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Functional neurological disorder: Engaging patients in treatment

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ABSTRACT

Patients with a functional neurological disorder can be difficult to engage in treatment. The reasons for this are complex and may be related to physician, patient and health care system issues. Providers contribute to difficulties in treatment engagement by giving confusing explanations for the patient symptoms, stigmatizing patients, and not allowing patients time to voice their questions and concerns. Patient factors include a lack of engagement after an explanation of the diagnosis, resistance to treatment, family/work dynamics and prior negative experiences with the health care system. The scarcity of providers skilled in the treatment of functional neurological disorder is yet another hurdle. This article will define these barriers and discuss good clinical practices to help improve outcomes by tackling those challenges and discuss why for many patients an integrated care team approach is needed.

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Introduction

Patients with a functional neurological disorder (FND) have symptoms of altered neurological function which are not compatible with any recognized macroscopic neurologic pathology. The diagnosis can be made by positive signs, a rule in diagnosis, given the findings on the neurologic examination. In the case of functional seizures the diagnosis is established based on the semiology of the events captured during video electroencephalogram (vEEG) monitoring that is devoid of epileptiform activity [1–3]. Having a co-existing psychiatric disorder or an identified precipitant is no longer a requirement for the diagnosis [4]. Patients who have FND are commonly initially evaluated by neurologists. A prospective study of patients referred to an outpatient neurology clinic with unexplained neurological symptoms revealed one third of such patients had symptoms not at all or only somewhat explained by structural pathology, many of which were ultimately diagnosed with FND, second only to headache [5]. The high incidence of FND in an ambulatory clinical practice has been noted [6]. Despite the frequency that neurologists encounter patients with FND, there are often delays to diagnosis and even in those who receive a definitive diagnosis, there is still discomfort in explaining the diagnosis so patients can understand, accept, and engage with

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Case

76-year-old right-handed lady with a history of fibromyalgia, gastroesophageal reflux disease, who believes she has chronic Lyme, presents for evaluation of tremors, speech difficulties and weakness. She has had years of fluctuating tremors involving her head and both arms, right greater than left. She also has diffuse weakness and speech problems of long standing duration. She had presented multiple times to the emergency room for evaluation. She reports difficulties with her memory and brain fog. She lives independently and manages all her own affairs.

Evaluation: lumbar spine MRI showed spondylosis, cervical spine MRI showed multilevel spondylosis with moderate central stenosis, multiple brain MRIs without contrast demonstrated mild white matter changes. MRA of neck and brain had moderate stenosis of the left M2 branch of the middle cerebral artery. Neuropsychological testing showed her cognitive profile to be within normal limits other than mild weaknesses in visual learning and variability in aspects of attention and executive function. The profile was not felt consistent with a neurodegenerative disorder.





Case Report

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She had seen 5 neurologists and was followed by Internal Medicine, Cardiology, Pulmonary, Psychiatry and Gastroenterology.

Past Medical History: depression, fibromyalgia, migraine, irritable bowel syndrome, reflux, diverticulitis, and cystitis. She has had multiple surgeries and listed 21 allergies.

On examination she was an alert, cooperative lady who was an excellent historian. Her eye movements were full and her face was symmetric. Her tongue was midline. Motor there was no drift to support focal weakness. She had a clear tremor with sustention and a head tremor. The tremor was variable and decreased with entrainment. On finger-to-nose testing on the right she had severe tremor without clear dysmetria and disappeared with distraction. Her gait was normal.

When asked about her understanding of the etiology of her neurologic symptoms, she attributed her problems to chronic Lyme disease. She reported that prior neurologists had told her that her symptoms were psychiatric and due to stress. She did not understand how stress could cause a tremor and weakness. She was referred to physical therapy, but did not understand how that would be helpful.

Conclusions: This lady was diagnosed with a FND. Her history of seeing multiple clincians and, having numerous tests without a clear diagnosis is not unusual. She clearly does not understand her diagnosis or why the treatment plan could be helpful. The diagnosis needs to be explained including how FND was ruled in by her neurological exam and why her symptoms are not due to chronic Lyme infection. Further, there needs to be an explanation as to how physical therapy is a useful treatment. She should be allowed time for questions and given FND educational websites to reinforce the explanation.

Communicating the diagnosis

Experts have indicated that a clear explanation of the diagnosis of FND can be a powerful treatment tool for patient engagement [9]. See Table 1 [10]. The elements usually covered during a discussion of the diagnosis include an explanation of how the diagnosis was made (positive criteria) that FND is a common disorder and another diagnosis does not account for the clinical presentation,

Table 1

Engaging Patients in Treatment Dos and Don'ts.

Do	Don't
Consider the patient's background experiences with the diagnosis of FND, adhere to trauma- informed care principles	Start with a psychological explanation
Consider your own biases about FND	Rush through the explanation
Be confident in the diagnosis	Order unnecessary testing and referrals
Explain that FND is a common diagnosis	Argue about precipitating events as inconsistent with the etiology of FND
Present psychological factors as contributors to developing FND	Discharge them from neurologic care before they are engaged in treatment
Discuss how you made the diagnosis on a clinical basis rather than due to negative testing (a rule in diagnosis)	Refer to psychiatry until the patient is ready
Share information including your	Imply that the disorder is
consultation and patient oriented education	insignificant or nondisabling
Be prepared to repeat the explanation in follow up visits	Forget to directly address patient's concerns of other potential diagnoses
Include other important care givers in the explanation	Assume patients are malingering or that FND is a voluntary disorder

a formulation highlighting risk factors with an individualized model on how symptoms may have developed and maintained, and review of treatment options and expectations for improvement [11]. In the CODES trial which randomized patients with functional seizures to cognitive behavioral therapy plus standardized medical care versus standardized medical care alone, the patient's acceptance of the diagnosis was high with 8/10 agreement in both groups [12]. Thus suggesting that an expert explanation is important. An incomplete discussion fuels diagnostic uncertainty, contributes to a lack of trust, drives a search for more diagnostic testing and additional opinions and can delay or derail treatment. Studies have shown that a long length of time before the diagnosis of FND is made can negatively influence prognosis [13]. Therefore, the sooner a discussion that FND is highly considered as a diagnosis to explain the symptom complex, the better the patient's acceptance.

Risk factors to develop FND include a history of psychiatric illness. Up to two thirds of patients have significant psychiatric disorder with depression and trauma-related disorders being the most common psychiatric comorbid conditions [14–16]. Focusing the initial discussion of the diagnosis on psychiatric risk factors could negatively interfere rather than help with patient engagement and trust building. The initial discussion should focus on what is the diagnosis leaving the why part of the discussion to later [17–19]. Thus, the discussion of risk factors and the role of stress, should be initiated when it is relevant and if the patient is ready. Postponing a discussion around vulnerability factors for a later time after treatment has begun can be a useful strategy for those patients resistant to the diagnosis.

Validation that a FND is common and treatable is the next step in the discussion. Many patients feel that they have some rare undiagnosed neurologic illness given their experience of seeing multiple specialists without receiving a cohesive diagnosis. If patients fear a particular diagnosis, clinicians should emphasize why the correct diagnosis is FND instead and how the clinical presentation is incompatible with the feared condition. For example, patients may be convinced that they have a particular neurologic disorder such as amyotrophic lateral sclerosis or multiple sclerosis when this was not in the differential consideration of the treating provider. This may happen if someone had an experience with a missed diagnosis in the past, or a family or friend with a debilitating disorder and causes significant anxiety that must be addressed.

The last element in this discussion includes a discussion of treatment options, including how they work and why cautious optimism for improvement is reasonable. Sharing self-help resources, explanatory websites, patient advocacy connections and other written material can further solidify a path forward. See Table 2 [20–26] Sharing clinical notes with patients where the diagnosis is confirmed is another way to be transparent and continue the educational dialogue.

Education about the diagnosis should be considered a process rather than a one-time action item and such communication should aim to reinforce the therapeutic connection between clinician and patient. Patients' level of acceptance can vary broadly and understanding where patients stand in the process can help more accurately tailor communication. For instance, referring to a psychiatrist when a patient is not in agreement with the diagnosis may likely not further the therapeutic process.

Barriers

Patient barriers

The barriers to patients initiating treatment are typically related to resistance to and/or misunderstanding of the diagnosis. Prior

Table 2

Helpful Information for Patients and Providers.

Web sites	Applications	Books	Papers
www.neurosymptoms.org educational material on the condition for patients and providers	MyFND	Overcoming Functional Neurological Symptoms: A Five Areas Approach	Nielsen G, Stone J, Matthews A, Brown M, et al. Physiotherapy for functional motor disorders: a consensus recommendation. J Neurol Neurosurg Psychiatry. 2015 Oct;86(10):1113–1119.
www.fndhope.org	Neurosymptoms	Retrain Your Brain (Cognitive Behavioral	Baker J, Barnett C, Cavalli L, et al. Management of functional
https://www.fndaction.org.uk/ patient advocacy websites	FND Guide	Therapy in 7 Weeks: A Workbook for Managing Depression and Anxiety)	communication, swallowing, cough and related disorders: consensus recommendations for speech and language
			therapy. J Neurol Neurosurg Psychiatry. 2021 Jul 1.
https://nonepilepticseizures.com/		Treating Nonepileptic Seizures: Therapist	Nicholson C, Edwards MJ, Carson AJ, et al. Occupational
informational web site for both the public and providers		Guide (Treatments That Work)	therapy consensus recommendations for functional neurological disorder. J Neurol Neurosurg Psychiatry. 2020 Oct; 91(10):1037–1045.
www.nonepilepticattacks.info		Psychogenic Non-epileptic Seizures: A	
educational information for patients and family on PNES		Guide	

experiences with the health care system influence patients' reception of the diagnosis. Some patients may have never been told that their symptoms were related to FND or may have been led to believe that some other diagnosis was to be discovered. Other patients may have felt offended at the suggestion of psychological factors playing a role in the development of the FND symptoms, misinterpreting that this implied that their symptoms were volitionally fabricated. However, for other patients a stress- based explanation can make sense as a precipitating factor for FND.

Even when a skilled clinician delivers the diagnosis, it may take a significant amount of time for patients to fully understand and process the information. A study looking at neurologist's assessment of the degree of patient's acceptance and understanding of the diagnosis of functional seizures following confirmatory testing showed that only 40% of patients understood the diagnosis when initially presented to them. Further acceptance of the diagnosis was linked to treatment outcome [27].

Family and work dynamics may perpetuate FND-related disability and contribute to ambivalence in engaging in treatment [28]. Fostering independence and self-management during treatment can lead to more positive outcomes. Involving family and caregivers early in treatment planning has been shown to be a positive predictor of likelihood of patient returning to follow up appointments. The presence of a care giver at the initial appointment when the diagnosis of functional seizures was discussed had a highly positive predictive effect that patients would return for a 6–12 month follow up appointment [27].

Motivational interviewing (MI) is a patient-centered communication method that can help address the patient's ambivalence to change their behavior. This technique uses the patient's responses as to how the disability has affected them to as a springboard for helping the patient plan behavioral changes. MI has been shown to be efficacious in engaging and improving adherence among patients with functional seizures [29].

Further barriers to access the health care system may include a patient's socio-economic status with limited insurance, poor health care literacy and fixed health and illness beliefs. This was illustrated in our case where the patient was convinced that her neurologic symptoms were due to chronic Lyme infection. Other common comorbidities including cognitive issues, pain and fatigue can pose significant barriers for some patients. These issues would all decrease the prognosis for improvement.

Psychiatric comorbidities and certain personality traits have also been shown to contribute to poorer outcomes and prognosis. Anxiety, depressive, fear/symptom avoidance, somatic and dissociative disorders are frequently comorbid in FND [30,31]. These comorbidities contribute to the vulnerability for the development of FND, but also interfere with engaging and maintaining patients in treatment [32]. For example, new FND symptoms and dissociative episodes may emerge during treatment, impacting the patient's ability to follow through with the recommended strategies from rehabilitative therapies. These would negatively impact treatment. If psychiatric symptoms interfere with progress in treatment, this should be detected and addressed early by redefining which symptoms should be prioritized in treatment. Altered emotional processing may represent a key link between these risk factors and the manifestation of FND.

A postulated biopsychosocial model for FND suggests that changes in emotional processing may influence the neurocircuits involved in self agency and emotional regulation [33]. Understanding of how vulnerability characteristics, past experiences and current circumstances cause a particular patient to manifest FND is important in designing a patient centered treatment regimen.

Clinician and system barriers

Clinicians are often uncomfortable discussing the diagnosis of FND. Some clinicians may simply focus on diagnoses that have been ruled out rather than providing an explanation on the actual diagnosis. Others may explain FND in a way that is not understandable to the patient. For instance, telling a patient that their weakness is related to "stress" does not make intuitive sense as demonstrated by the patient in the clinical vignette. One very helpful technique that can be incorporated is showing the patient the findings on their examination that are confirmatory. This needs to be individualized for the specific type of FND. For motor FND demonstrating the Hoover's maneuver or how distraction altered their movement or gait disorder. [34] In patients with a functional cognitive disorder discussing the incongruity between the oftendetailed historical examples of their memory disorder, their current level of function at home or on the job and the reported cognitive impairment. In patients who have episodic symptoms a discussion about your knowledge of the disorder and how confirmatory testing such as a vEEG distinguishes between other diagnostic possibilities is important. These techniques could help with building trust between the patient and provider and allows one to begin an explanation of how treatment can be geared to improve symptoms. After the delivery of the diagnosis, it is helpful to gauge a patient's level of understanding and offer an opportunity to ask questions before moving on to treatment discussions. Some patients will show good understanding and inquire about available treatments. Others may have questions about the diagnosis itself, and the extent to which treatment options will be discussed with these types of cases will vary.

Patients with FND may have seen multiple clinicians who offered varying explanations for the presenting problem/s and ordered a myriad of tests. In such cases, discussion of the diagnosis will be more time consuming, an inconvenience for a busy ambulatory clinic. When different clinicians approach patient's symptoms in different ways, or fail to name the disorder and adequately explain it, patients are left with further mistrust in the healthcare system. Coordinating explanations among multiple clinicians, especially with those who the patient already trusts, can prove to be a worthy time investment that can prevent prolonging engagement in treatment.

A diagnosis of FND does not rule out the possibility of another comorbid neurological disorder. In fact, having a neurological disorder is a risk factor for FND. It is important to note and address the possibility of other concurrent or future medical comorbidities like comorbid epilepsy or Parkinson disease [35].

Stigmatizing by health professionals towards disorders with psychiatric factors can also present barriers and increase patient suffering. This issue is magnified by a poor understanding of the diagnosis as well as a lack of biomarkers for FND [36]. Further, some physicians may be concerned that the patient is malingering eroding trust in the doctor/patient relationship.

A scarcity of local resources including physical, occupational, and speech therapists with specific knowledge and training in FND, as well as access to FND-informed psychotherapy and poor insurance coverage are other barriers to care. Self- help resources such as books, applications and web sites can be useful. See Table 2 Using tertiary clinicians as consultants to local clinicians and using telemedicine visits are potential ways to overcome some of these obstacles and broaden a network of clinicians who offer treatment at the local level. The barrier is that this kind of interaction is not currently reimbursed except if done on the same day as a clinical appointment. Thus, advocacy is needed on a national level to reimburse such services, to improve care delivery and decrease care fragmentation and costs.

Although not the focus of this manuscript, training in FND remains limited among the medical and allied health professions involved in the diagnosis and treatment of FND. Training efforts should start early and include all disciplines that interact with patients with FND [37]. Further the absence of this topic in curricula and research priorities also limits the interest in FND. Patient advocacy and support groups have played major roles in both public awareness and education to this often- neglected population.

Care model

A patient-centered integrated team approach to care is needed for many FND patients as they often have multiple clinicians in multiple specialties, and this can be further complicated if clinicians are in different institutions using different electronic health records [38]. Regular team meetings to discuss clinical challenges are important and ideally would include the primary treating physician (often the primary care physician or primary neurologist) and all involved providers- psychiatrist, physical, occupational, speech therapists and social workers. Ideally these communications should be reimbursed and with telehealth access for providers from multiple different locations. Treatment augmentation with multiple simultaneous modalities can be particularly helpful if the involved providers (for instance, a physical therapist and a psychotherapist) agree on delivering similar messages and rely on skills learned in each other's treatment. Support from reliable patient advocacy resources should ideally reinforce participation in treatment.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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