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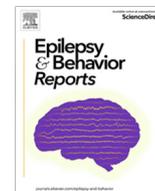
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Case Report

Functional seizures: The patient's perspective of a diagnostic and treatment odyssey

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ABSTRACT

Functional seizures can be challenging to properly diagnose, often leading to delays in treatment. The etiology of functional seizures is multifactorial, with psychological factors identified in many, but not all cases. Misdiagnosis may occur due to clinical features mimicking other medical conditions. Once a correct diagnosis is reached, delivery of definitive, evidence-based treatment may be challenging due to limited availability of specialized resources. Research shows psychological education and cognitive behavioral therapy (CBT) have the greatest efficacy. However, individual differences, including acceptance of the diagnosis, therapeutic alliance, duration of symptoms, comorbidities, and access to care may influence outcomes. There is a critical need for reports that can help identify barriers to effective diagnosis and treatment. We present the diagnosis and treatment of a woman who visited the emergency room after an attack of predominant left-sided paralysis, speech dysfunction and altered awareness. Following multiple daily episodes and visits to multiple medical practitioners, testing led to a diagnosis of functional seizures. While the patient was recommended to undergo a variety of therapeutic interventions, including CBT, she ultimately terminated treatment. In a subsequent interview, the patient revealed her personal experience with perceived limitations of acute management strategies. We explore the complexities of diagnosing and treating individuals with functional seizures.

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1. Introduction

Functional seizures, described in the Diagnostic and Statistical Manual, 5th edition as Psychogenic Non-epileptic Seizures (PNES), are a symptom of Functional Neurologic Disorder (FND), which is also referred to as a conversion disorder [1]. They are characterized by transient seizure-like symptoms and can be challenging to diagnose and treat.

The condition can be clinically mistaken for epileptic seizures, resulting in misdiagnosis [2,3]. Due to this, there is great variability in estimates of the prevalence of functional seizures in the general population, ranging from 2 to 33 individuals per 100,000 [4]. Though studies are limited, cognitive behavioral therapy (CBT) and psychoeducation show the best evidence for treatment of functional seizures [5–10]. When accurately diagnosed and properly treated, patients with functional seizures often have good outcomes [11].

One approach to improving our ability to diagnose and treat functional seizures is to leverage the patient's experiential perspective to better understand the challenges they faced. By exploring the diagnosis of functional seizures from the patient's point of view, methods for improving doctor-patient communication could be identified [12]. However, such an approach is relatively uncommon. For example, we performed a literature review of *Epilepsy and Behavior*, *Epilepsy and Behavior Reports*, and *Epilepsy and Behavior Case Reports* for all articles written on “psychogenic non-epileptic seizures,” or “psychogenic nonepileptic seizures,” or “functional seizures,” or “functional neurological disorder” between 2000 and 2020. Among these articles (393), we identified only 8 (2%) that included interviews providing the patient perspective on some aspect of their diagnosis or treatment [13–20].

Here, we describe the process of diagnosis and treatment for a patient with functional seizures and contextualize it using a qualitative interview with the patient. Our case study provides insight into obstacles that can arise even when significant resources are brought to bear in diagnosis and treatment of this condition and the role of proper psychological education in achieving better outcomes for patients with functional seizures.

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2. Narrative of case history

We detail the pathway to diagnosis for a 44-year-old woman who was rushed to an emergency department following an acute onset of altered consciousness on February 11th (Fig. 1). The event began as a sudden “wave of exhaustion” while attending a social event. Numbness began on the left side of her face, corresponding with an inability to speak. Sensory changes subsequently spread to her left arm, then to her left leg. Since she was alert and her right hand was unaffected, she communicated her symptoms via text messages on the way to the medical center. Upon arrival, she was immediately treated with lorazepam, haloperidol, corticosteroids, and diphenhydramine. Haloperidol and steroids (Solu-Medrol) were administered empirically to relieve her symptoms because the patient shared her recollection of having received the medication during a similar event 23 years prior. Subsequently, both a computerized tomography (CT) scan and a CT angiogram of the brain were conducted and noted to be unremarkable. The patient gradually returned to baseline over the course of 45 min. She was monitored for a few more hours in stable condition with normal vitals and then discharged once able to ambulate freely. The patient had no history of substance abuse or diagnosed mental illness. The diagnosis was unclear, with the clinical suspicion of a “stroke or transient ischemic attack (TIA).” No medications were recommended on discharge.

Ten days later, she was readmitted to the same medical center following a second, nearly identical, but less severe episode that occurred while shopping. During her admission, a brain MRI with and without contrast was performed, along with labs including basic metabolic panel and complete blood count with differential. All studies were unremarkable. She was treated with lorazepam, haloperidol, and diphenhydramine again due to correlation with symptom relief during the previous episode. Based on the updated evaluation, stroke, TIA, and Bell’s Palsy were ruled out.

The following day, the patient was referred to a neurologist for a consultation to exclude a diagnosis of epilepsy. The evaluation consisted of a brain MRI (with and without contrast), brain CT, and CT angiogram, which were all found again to be unremarkable. The neurologist concluded his evaluation with a diagnosis of complex migraines.

The next month, she visited another medical center for evaluation. Her diagnosis was specified as intractable hemiplegic migraine without status migrainosus with associated insomnia. She was advised to continue lamotrigine, which had been prescribed after her second episode. She was also provided haloperidol upon request, due to this medication having been previously associated with symptom relief. Amitriptyline was also prescribed. An electroencephalogram (EEG) was completed during an asymptomatic time and it was found to be unremarkable for abnormality.

Event frequency rose from two to three per day at initial presentation to 20 per day, lasting between 5 and 45 min over approximately one month’s time (as may be considered consistent with PNES status [21]). She was instructed to switch anticonvulsant medication from lamotrigine to levetiracetam. Levetiracetam was subsequently replaced with divalproex. Though medication changes were made empirically, the patient did not have any tongue biting, urinary incontinence, or persistent encephalopathy to suggest status epilepticus due to epileptic, rather than functional seizures.

Due to the worsening clinical picture, the patient underwent another full evaluation at a third medical center. At this point, her symptoms changed from being unilateral to full-body paralysis. They became preceded by unresponsiveness rather than sensory changes. Episodes were described in the records as “prolonged diffuse atonia” with absence of postictal state or amne-

sia. Continuous video-EEG was performed and captured several typical events, interpreted as “PNES and paralysis migraines.” All neurologic examinations and laboratory results were reported as normal with exception of low creatinine levels. During this visit, the patient’s husband corroborated increased levels of family stress over the prior two to three months due to her brother going missing in a foreign country, a friend being diagnosed with brain cancer, and stress with in-laws.

After a diagnosis recorded in the medical records as “functional stereotypic spells,” all antiseizure medications and haloperidol were discontinued. However, clinicians indicated an inability to completely exclude epilepsy based on the evaluation. The patient was discharged with a recommendation for “multimodal therapies, including physical therapy and CBT.” Physical therapy was initiated per her neurologist’s recommendation to address the paresis, vertigo, neck and back pain that resulted after the episodes.

Beginning on March 13th, the patient began physical therapy. Sessions continued for a duration of three months with a total of 21 visits. The patient was educated on and encouraged to complete a home exercise program and relaxation techniques. At some point, cyclobenzaprine was prescribed to alleviate pain and stiffness from muscle spasms. She consistently reported that the pain severely worsened after each episode but was alleviated with massage. By the end of three months, the patient reported an increased ability to control episodes, with lower frequency and duration. She was no longer having them while standing or moving.

On March 14th, after speaking with a family member about pain management, the patient began acupuncture sessions for neck and back pain. The acupuncture sessions were intended to promote relaxation and reduce stress and anxiety. However, the patient stopped attending after seven sessions due to perceiving no significant progress in managing episodes.

The patient returned to her neurologist on April 6th for an evaluation of functional seizures (described as PNES in the medical records). During the visit, she experienced one episode, which began as pressure in her head and numbness in her face. The neurologist reported that the episode lasted four and a half minutes. No movement was observed aside from “facial twitching,” which was not noted as an occurrence with previous episodes. The patient was referred to a hypnotherapist by her neurologist for management of episodes. There were no records to confirm attending or any progress during hypnotherapy.

On April 17th, the patient reported an overall increase in the frequency of episodes but a decrease in duration of each episode and that her vertigo had resolved. She reported engaging in more independent activities for short periods of time. During one of her last visits, the patient experienced a longer spell, lasting 30 min, which was thought to be correlated with encountering a close friend she had not seen for a long time. The patient did not continue physical therapy after June 7th and was temporarily out of the country.

From May through June 3rd, the patient attended six biofeedback sessions, although whether or not this was recommended by a doctor is unknown. Despite an increase in sleep duration, the patient reported that biofeedback psychotherapy appeared to be causing intense fatigue, to the point where she was unable to complete daily tasks. She stopped attending these sessions due to this intense fatigue.

The patient visited a fourth medical center for re-evaluation of her condition on June 20th. During the visit, a neurologist observed an episode and again confirmed her episodes were not epileptic and could not be traced back to an organic cause. Ultimately, her diagnosis changed specifically to functional seizures for the first time. Medical records indicate that the diagnosis was explained to the patient and the patient indicated that they understood;

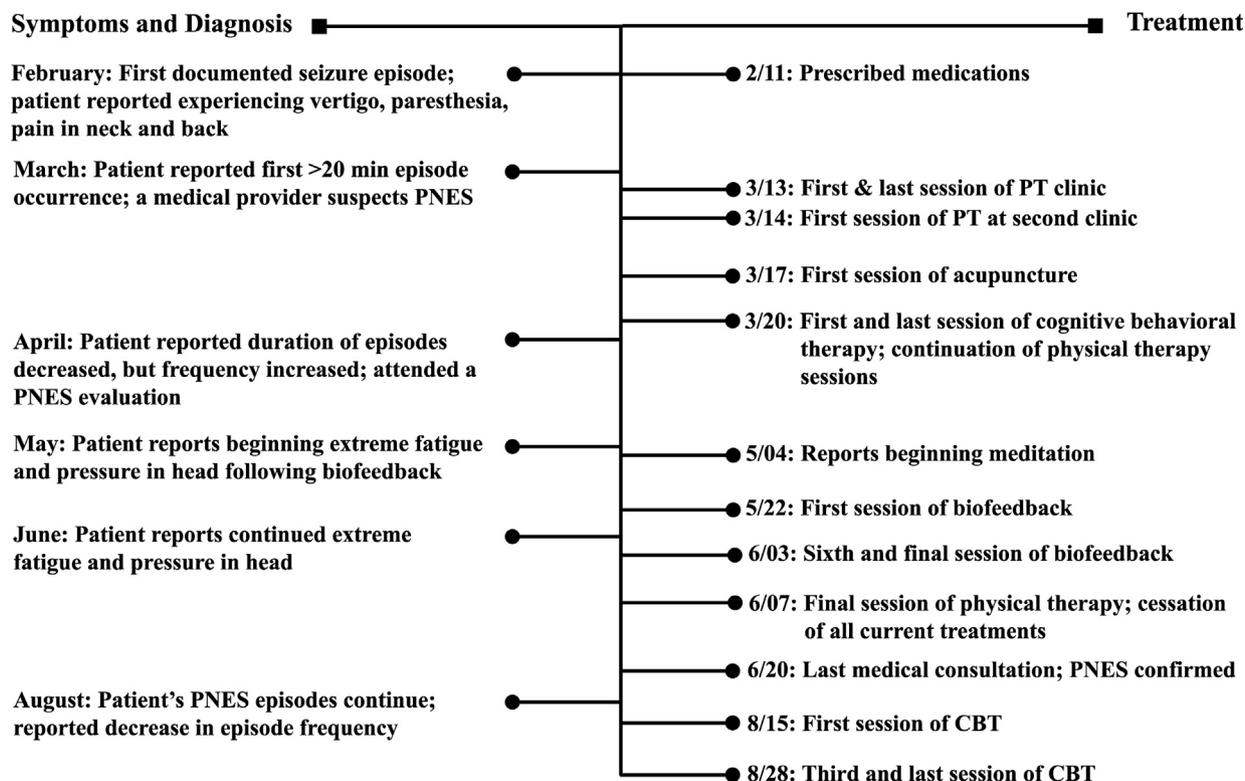


Fig. 1. The timeline for diagnosis and treatment of a patient's functional seizures over the course of five months. Here, we adopt the language of psychogenic nonepileptic seizures (PNES) used in the medical records.

there are no additional written records of the patient's response to the diagnosis.

CBT was the last known treatment this patient pursued, beginning on August 15th for three sessions and ending on August 28th. This treatment was recommended by a prior ER physician. The CBT therapist acknowledged the patient's missing brother (resolved) and close friend's brain cancer diagnosis to be significant stressors and potential precipitators for functional seizures. The medical records from the CBT therapist were also the first and only to note that the patient's mother experienced anxiety and depression associated with spousal infidelity and being bitten by a dog when the patient was 15 years old. No prior history of therapy was indicated. During the second session, the CBT therapist explained functional seizures episodes as a "conversion disorder" and that the focus was on accepting and integrating the condition into the patient's life. A plan to reintroduce hypnotherapy and introduce breathing techniques to manage the episodes was initiated. However, the patient stopped attending CBT after the third session and ceased all other treatments as well.

3. Interview

To understand the patient's perspective on her diagnosis of functional seizures and treatment, we pursued a structured remote audiovisual interview. This interview was conducted four years after the diagnosis. The patient was asked about her understanding of functional seizures as a diagnosis when delivered by medical providers, her experiences with a diverse set of treatments and her perspective on how to care for individuals with functional seizures.

As a result of uncertainty surrounding the prognosis, the patient expressed feeling more fearful than relieved upon receiving functional seizures as a diagnosis (N.B., the patient referred to her diag-

nosis as "PNES" in the interview, rather than functional seizures). She explained that the diagnoses changed with each medical provider and she felt "there [was] nothing [she] could do [...] It was scary," and that it was terrifying to be told that most medical providers have limited experience with functional seizure patients. Additionally, she does not recall being provided with resources for how to cope with functional seizures or instruction on lifestyle management, further compounding her initial fear of living with the disorder. The patient was informed that there were no medications available to treat functional seizures. At the same time, discussion of the rationale for psychotherapy for functional seizures was lacking. An overall lack of understanding led to a disconnect between the patient's own goals for managing the condition and definitive care.

CBT sessions encouraged relaxation techniques, but these paradoxically caused increased stress and anxiety. She did not understand how the techniques directly contributed to relieving her functional seizures. Similarly, the patient was engaged in discussion of past traumatic events but did not understand how they related to the manifestation of functional seizures. The disconnect between the patient's conceptualization of functional seizures and the therapeutic objectives appeared to be the single most important miscommunication during this patient's pursuit of treatment.

The patient was discouraged by the experience of not feeling validated by providers for how terrifying it was to experience an episode. She was referred to a number of different treatments intended to help the episodes, but she felt that none of the health-care professionals were experienced enough with functional seizures to help her. She stated that she had "talked to many therapists who wanted to see her but really did not have any experience," leaving her feeling at a loss for what to do.

Ultimately, the patient felt that none of the treatments provided lasting progress and ceased pursuing them after less than seven months. Despite this, she stated that she is currently maintaining

a nearly normal lifestyle because she is able to predict the onset of episodes. She uses feelings of sudden exhaustion as a cue to either stop all physical activity and sit down or increase movement until the exhaustion passes. A recent back injury has also seemingly correlated with an overall absence of functional seizures. Rather than professional treatment, the patient believes personally exploring changes in lifestyle has contributed the most to recovery. Decreasing work duties and daily responsibilities has also reduced stress and correlated with decreased the frequency and duration of episodes.

With respect to the patient's perspective on how to care for individuals with functional seizures, the patient attributes most of her functional seizure episode management to self-directed learning about the triggers and warning cues for when episodes will occur. The patient would advise others with functional seizures to "listen to [their] body [...] understand [their] body, learn [their] body, and move if [they] don't want to get an attack." Individuals with functional seizures may require significant lifestyle adjustments considering how the frequency and duration of episodes may impact daily routines. Lastly, the patient believes widespread education on functional seizures within the general population and increased awareness among medical providers will better assist individuals who have functional seizures. In the future, she hopes patients are able to receive more resources and information about how to manage episodes.

4. Discussion

Medical practitioners specializing in functional seizures are often challenging to identify and are not universally accessible. Patients may not have adequate resources to obtain the professional expertise and testing commonly used to distinguish between functional seizures and epileptic seizures [5]. On average, there is a seven-year time period between the first onset of functional seizures and a definitive diagnosis [5,22]. This is particularly important, as patients with an earlier diagnosis tend to have a better prognosis [23]. In this case, the patient received an unusually rapid diagnosis. The time between the first episode and the functional seizures diagnosis was less than five months. There was also access to an urban medical center with extensive resources (e.g., EEG, on-call neurologist) and a variety of treatment methods. However, a rapid and accurate diagnosis does not always guarantee that treatment goals will be attained.

A patient's emotional response to a diagnosis of functional seizures may predict the patient's outcome [12]. For those initially misdiagnosed with epileptic seizures, a sudden change in diagnosis to functional seizures, classified as a mental health disorder, may result in the patient's denial of the final diagnosis and worsened symptoms [14]. Diagnosis of this condition is often a very emotional experience, therefore the explanation of the disorder and support rendered by others can impact the likelihood of diagnosis acceptance [12]. In contrast, not accepting the diagnosis can reduce chances that the patient will seek and buy-in to treatment [12]. In this case, the patient accepted the diagnosis, perhaps without fully understanding it. She attended some CBT sessions to address the condition, although she reported feeling confused and at a loss for how to manage her episodes throughout treatment.

Even if patients accept their diagnosis, other obstacles arise due to a lack of understanding of the condition as a whole [24]. Healthcare staff may also have misconceptions about functional seizures. For example, functional seizures patients are perceived to have more control over their condition than people with epilepsy [24]. As a result, functional seizures patients may worry about others thinking they are feigning illness and as a result may feel that they are not being taken seriously by healthcare professionals [24,25].

Furthermore, the causes of the symptoms experienced by patients are not always agreed upon between medical providers and patients [14,26]. Some doctors believe the symptoms are a manifestation of the patient's mental illness or distress, while patients believe the cause is mostly physical [14]. This patient experienced rapid changes in diagnosis and differing opinions with each medical practitioner, who contributed to her initial fear and lasting confusion about the condition. Therefore, she did not feel her condition was well understood, as she did not feel she received specific guidance to manage her functional seizures. In this case, the therapeutic alliance failed, consequently influencing her decision to discontinue treatment.

The first step in triaging patients with functional seizures to initiate treatment is to conduct a formal psychiatric assessment by an expert in the field. Though individual neuropsychiatric factors may ultimately determine best treatment, modalities such as CBT show promise for PNES and/or secondary mental health measures [8,27,28]. The treatment of functional seizures usually takes months because of the time it takes for the patient to finally come to terms and accept their condition [29]. Studies have shown that episodes can cease in many patients without treatment within 3–6 months [7,30]. In this case, referral to definitive, evidence-based care was delayed after diagnosis, after the patient spent significant efforts pursuing alternative therapies. Ultimately, she did not feel that her treatment was responsive to her needs and in less than 8 months ceased pursuing therapy. Her case illustrates the value of having continuity with a provider who takes ownership of the overall treatment plan for functional seizures. This is ideal for triaging to appropriate care, assessing outcomes and working through the patient's conceptualization of the condition [12].

It would appear that there was a communication breakdown between clinicians and the patient relative to (a) identifying the reasons for treatment with a particular form of therapy (e.g., explaining the relevance of processing past trauma), (b) providing a reasonable expectation of the treatment course and timeline and (c) providing practical strategies to manage the distress associated with events themselves. Many mental health conditions, including PTSD and panic disorder are ideally first treated via a "top-down" approach [31]. As such, patients are empowered with skills to stabilize distressing symptoms in preparation for potentially processing more challenging material if needed. During the interview several years later, the patient continued to express that discussion of past events in CBT felt irrelevant, despite concern by providers that they may be linked [32]. Notably, she stated "all he talked about was about my life and my family and my relationships and my work, but it wasn't really dealing with what I'm going through. [...] I felt that I could be a better therapist for myself because I felt there was no connection. They had no idea. They were treating it as a normal therapy session and that wasn't what I needed, so I stopped." Patients who cannot correlate stressors to their condition may have a reduced ability to identify with their diagnosis of functional seizures [12,14]. Thus, it appears that lack of understanding between this patient and the medical practitioners presented the most significant barrier to pursuing effective treatment and progress for resolving her functional seizures.

5. Conclusion

Despite a relatively rapid diagnosis of functional seizures, general acceptance of the diagnosis and willingness to pursue the treatments that were recommended by her healthcare team, the patient's condition did not resolve. In this case, lack of transparency around the goals and purpose of therapy made it challenging for the patient to see them as relevant for her situation. The primary barrier appeared to be a mismatch between treatment

recommendations and what the patient perceived to be applicable to her problem. Compounded by missed opportunities to develop psychological and behavioral skills to manage functional seizures acutely, the patient's motivation to continue therapy was ultimately lost.

The patient's withdrawal from therapy may have been avoidable. Making explicit the basis for the underlying approach to treatment may be a simple means of improving outcomes for patients with functional seizures. Explaining the treatment rationale and providing focused psychological education is key in initial sessions. Focusing on the physical symptoms, while gradually drawing parallels to life stressors, may help the patient understand potential correlations. Early focus on strategies to manage the physical symptoms of functional seizures may help build confidence and nourish therapeutic relationships, thereby optimizing treatment retention. Providing validating support and consistently working together to implement individualized, evidence-based care may afford the best chance for recovery.

Ethical Statement

The case study was conducted with an approved IRB and informed consent was obtained in writing. Research was carried out following the WMA International Code of Medical Ethics.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: One of the authors of this case study has a personal association with the patient of interest, but purposefully did not interact directly with the individual regarding this research. This case study was completed following all IRB guidelines.

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