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## **Working towards the ideal situation: A pragmatic Epi-Psy approach for the diagnosis and treatment of psychogenic non-epileptic seizures**

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**TITLE: Working towards the ideal situation: A pragmatic Epi-Psy approach for the diagnosis and treatment of psychogenic non-epileptic seizures**

***Abstract:***

***Medical international guidelines recommend regular psychiatric consultations for patients with epilepsy, in order to detect comorbidities. However, there is a lack of guidance about PNES that constitute both a differential diagnosis and a comorbidity of epilepsy. While waiting for the ideal collaboration between neurologists and psychiatrists, we develop a pragmatic approach. Wrong diagnosis between epilepsy and Psychogenic non-epileptic seizures (PNES) is frequent and may lead to iatrogenic consequences for patients. To limit the risk of misdiagnosis, psychiatrists and neurologists should collaborate and be more trained about epilepsy, PNES and their comorbidities. We illustrate the aim of this collaboration through the case of a patient, initially diagnosed with epilepsy, then with PNES only and finally with comorbid epilepsy and PNES. The correct final diagnosis would not have been performed without the collaboration of psychiatrists and neurologists, trained in “Epi-Psy” approach.***

**A problematic situation...**

Psychogenic non-epileptic seizures (PNES), neurological paroxysmic symptoms caused by a suspected psychopathological process, are a syndrome at the intersection of neurology and psychiatry(1). In the 19<sup>th</sup> century, PNES were described by the neurologist Jean Marie Charcot as part of his work on hysteria, (4) and later by Sigmund Freud. The concept of hysteria was later fortunately reconsidered. There are still, however, some persisting ideas which are the legacy of this early way of thinking of PNES. Communication between psychiatrists and neurologists has been decreased, particularly for disorders such as PNES, and functional neurological disorders in general.

And yet, PNES is believed to be the third biggest cause of loss of consciousness today.(2) In western countries, it is usually the neurologist who makes the diagnosis, and the psychiatrist who is responsible for the treatment.(3) General practitioners and emergency doctors tend to have more difficulty referring patients to the proper practitioners. This results in significant delays in diagnosis,(4) exposure to the iatrogenic consequences of treatment for misdiagnosed epilepsy,(5) (6) psychosocial consequences,(7) (8) and a lack of patient involvement in their care.(9) Many patients have described this as a painful experience in which they felt like a ping pong ball being bounced back and forth between different specialists. The professionals, meanwhile, report that they feel uncomfortable treating PNES, often due to a lack of knowledge(10) or the difficulty of referring patients to PNES-trained therapists.(9) (10) This situation causes a certain amount of harm to patients and their families.

### Hoping the ideal situation...

A recent paper(11) highlighted the lack of collaboration between neurologists and psychiatrists in France, particularly where patients with epilepsy (PWEs) were concerned. The International League Against Epilepsy provided guidelines about detection and treatment of psychiatric comorbidities in PWE. (12) Recently, the French National Authority for Health has recommended regular psychiatric consultations for PWE. (13)

This led them to propose a new area of specialization, which they called “Epi-Psy”.(11) Currently, however, there is no clinical guidance for collaboration between neurologists and psychiatrists on PNES.

And so we have a dream of how the ideal situation across the world would be:

- Every patient and their relatives would understand this neuropsychiatric disorder and would accept their key roles in its treatment.
- There would be no prejudices against or stigmatization of these patients.
- The doctors on the frontline (general practitioners, emergency doctors) would develop the competence to make a diagnosis hypothesis with compassion.
- An epileptologist with unlimited access to video EEG would be available to rapidly examine home videos of seizures taken by the families of patients.
- Mental health caregivers would be geographically and financially accessible to all without delay.
- Every psychiatrist and psychologist would have a thorough knowledge of PNES and an interest in their treatment.

### Some pragmatic keys...

While waiting for this dream to become a reality, we have devised a pragmatic and transdisciplinary method for the diagnosis and treatment of PNES based on collaboration between psychiatrists and neurologists. Our aim is to provide a better healing process for patients with PNES.

Should psychiatrists really have a role in the diagnostic process?(14) How could psychiatrists improve this process? Can we talk about a “psychiatric degree of certainty” for PNES diagnosis? We believe the answer is a resounding yes. In many situations, analysing and understanding the 3Ps (predisposing, precipitating and perpetuating factors) and identifying an individual’s unique psychopathological profile is beneficial for diagnosis and treatment.(15) (16) By identifying certain traumatic factors, for example, we can predict the course of seizure frequency.(17) The psychiatrist

has also an important role in case of comorbidity between PNES and epilepsy as we demonstrated later in this article.

What role in treatment, then, should neurologists play? How could the transition to psychotherapies be facilitated? It is our belief that a transdisciplinary approach should be taken in which nonmedical staff also have an important role to play in treatment. Moreover, it is our conviction that the patient is the main agent of their own medical care, and that self-help tools can be extremely beneficial: patients' quality life seems to depend on the number of therapeutic sessions, regardless of whether the therapist is a non-specialist.(18) Given the limited number of psychiatrists and psychologists trained in functional neurological disorders, we have devised an approach that would allow any psychotherapist to treat patients with PNES as long as the therapeutic goals are properly identified and communicated by a trained professional.(19)

While waiting for our dreams to become a reality, we are taking pragmatic steps in working towards better care for PNES patients.

#### *A pragmatic Epi-Psy approach through a clinical illustration*

##### *Diagnosis step*

As an example, we report the following case of a 27-year-old woman for whom Epi-Psy collaboration limited the misdiagnosis.

Her seizures had occurred since the age of nine, after her grandfather's death. She was diagnosed of epilepsy, seizures were very frequent and immediately drug-resistant: phenobarbital, valproic acid and levetiracetam had been used to treat her. Seizure frequency was high, occurring in clusters of between 5 and 12 seizures a day. She reported seizures occurring during the night, associated with lateral tongue biting and postictal muscular pain. This would appear to suggest an epileptic syndrome. However, all interictal EEGs were normal, as were the postictal EEGs. She was hospitalized once in a resuscitation unit for a convulsive status. After-status EEGs were normal with no epileptic markers. Physicians thus strongly suspected "non-epileptic status" and the diagnosis of PNES and referred the patient for a diagnosis confirmation. The patient was hospitalized at our unit in order to confirm a diagnosis of PNES using a prolonged video-EEG, and to stop antiepileptic drugs. At the time of her admittance, she was taking 400 mg/d carbamazepine and 150 mg/d phenobarbital. Neurological evaluation found a history of asthma, sexual abuse, and no predisposing factor for epilepsy. During the video-EEG at our unit, the first interpretation found no epileptic abnormality and a typical PNES was recorded. Hence, neurologists concluded to the diagnosis of only PNES and

decreased the medication. Nonetheless, the protocol for the diagnosis of PNES at our unit also requires a psychiatric assessment.(20) (16)

Psychiatric evaluation found learning disabilities between the ages of 6 and 11, an eating disorder (anorexia nervosa) during her teenage years, a major depressive disorder at the age of 15 and a suicide attempt at the age of 16. She also had a history of multiple traumas: repeated sexual abuse during her childhood (between the ages of 9 and 12) and emotional abuse from her husband as an adult. She also presented symptoms of post-traumatic stress disorder, borderline personality traits (impulsivity, emotional dysregulation, dissociative symptoms) and coping by avoidance. Psychometric evaluation confirmed a strong dissociative tendency (DES score of 43.9), an alexithymia (TAS-20 score of 66), and emotional abuse/neglect and sexual abuse (using the Childhood Trauma Questionnaire). This profile was highly compatible with the diagnosis of PNES.

However, the psychiatrist pointed out something, that was clearly atypical following a “non-epileptic” status:

- A history of two stereotyped psychotic episodes occurring a few days after a status (initially considered “non-epileptic”) and whose symptoms strongly suggested postictal psychosis: sudden onset without confusion, delusion of persecution and misidentification, terrifying visual hallucinations dominated by red tones (blood, severed heads), auditory hallucinations (hearing negative voices), mental automatism, and also an interpretative mechanism. She had a depressed mood with suicidal thoughts. These episodes lasted between 15 days and one month and had resolved themselves completely without the need for antipsychotics. This clinical description fulfils all the criteria for postictal psychosis set out by Logsdail et al. (1988).(21)

Based on this clinical description, the psychiatrist concluded that predisposing, precipitating and perpetuating factors for PNES were indeed present. Nevertheless, the psychiatrist urged the neurologist to look for a comorbid epilepsy. Neurologists proceeded to a second interpretation of the video-EEG and found rare diffuse synchronic spike-waves that clearly suggested an unclassified epileptic syndrome with diffuse EEG abnormalities. The conclusion was therefore that the patient had PNES and comorbid epilepsy.

Modifications after revision [figure 1 (EEG snapshot) removed / figure 2 and 3 were respectively renamed, figure 1 and 2]

This case illustrates the need for a psychiatric assessment, performed by clinicians with an understanding of “Epi-Psy”, in cases of suspected PNES (Figure 1). Indeed, a patient’s

psychopathological profile plays an important part in establishing the degree of certainty needed to reach a PNES diagnosis.(20) Furthermore, psychiatric syndromes comorbid to epilepsy, and postictal psychosis in particular, have clinical particularities that are almost pathognomonic. In 1861, Falret developed the hypothesis that postictal psychosis syndrome is so specific that a diagnosis of epilepsy could be made simply on the basis of psychiatric signs.(22) In this case, the good collaboration between a neurologist and a psychiatrist used to work together and trained in “Epi-Psy” avoided misdiagnosis.

### *Treatment step*

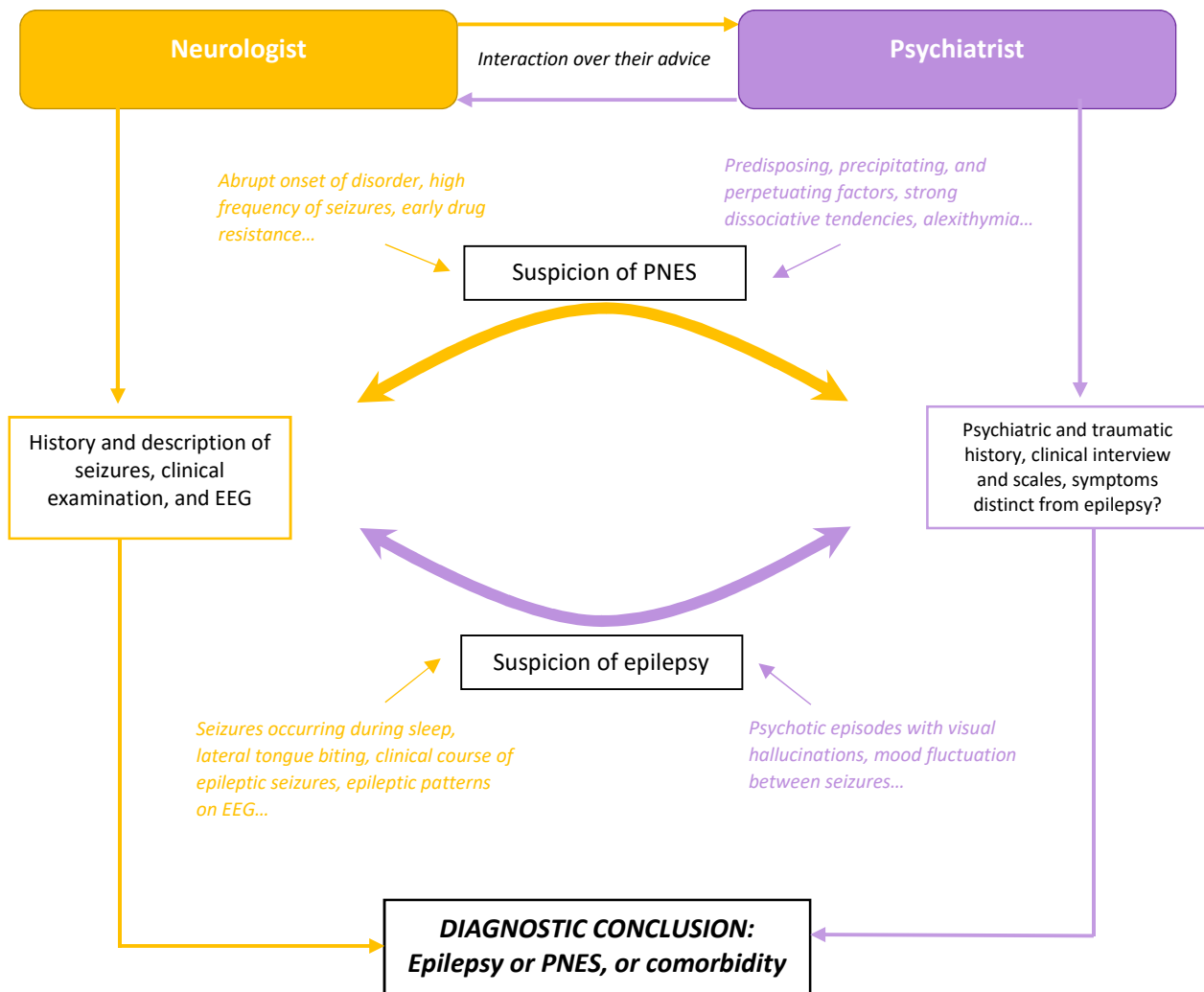
The treatment of PNES should involve both neurologist and psychiatrist, specialized in epilepsy, for the different facet of the cares. For this patient, the neurologist was responsible for the first diagnosis announcement of PNES and epilepsy, the aftercare and treatment/medication for epilepsy: he reduced phenobarbital dosage and kept carbamazepine for stabilizing the patient’s epilepsy to prevent recurrence of postictal psychosis.(23) Neurologist also provided explanations about PNES, in order to enhance psychoeducation. The psychiatrist performed a second diagnosis announcement of PNES to make sure of the patient’s acceptance (the diagnosis could be sometimes announced by the neurologist and psychiatrist together in one consultation). Moreover, the psychiatrist explained the different causal factors of her PNES (predisposing, precipitating, and perpetuating), and talked about some self-help techniques in order to make the patient as the main actor of the recovery. During this consultation, in this case, it was essential to explain the efficiency of trauma-centered therapy, and to encourage the patient’s motivation. Next, the psychiatrist established the different therapeutic objectives and referred the patient to a colleague for the aftercare and outpatient treatment for post-traumatic stress with EMDR and relaxations techniques that seemed more suitable for this patient (19).

### *A schematic representation of Epi-Psy approach*

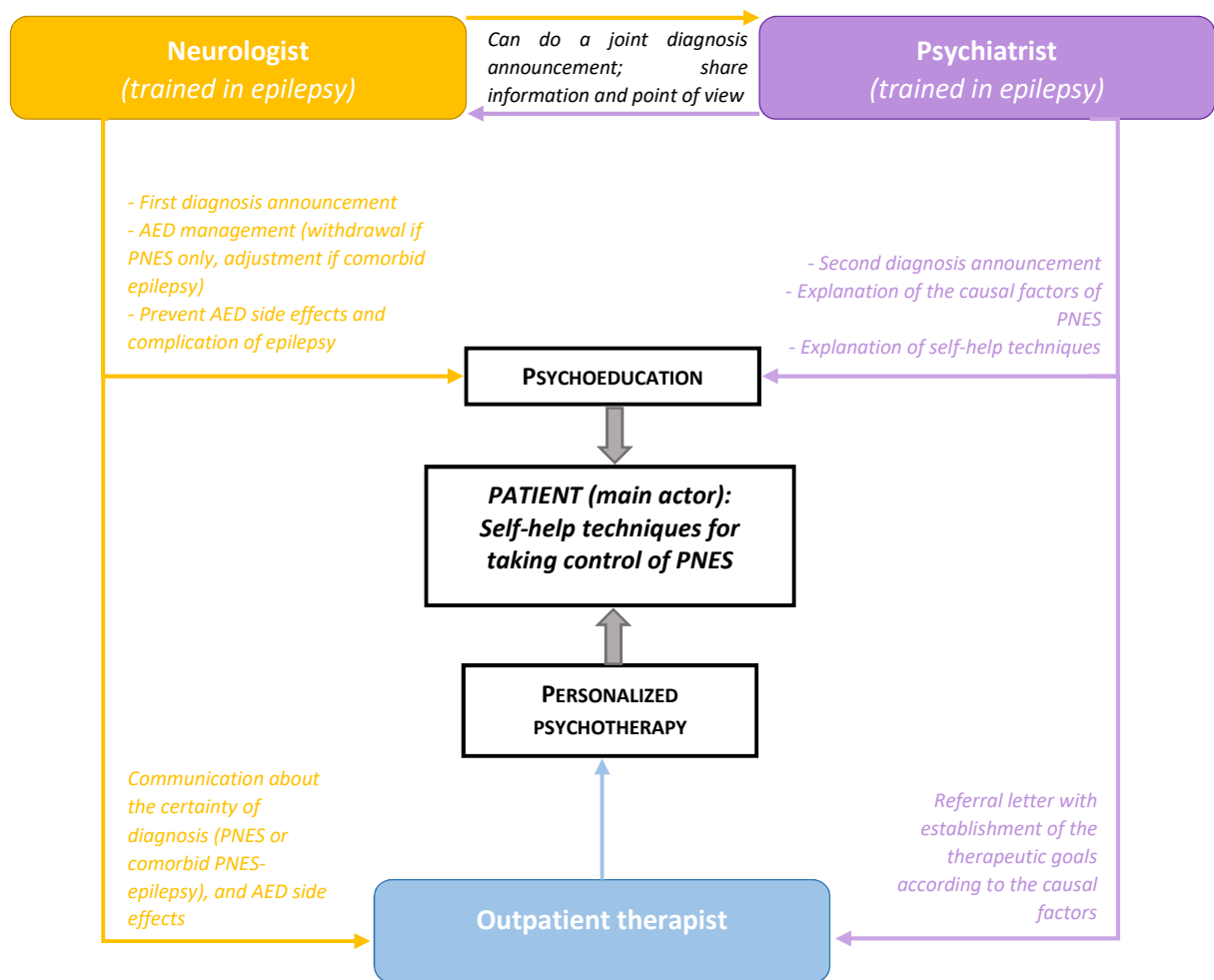
The need for collaboration between psychiatrists and neurologists is thus real and could be supported by common training provided to residents of both specialties: neuropsychiatric syndromes are often underrecognized, particularly in patients with epilepsy.(24) Promoting and teaching Epi-Psy seems to be a necessary step to improve the quality of care received by patients with seizures epileptic or not, notably by avoiding the risk of misdiagnosis.

So, we proposed a schematic representation of neurological and psychiatric approaches for the diagnosis within patients with epileptiform seizures (figure 1). We illustrated different clinical arguments collected either by the neurologist or the psychiatrist trained in epilepsy, that allows a good degree of certainty for diagnosis of PNES only, or comorbid with epilepsy. Similarly, we

illustrated schematically the treatment phase, where the patient, the psychiatrist trained in epilepsy, the neurologist and the therapist have their own role in the care (figure 2).



**Figure 1.** Illustration of “Epi-Psy” collaboration between neurologists and psychiatrists in the diagnosis phase



**Figure 2.** Illustration of “Epi-Psy” collaboration between patient, neurologists, psychiatrists, and therapists in the treatment phase (AED: anti-epileptic drugs)

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