#]
I provide follow-up for patients with PNES.	39 (38.2)	19 (33.9)	20 (43.5)	0.413[#]
12. Please give an estimate of the number of patients with PNES to you diagnose per year?				0.574*
0	8 (7.8)	3 (5.4)	5 (10.9)	
1-5	47 (46.1)	25 (44.6)	22 (47.8)	
6-10	22 (21.6)	12 (21.4)	10 (21.7)	
11-20	13 (12.7)	7 (12.5)	6 (13.0)	
>20	12 (11.8)	9 (16.1)	3 (6.5)	
13. Please give an estimate of the number of patients with PNES under your current care?				0.151*
0	36 (35.3)	16 (28.6)	20 (43.5)	
1-5	46 (45.1)	28 (50.0)	18 (39.1)	
6-10	7 (6.9)	5 (8.9)	2 (4.3)	
11-20	4 (3.9)	1 (1.8)	3 (6.5)	
20-50	4 (3.9)	4 (7.1)	0 (0.0)	
>50	5 (4.9)	2 (3.6)	3 (6.5)	
14. Which of the following options best describes your level of confidence about diagnosing PNES?				**0.002[#]**
I do not really know how to distinguish between PNES and epilepsy.	13 (12.7)	5 (8.9)	8 (17.4)	
I am aware of the differences in the appearance of epileptic seizures and PNES but I am uncertain about the diagnosis and do not know how to explain it to patients.	26 (25.5)	10 (17.9)	16 (34.8)	
I have seen epileptic seizures and PNES in real life, on video or in video-EEG recordings, am familiar with the typical appearance of PNES and make the diagnosis occasionally.	44 (43.1)	24 (42.9)	20 (43.5)	
I have seen epileptic seizures and PNES in real life, on video or in video-EEG recordings, am familiar with the typical	19 (18.6)	17 (30.4)	2 (4.3)	

appearance of PNES and make the diagnosis often.				
15. Which of the following options best describes your level of confidence about treating PNES?				**<0.001***
I do not know how to explain PNES or how to treat this disorder.	12 (11.8)	6 (10.7)	6 (13.0)	
I know how to explain the diagnosis of PNES but do not know how to treat this disorder.	36 (35.3)	10 (17.9)	26 (56.5)	
I know how to explain the diagnosis of PNES and what the treatment options are but I am not experienced with arranging or offering treatment.	37 (36.3)	23 (41.1)	14 (30.4)	
I am very familiar with PNES and know how to explain the diagnosis, propose treatment options and arrange treatment.	13 (12.7)	13 (23.2)	0 (0.0)	
I am very familiar with PNES and provide treatment for the disorder.	4 (3.9)	4 (7.1)	0 (0.0)	
16. As how familiar with psychotherapy would you describe yourself?				0.109*
I do not know anything about psychotherapy or how it might work for PNES.	7 (6.9)	2 (3.6)	5 (10.9)	
I know about psychotherapy in theory but could not describe what it involved and how it might work.	59 (57.8)	29 (51.8)	30 (65.2)	
I know about psychotherapy, can describe the process in principle but not specifically in relation to PNES.	27 (26.5)	18 (32.1)	9 (19.6)	
I am well informed about a range of psychotherapeutic approaches and can describe who different approaches that could help patients with PNES.	9 (8.8)	7 (12.5)	2 (4.3)	

Bold data show statistical significance at < 0.05.

Chi-square test.

* Fisher's exact test

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as number (%).

Table 3. Situation about patients with PNES in the participants' areas

Questions[a] and options / answers	Responses[b]
17. What do you estimate is the gender distribution of your patients with PNES? (n=94)[C]	
I have only seen PNES in women	8 (8.5)
I have seen PNES more often in women than in men	70 (74.5)
I have seen PNES in as many women as in men	9 (9.6)
I have seen PNES more often in men than in women	7 (7.4)
I have only seen PNES in men	0 (0)
18. In what proportion of your patients do you recognise the following possible aetiological factors? (n = 102)	
Poverty	9.3 ± 16.3 (0-70)
Ethnic / racial discrimination	4.9 ± 16.2 (0-100)
Childhood emotional / physical neglect	30.4 ± 28.2 (0-100)
Childhood emotional / physical abuse	18.5 ± 21.6 (0-90)
Childhood sexual abuse	11.0 ± 20.7 (0-80)
Bullying	18.6 ± 22.7 (0-80)
School pressures	29.8 ± 26.3 (0-95)
Adulthood sexual trauma	15.1 ± 22.4 (0-80)
Family conflict / pressures	27.6 ± 25.8 (0-100)
Alcohol	9.8 ± 15.6 (0-60)
Epilepsy	17.5 ± 20.2 (0-90)
Medical problems other than epilepsy	13.7 ± 16.7 (0-80)
Accumulated life stress	27.3 ± 23.7 (0-80)
Religious and cultural factors	7.4 ± 16.2 (0-80)
HIV and stigma from HIV	4.4 ± 11.7 (0-70)
Gender based violence	7.9 ± 15.8 (0-80)
Anxiety	26.5 ± 26.2 (0-95)
Depression	21.8 ± 22.3 (0-90)
Personality disorder	15.6 ± 20.7 (0-90)
Volitionally produced seizures	20.8 ± 25.8 (0-100)
Gender identity issues	6.2 ± 14.2 (0-80)
Personal sexuality issues	4.3 ± 11.3 (0-80)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

[C] The denominator was the number of participants who diagnosed ≧ one patient with PNES per year (according to question 12).

Table 4. Availability of diagnostic tests for the health professionals and patients of PNES (n = 102)

Options (diagnostic tests)	Questions[a] and responses[a]	
	19. Which diagnostic tests do you have access to?	20. Roughly what proportion of your patients with a diagnosis of PNES would in reality have access to the following tests？
Routine EEG (30 minute recording)	65 (63.7)	65.4 ± 39.0 (0-100)
Routine EEG with video (30 minute recording)	50 (49.0)	33.8 ± 38.5 (0-100)
Prolonged outpatient EEG without video (1-8 hour recording)	21 (20.6)	26.0 ± 36.5 (0-100)
Prolonged outpatient EEG with video (1-8 hour recording)	41 (40.2)	29.5 ± 35.2 (0-100)
Outpatient ambulatory EEG	33 (32.4)	26.2 ± 35.7 (0-100)
Inpatient video-EEG (longer than 8 hours)	85 (83.3)	57.8 ± 35.4 (0-100)
Video-EEG in patients’ homes	13 (12.7)	5.6 ± 17.7 (0-100)
Neuropsychological testing	62 (60.8)	44.5 ± 39.1 (0-100)
Postictal prolactin measurement	6 (5.9)	10.0 ± 24.4 (0-100)
Computed tomography of the head	46 (45.1)	47.1 ± 40.5 (0-100)
Magnetic resonance imaging of the head	84 (82.4)	66.1 ± 35.5 (0-100)
Tilt-table examination	23 (22.5)	17.0 ± 29.6 (0-100)
Routine heart recording (ECG/EKG, less than 5 minutes)	61 (59.8)	57.1 ± 43.8 (0-100)
24 hour ambulatory heart recording	58 (56.9)	34.0 ± 37.8 (0-100)
24 hour ambulatory blood pressure recording	40 (39.2)	24.6 ± 35.8 (0-100)
Longterm heart rhythm monitoring with implantable device	4 (3.9)	2.6 ± 12.5 (0-100)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

Table 5. Diagnose rate by the “gold standard”, and the application of psychiatry / psychological assessments (N=102)

Questions[a] and options / answers	Responses[b]
21. Roughly what proportion of your patients have a diagnosis of PNES supported by the “gold standard” of the recording of a typical attack with simultaneous video-EEG?	54.5 ± 32.2 (0-100)
22. What proportion of your patients will undergo:	
Psychiatric or neuropsychiatric evaluation	49.8 ± 36.2 (0-100)
Psychotherapeutic assessment	39.0 ± 34.9 (0-100)
Psychological assessment	49.1 ± 37.3 (0-100)
Neuropsychological testing	50.8 ± 36.4 (0-100)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

Table 6. Situation about management of PNES (n=102)

Questions[a] and options / answers	Responses[b]
23. Who typically first communicates the diagnosis of PNES to your patients?	
Neurologist	83 (81.4)
Psychiatrist	7 (6.9)
Psychologist	5 (4.9)
Neuropsychologist	4 (3.9)
Counsellor/Therapist	2 (2.0)
Neuropsychiatrist	1 (1.0)
24. How is the diagnosis of PNES usually communicated to the patient?	
Letter to the patient	21 (20.6)
Face to face explanation to the patient	56 (54.9)
Face to face explanation to the patient's family if present	86 (84.3)
Letter to another healthcare practitioner	2 (2.0)
Leaflet about PNES for patient / family	13 (12.7)
Patient referral to websites about PNES	9 (8.8)
Patient referral to self-help groups	4 (3.9)
Diagnosis of PNES is not explicitly communicated	8 (7.8)
25. Which of the following statements would you typically include in your discussion of PNES?	
I do not discuss the diagnosis of PNES with patients.	21 (20.6)
I say that the events are medically unexplained.	12 (11.8)
I do not offer a detailed psychological explanation.	30 (29.4)
I say that the events are a response to stress.	24 (23.5)
I say that the events may be a sign of suppressed traumas from the past or ongoing conflicts.	40 (39.2)
I say that PNES are often the result of trauma.	16 (15.7)
I say that PNES are often the result of sexual abuse.	5 (4.9)
I say that the causes of PNES are complicated and that there may be predisposing factors, factors which first started attacks and factors which maintain the problem.	71 (69.6)
I say that the events are a form of epilepsy which does not need drug treatment.	5 (4.9)
I say that the events are not a form of fits or epilepsy and do not cause any lasting damage.	29 (28.4)
I say that the events are not a form of possession by evil spirits and that it is a medical or psychiatric condition.	46 (45.1)
I say that the person is not deliberately producing those events.	36 (35.3)
I say that the person is not aware of PNES.	33 (32.4)
I say that PNES are a mental health problem.	57 (55.9)
I say that antiepileptic drugs do not work for PNES.	27 (26.5)
I say PNES are a form of seizures which can improve with psychotherapy.	56 (54.9)
26. Which of the following reasons would lead you to continue following patients up after the communication of the diagnosis?	

I do not follow patients with PNES up once I have made the diagnosis.	22 (21.6)
I follow up patients who continue to doubt the diagnosis	60 (58.8)
I follow up patients with PNES and additional epilepsy.	76 (74.5)
I follow up patients with PNES and additional mental health problems.	36 (35.3)
I follow up patients with PNES reducing antiepileptic drugs.	52 (51.0)
I follow up patients with PNES whose seizures have stopped but could return.	36 (35.3)
I follow up patients who have not yet engaged with a psychiatric / neuropsychiatric service.	20 (19.6)
I follow up patients who have not yet engaged in psychotherapy.	15 (14.7)
I follow up patients with PNES for whom I have prescribed medication.	28 (27.5)
As a rule I offer all patients with PNES at least one follow up appointment after I have explained the diagnosis.	16 (15.7)
27. What is your best estimate of the percentage of patients with PNES who you invite to come back to you for at least one follow-up visit after the diagnosis has been communicated to them?	41.2 ± 27.6 (0-100)
28. Which of the following treatment options would you consider the most effective treatment for PNES?	
Individual psychological treatment (Cognitive Behavioural Therapy or other forms of psychological treatment)	75 (73.5)
Group psychotherapy	3 (2.9)
Antidepressant drugs	7 (6.9)
Antipsychotic drugs	4 (3.9)
Benzodiazepines	2 (2.0)
Placebo drug treatment	8 (7.8)
Homeopathic preparations	2 (2.0)
Hypnosis	1 (1.0)
29. Roughly what proportion of your patients with a diagnosis of PNES would in reality have access to the following treatments	
Education (telling the patients +/- their family about the diagnosis of PNES)	56.7 ± 33.9 (0-100)
Support groups	14.1 ± 23.2 (0-100)
Individual outpatient psychological treatment (Cognitive Behavioural Therapy or other forms of psychological treatment)	40.5 ± 31.7 (0-100)
Outpatient psychological group treatment	19.3 ± 24.7 (0-100)
Outpatient psychological family therapy	19.8 ± 26.3 (0-100)
Inpatient treatment (eg. including psychotherapy, rehabilitation)	23.2 ± 26.3 (0-100)
Antidepressant drugs	31.0 ± 28.9 (0-100)
Antipsychotic drugs	24.0 ± 28.6 (0-100)
Anti-epileptic drugs	21.7 ± 28.3 (0-100)
Beta-blockers	14.5 ± 25.1 (0-100)
Benzodiazepines	20.5 ± 27.6 (0-100)
Occupational therapy	12.4 ± 23.0 (0-100)
30. Is psychotherapy (Cognitive Behaviour Therapy or other forms of psychological treatment) available in your area?	
No psychotherapy is available in my area	13 (12.7)

Psychotherapy is available for private patients	77 (75.5)
Psychotherapy is available for publicly insured patients	74 (72.5)
Psychotherapy is available via telemedicine / telehealth / internet-based services	16 (15.7)
31. What is your best estimate of the proportion of your patients with PNES who will be offered at least one appointment for psychological treatment?	35.5 ± 24.0 (0-100)
32. If psychological treatment is offered in your area, what is the typical waiting period from the time of referral to the first appointment in months? (n=88)	0.9 ± 0.7 (0-3.5)
no psychotherapy is available	14 (13.7)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

Table 7. The health service for patients with PNES (n=102)

Questions[a] and options / answers	Responses[b]
33. How is the care you provide for patients with PNES paid for?	
Out-of-pocket / self-pay	45.8 ± 29.0 (0-100)
Social Insurance / government (state) health care	42.4 ± 27.1 (0-95)
Private Insurance	6.0 ± 10.3 (0-50)
Private Foundation	1.7 ± 6.4 (0-40)
Free medical aid	1.8 ± 7.1 (0-60)
34. May patients you see receive state disability benefits because of their PNES?	
Yes	3 (2.9)
No	99 (97.1)
35. Please estimate the proportion of your patients who have difficulties with accessing your diagnostic or treatment services for PNES for the following reasons.	
Illiteracy	44.0 ± 29.1 (0-100)
Language / communication difficulties with healthcare professionals	20.3 ± 22.2 (0-100)
Problems with travel / geographic access to healthcare provider	22.6 ± 22.6 (0-90)
Lack of money for tests	20.3 ± 20.3 (0-80)
Lack of money for appointments with non-specialist healthcare professional	15.8 ± 21.2 (0-90)
Lack of money for appointment with seizure expert	15.2 ± 19.9 (0-90)
Lack of accessible healthcare practitioners who know about PNES	40.5 ± 30.3 (0-90)
Lack of psychological treatment services	38.6 ± 31.4 (0-100)
Lack of money for psychotherapy	21.1 ± 22.5 (0-80)
Lack of money for drug treatment	14.9 ± 19.0 (0-80)
Stigma associated with PNES	25.0 ± 26.3 (0-100)
Lack of a referral system to seizure experts	32.3 ± 31.7 (0-100)
Lack of liaison between traditional healers and health professionals	30.5 ± 29.9 (0-100)
Lack of popular awareness of PNES	51.0 ± 32.0 (0-100)
Lack of access to information resources about PNES (such as leaflets / internet)	36.7 ± 31.9 (0-100)
Lack of intellectual capacity (for instance because of intellectual disability)	15.4 ± 18.3 (0-100)

[a] The questions begin with the same numbers as them were numbered in the questionnaire.

[b] Data are expressed as Mean ± SD (range) or number (%).

Table 8. Summary of key points in diagnostic and treatment services for patients with PNES in urban China

Gender distribution mostly seem in PNES	More often in women than in men
Major etiologic factors	Childhood emotional / physical neglect Family conflict / pressures Accumulated life stress
The confident level mostly reported with regard to the diagnosis of PNES	Be familiar with the typical appearance of PNES and make the diagnosis occasionally
The most accessible diagnostic tests for patients with PNES	Routine EEG and/or video-EEG Magnetic resonance imaging of the head Routine heart recording
Proportion of PNES patients diagnosed by the “gold standard”	About half
Who typically first communicates the diagnosis of PNES to the patients?	Neurologist
The most common methods of communication	Face to face explanation to the patient and/or their family
The most common statement typically included in the discussion of PNES	The causes of PNES are complicated and that there may be predisposing factors, factors which first started attacks and factors which maintain the problem.
The most common reasons leading to follow-ups of patients with PNES	If the patients have additional epilepsy If the patients doubt the diagnosis If the patients are reducing antiepileptic drugs
Percentage of patients with PNES coming back for at least one follow-up visit	About forty percent
The confident level mostly reported with regard to the treatment of PNES	Know how to explain the diagnosis of PNES but in short of knowledge or experiences about treatment of this disorder
The familiarity degree mostly reported with regard to psychotherapy	Know about psychotherapy in theory but could not describe what it involved and how it might work
The treatment considered most effective for PNES	Individual psychological treatment
The most accessible treatment for patients with PNES	Education (i.e. communicating the diagnosis)
Proportion of patients with PNES to whom psychological treatments were really offered	About one third
Medical payment of the highest percentage	Out-of-pocket / self-pay Social Insurance / government (state) health care
Could patients receive state disability benefits because of their PNES?	Barely
Major hurdles to the diagnosis and treatment of PNES	

Lack of popular awareness of PNES
Illiteracy
Lack of accessible healthcare practitioners who know about PNES