Case Report

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 treatment. Thus, patient adherence to treatment recommendations remains limited, which has a negative impact on outcomes [7,8].

The issues that contribute to poor treatment adherence include communication gaps as well as patient, provider, and system barriers. We will discuss each issue in more detail and present some possible solutions. Here is an illustrative case of a patient with FND demonstrating some of these challenges.

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 spondylolisthesis, cerebral 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.
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 neuroligic 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 clinicians 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.

| 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 Be confident in the diagnosis | Rush through the explanation Order unnecessary testing and referrals |
| Explain that FND is a common diagnosis Argue about precipitating events as inconsistent with the etiology of FND | Discharge them from neurologic care before they are engaged in treatment Refer to psychiatry until the patient is ready |
| Present psychological factors as contributors to developing FND | Discharge them from neurologic care before they are engaged in treatment Refer to psychiatry until the patient is ready |
| Discuss how you made the diagnosis on a clinical basis rather than due to negative testing (a rule in diagnosis) | Imply that the disorder is insignificant or non-disabling |
| Share information including your consultation and patient oriented education | Imply that the disorder is insignificant or non-disabling |
| 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
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 re-defining 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 the patient’s ability to follow through with the recommended strategies is important.

Clinic and system barriers

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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 or seeking 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.

References

[1] Espay AJ, Aybek S, Carson A, Edwards MJ, Goldstein LH, Hallett M, et al. Current concepts in diagnosis and treatment of functional neurological disorders. JAMA Neurol 2018;75(9):1132. https://doi.org/10.1001/jamaneurol.2018.1266.
[2] Daum C, Hubschmid M, Aybek S. The value of ‘positive’ clinical signs for weakness, sensory and gait disorders in conversion disorder: a systematic and narrative review. J Neurol Neurosurg Psychiatry 2014;85(2):180–90.
[3] Avberek A, Sisodiya S. Does the primary literature provide support for clinical signs used to distinguish psychogenic nonepileptic seizures from epileptic seizures? J Neurol Neurosurg Psychiatry 2010;81(7):719–25.
[4] American Psychiatric Association. Diagnostic and Statistical Manual of Mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
[5] Carson AJ, Ringbauer B, Stone J, et al. Do medically unexplained symptoms matter? A prospective cohort study of 300 new referrals to neurology outpatient clinics. J Neurol Neurosurg Psychiatry 2000;68:207–10.
[6] Ahmad O, Ahmad KE. Functional neurological disorders in outpatient practice: an Australian cohort. J Clin Neurosci 2016;28:93–6.
[7] Tolchin B, Dworetzky BA, Baslet G. Long-term adherence with psychiatric treatment among patients with psychogenic nonepileptic seizures. Epilepsia 2018;59(1):e18–22. PMID: 29218816.
[8] Tolchin B, Dworetzky BA, Martino S, Blumenfeld H, Hirsch LJ, Baslet G. Adherence with psychotherapy and treatment outcomes for psychogenic nonepileptic seizures. Neurology 2019;92(7):e675–9. PMID: 30160097.
[9] Stone J, Carson A, Hallett M. Explanation as treatment for functional neurological disorders. Handb Clin Neurol 2016;139:543–53.
[10] Baslet G, Dworetzky BA. Communication challenges in functional movement disorder. Functional movement disorder: an interdisciplinary case-based approach (Current Clinical Neurology). Springer to be published. [chapter 19].
[11] Baslet G, Seshadri A, Bermejo-Otavía A, Willment K, Myers L. Psychogenic nonepileptic seizures: an updated primer. Psychosomatics 2016;57(1):1–17. https://doi.org/10.1016/j.psym.2015.10.004. Epub 2015 Oct 22. PMID: 26791511.
[12] Goldstein LH, Robinson EJ, Mellors JDC, et al. CODES study group. Cognitive behavioural therapy for adults with dissociative seizures (CODES): a pragmatic, multicentre, randomised controlled trial. Lancet Psychiatry 2020;7(6):491–505.
[13] Claff J, Stone J. Prognosis of functional neurologic disorders. Handb Clin Neurol 2016;139:523–41.
[14] Carson AJ, Ringbauer B, MacKenzie L, et al. Neurological disease, emotional disorder, and disability: they are related: a study of 300 consecutive new referrals to a neurological outpatient department. J Neurol Neurosurg Psychiatry 2000;68:202–6.
[15] Singh SP, Lee AS. Conversion disorders in Nottingham: alive, but not kicking. J Psychosom Res 1997;43(4):425–30.
[16] Roelofs K, Kreijers GP, Hoogduin KL, Näring GWB, Moore FC. Childhood abuse in patients with conversion disorder. Am J Psychiatry 2002;159(11):1908–13.
[17] Carson A, Lefin A, Ludwig L, Stone J. Explaining functional disorders in the neurology clinic: a photo story. Pract Neurol 2016;16(1):56–61.
[18] Reuber M. Dissociative (non-epileptic) seizures: tackling common challenges after the diagnosis. Pract Neurol 2019;19(4):332–41.
[19] Adams C, Anderson J, Madva EN, LaFrance Jr WC, Perez DL. You’ve made the diagnosis of functional neurological disorder: now what? Pract Neurol 2018;18(4):323–30.
[20] Nielsen G, Stone J, Matthews A, Brown M, Sparkes A, Farmer R, et al. Adherence with psychotherapy and treatment outcomes for psychogenic nonepileptic seizures. Neurology 2019;92(7):e675–9. PMID: 30160097.
[21] Baker J, Barnett C, Cavalli L, Dietrich M, Dixon L, Duffy JR, et al. Management of functional communication, swallowing, cough and related disorders: consensus recommendations for speech and language therapy. J Neurol Neurosurg Psychiatry 2021;92(10):1112–25.
[22] Nicholson C, Edwards MJ, Carson AJ, Gardiner P, Golder D, Hayward K, et al. Occupational therapy consensus recommendations for functional neurological disorder. J Neurol Neurosurg Psychiatry 2020;91(10):1037–45.
[23] Williams C, Carson A, Smith S. Overcoming functional neurological symptoms: a five areas approach. CRC; 2011.
[24] Retrain G3. Your brain: cognitive behavioral therapy in 7 weeks: a workbook for managing depression and anxiety. Blackstone publishing; 2016.
[25] LaFrance WC, Wincze JP. Treating Nonepileptic Seizures: therapist guide (treatments that work). Oxford press; 2015.
[26] Myers L. Psychogenic non-epileptic seizures: a guide. Createspace Independent Publishing Platform; 2014.
Duncan R, Graham CD, Oto M. Neurologist assessment of reactions to the diagnosis of psychogenic nonepileptic seizures: relationship to short- and long-term outcomes. Epilepsy Behav 2014;41:79–82.

Tolchin B, Baslet G. Readiness to start treatment and obstacles to adherence. In: Psychogenic nonepileptic seizures: towards the integration of care. Oxford University Press; 2017. p. 218–32.

Tolchin B, Baslet G, Martino S, Suzuki J, Blumenfeld H, Hirsch LJ, et al. Motivational interviewing techniques to improve psychotherapy adherence and outcomes for patients with psychogenic nonepileptic seizures. J Neuropsychiatry Clin Neurosci 2020;32(2):125–31.

Pun P, Frater J, Broughton M, et al. Psychological profiles and clinical clusters of patients diagnosed with functional neurological disorder. Front Neurol 2020;11:580267.

O’Brien FM, Fortune GM, Dicker P, O’Hanlon E, Cassidy E, Delanty N, et al. Psychiatric and neuropsychological profiles of people with psychogenic nonepileptic seizures. Epilepsy Behav 2015;43:39–45.

Brown RJ. Dissociation and functional neurologic disorders. Handb Clin Neurol 2016;139:85–94. https://doi.org/10.1016/B978-0-12-801772-2.00008-4. PMID: 27719880.

Pick S, Goldstein LH, Perez DL, Nicholson TR. Emotional processing in functional neurological disorder: a review, biopsychosocial model and research agenda. J Neurol Neurosurg Psychiatry 2019;90(6):704–11.

Stone J, Edwards M. Trick or treat? Showing patients with functional (psychogenic) motor symptoms their physical signs. Neurology 2012;79(3):282–4.

Wissel BD, Dwivedi AK, Merola A, Chin D, Jacob C, Duker AP, et al. Functional neurological disorders in Parkinson disease. J Neurol Neurosurg Psychiatry 2018;89(6):566–71.

MacDuff KE, Grubbs L, Best T, et al. Stigma and functional neurological disorder: a research agenda targeting the clinical encounter. CNS Spectr 2020;1–6.

Medina M, Giambarderi L, Lazarow SS, Lockman J, Faridi N, Hooshmad F, et al. Using patient-centered clinical neuroscience to deliver the diagnosis of functional neurological disorder (FND): results from an innovative educational workshop. Acad Psychiatry 2021;45(2):185–9.

O’Neal MA, Baslet GC, Polich GR, Raynor GS, Dworetzky BA. Functional neurologic disorders: the need for a model of care. Neurol Clin Pract 2021;11(2):e152–6.