

Functional Neurologic Disorders

The Need for a Model of Care

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Abstract

Neurologists are commonly consulted for patients with a functional neurologic disorder. Best practices as to their diagnosis and treatment have been established, and multiple academic centers have programs in place for their treatment. However, given the number of patients suffering from this condition, a comprehensive model of care that can be broadly implemented needs to be developed and applied beyond specialized academic programs.



Functional neurologic symptoms are among the most common reasons for ambulatory neurologic consultations. In fact, approximately one-third of new patients referred to an ambulatory neurology clinic have “medically unexplained symptoms,” many of whom suffer from functional neurologic disorder (FND).¹ The Scottish Neurological Symptom Study, a prospective multicenter investigation, found that of 3,781 new outpatient neurologic consultations, 16% were related to FND, making it the second most common diagnosis after headache.² The diagnosis of FND is positively defined by corroborating the incongruity between the presenting complaint and the intact underlying neurologic function, which confirms normal preserved neuroanatomy. Electrophysiologic testing may be needed to confirm intact neurologic function such as electroencephalography capturing a spell as the gold standard for the diagnosis of psychogenic nonepileptic seizures (PNESs), a subtype of FND, and electrophysiologic studies for functional tremor.^{3,4}

The pathophysiology of FND is believed to be related to a complicated interaction of biology, psychological factors—high association with anxiety, trauma, depression, and certain personality traits—and social issues. The neurobiological underpinnings of this disorder are corroborated by studies showing changes in patients’ autonomic nervous system, brain anatomy, functional activation and connectivity, electrophysiologic responses, and levels of stress hormones.⁵ Thus, prevention of FNDs would require recognizing and early treatment of those individuals at risk. Prompt and correct diagnosis has important healthcare consequences and might improve patient outcomes. Our proposed model is a collaborative approach to treatment of FND.

Why a Care Model Is Needed

Disability in FND is similar to patients with structural neurologic disease, and outcomes and quality of life are often poor.⁶ Furthermore, patients with FND are known to be high users of the healthcare system, and their care is costly. A study of individuals with FND followed over 3

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years within a single hospital system found an average for each patient of 6 emergency department visits and 5 hospital admissions with an average stay of 24 days⁷ Information on healthcare costs associated with FND can be extrapolated from information about patients with related disorders. For example, patients with somatic symptom disorder have approximately twice the health care utilization and the annual medical costs compared with patients without this condition.⁸ Studies on healthcare costs of patients with unconfirmed PNES show costs comparable with those of patients with refractory epilepsy.⁹ Several studies have shown that accurate early diagnosis of PNES decreases cost. One study used electronic medical record data to look at the costs in the year before a definitive diagnosis of PNES compared with costs afterward. It showed a decline in the number of all medical visits with reduced costs.¹⁰ We also demonstrated in a small retrospective record review involving patients with FND a decrease in healthcare utilization in the 6 months after the diagnosis of FND compared with the previous 6 months (before diagnosis). These decreases included the average number of emergency department visits, number of hospitalizations, and number of completed imaging studies.¹¹ By contrast, a retrospective study evaluating an intensive inpatient program for motor FND demonstrated improvement in level of disability, but no decrease in healthcare utilization after the program completion.¹²

In many cases, disability can unfortunately become longstanding. Therefore, the management of patients with FND needs to go beyond an early and accurate diagnosis and include a comprehensive and sustainable recovery plan focusing on the return to work, better ability to engage in activities of daily life, and decreased reliance on assistive devices.

Owing to the complexity of care required, patients with FND are typically referred to a multitude of specialists often in a fragmented manner, with no comprehensive clinical services unifying and streamlining their care. It is likely that the lack of integrated clinical care contributes at least partially to the high healthcare costs and poor outcomes. Owing to rising concerns over cost, significant disability, and access to care, many academic centers have begun to develop clinical programs designed to improve and assist in the care for patients with FND. However, given the high volume of patients and limited availability of community providers with interest and/or expertise in treating them, resources in these centers can easily be exhausted. It is therefore imperative that a model be designed to extend clinical care beyond tertiary academic centers.

Barriers to Care

There are multiple barriers to treating patients with FND which need consideration when building a clinical care

model. Barriers may be because of factors related to the patient, clinician, or the healthcare system.¹³

Patient-related barriers include the heterogeneity of neurologic complaints (which often morph over time and may shift attention in patients and clinicians from one symptom to another), lack of acceptance or ambivalence toward the diagnosis, and frequent psychiatric comorbidities. Moreover, care in FND may be complicated by perpetuating (and usually reinforcing) psychosocial factors such as difficulties in the work environment or complex family dynamics.

Physicians' attitudes and lack of knowledge about FND may limit access to adequate care. The mistaken idea that patients with FND are feigning their symptoms and/or do not suffer from a "serious" or "real" disorder leads patients to feel that their symptoms are not taken seriously, and therefore, they become victimized by the healthcare system (in many cases a recapitulation of past invalidating or even outright traumatizing experiences).¹⁴ This same mistaken belief can also lead clinicians to feel like their time is not being well spent or worse that patients are trying to manipulate them, further fueling disinvestment. Moreover, many clinicians do not understand and have difficulty discussing this diagnosis with patients. This can lead to prescribing or supporting treatments that are not indicated and can cause iatrogenic consequences. Finally, physicians may not engage in the time-consuming task of working collaboratively with other professionals to help patients access necessary treatments in their own communities.

Our healthcare system is not designed to target the challenges typically faced by patients with FND. FND-informed mental health professionals are difficult to access, and treatment resources such as cognitive behavioral therapy and effective psychiatric care are scarce. Furthermore, these services may not be covered by insurance. There is also limited supply and availability of FND-informed physical, occupational, and speech therapists. Frequently, multiple subspecialists are involved in the care of patients with FND, without a clear and unifying message regarding the underlying common etiology of the patient's usually various functional complaints. This can result in discordant messages to patients, polypharmacy, and unnecessary medical testing. More importantly, this postpones indicated and necessary treatments.

How To Do It

Experts have suggested a stepped model of care that starts with a neurologist appropriately communicating and explaining the diagnosis, validating their belief in the patient's reported experience, and conveying a clear message that FND is common and that evidence-based treatments exist.¹⁵ For a subset of patients, this explanation and guidance to appropriate treatment alone can be therapeutic and lead to

symptomatic improvement.^{16,17} Other patients will respond to short-term evidence-based treatments that may provide lasting symptom control.^{18–20}

Unfortunately, there is a considerable number of patients who remain chronically disabled and require ongoing care for their FND symptoms.^{21,22} For such patients, a model used to treat FND like other chronic illnesses should be considered as the standard of care. This collaborative model aims to identify the major factors affecting care in patients with chronic illness and strives to improve care delivery. The model has been validated for patients with other psychiatric diagnoses including depression, bipolar disorder, and anxiety.²³ Table^{24–29} shows how a chronic care model could be extrapolated and applied to complex patients with FND.³⁰

Care coordination is an essential ingredient in a successful comprehensive program, enabling providers to deliver a cohesive message and minimizing unnecessary testing and hospitalization.³¹ Tertiary and quaternary hospitals are well situated to provide the needed expertise for patients with FND; however, their resources are limited. Team members ideally come from multiple disciplines that can help craft an individualized and targeted treatment plan (primary care, neurology, psychiatry, physiatry, other mental health providers, and rehabilitation specialists—figure).

Members from these diverse specialties can offer distinct and necessary skills to the care of patients. The team should meet

regularly to discuss patients, individualize their treatment plans, understand challenges, and target roadblocks. A team leader should be identified and assume the responsibility of communicating recommendations to the patient and coordinating care.³² The treatment team for each patient should extend beyond the professionals at the multidisciplinary program and include patients' local providers, family, and community supports.

The inclusion of the local care team in treatment planning is essential to ensure a successful implementation of the plan. Communication between specialists and community providers could take a variety of forms. The FND team's thoughts and recommendations could be relayed to the other members of the patient's local care team by a written summary or by means of a phone call. Team meetings could be recorded and teleconferenced to allow for the participation of local providers (outside the FND team) to become educated about FND, participate in meetings, and ask specific questions regarding their patient's care. This would help to coordinate care, deliver a consistent message, and provide suggestions as to how to overcome roadblocks. If a patient with FND is already receiving treatment by a local community mental health or physical therapist, the FND specialist from the team should coordinate with these community clinicians to provide FND-specific education and recommendations.

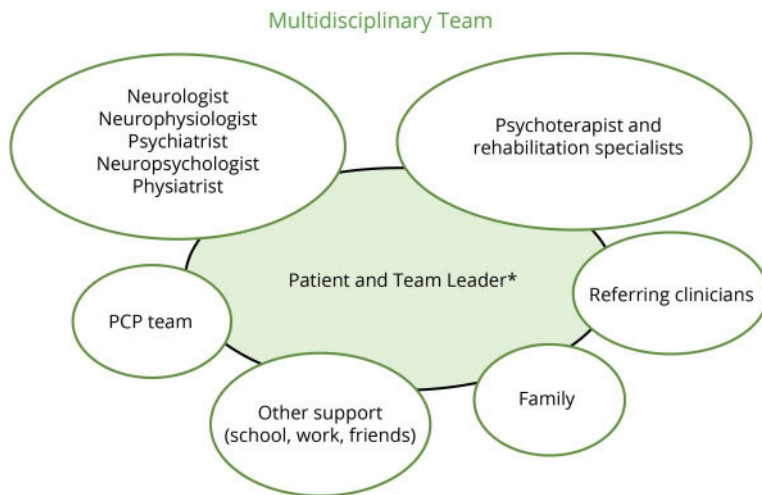
Telehealth technology can be used to help access remote expertise and guidance.³³ Virtual care (also called e-care) is being used increasingly to address the fragmented health

Table A Chronic Care Model Applied to Patients With FND

Elements of the chronic care model	Explanation	Example
Self-management support	Facilitate self-management in patients and their families.	Robust website with links to FND resources (self-help manuals, support groups, and patient educational videos) ^{24–26}
Community resources	Links to community-based resources	Web links to FND-informed providers, educational programs/videos for providers
Healthcare organization	Organizational goals to prioritize sustainable chronic care	Leverage telehealth resources to deliver direct care to patients and/or clinical guidance to providers (e-consults)
Delivery system redesign	Transition to team-based care	A dedicated FND team (partnered with patient-specific community providers) to diagnose, treat, and manage care
Decision/treatment plan support	Use of evidence-based guidelines as standard of care	Care coordinator to ensure patient compliance with evidence-based treatment ^{27–29}
Computer information systems	Roles: 1. Reminders of compliance with treatment 2. Performance feedback 3. Registries to plan individual and population-based care	1. Using technology to record patient-reported outcome measures 2. Use population-based data to predict best treatment options

Abbreviation: FND = functional neurologic disorder.

Figure The Ideal Multidisciplinary Care Team for a Patient With FND



Members of the team interact in a fluid nature as determined by the patient's needs. A neurologist may be the referring clinician or part of the multidisciplinary team.

*The Team Leader is the individual most engaged with the patient. This could be the PCP, neurologist, or one of the mental health providers.

FND = functional neurologic disorder; PCP = primary care provider.

system. Telehealth visits to manage the care for selected established patients and for consults between a local clinician to a specialist (also called e-consults) are platforms that allow community providers caring for patients with FND easy access to a comprehensive specialized team. Virtual visits between the FND specialist and an established patient are ideal to help manage patients who live remotely, either as the primary clinician or a periodic consultant. We would propose developing a telehealth management platform where any clinician caring for a patient with FND could access the FND team for the management/treatment advice. If no appropriate providers exist in the patient's area, management could include guided self-management manuals, bolstered with virtual visits with FND specialists and management consultations with primary providers.^{24–26}

By providing direct training and guidance through multidisciplinary collaboration, telehealth resources can help community providers become more skilled and confident in treating patients with FND. This approach could address the disparities in specialist care for patients living in rural areas, improve education and training gaps in FND, and reduce healthcare costs, allowing patients to receive their care locally.

In addition to connecting local community providers with specialist care, we also advocate for broader education and training in understanding FND, accessing resources, and implementing best practices. For the community clinicians, national and regional educational programs on FND can provide information and training on updated evidence-

based treatments. Short videos made by FND-informed experts placed on a website could address some of the most common challenges faced by providers. Potential topics could include the following: "How to make the diagnosis," "Delivering the diagnosis," "Pathophysiology," "The importance of limiting testing," "How to decide on a treatment plan," "The essential elements of treatment protocols- cognitive behavioral and physical therapy," and "Where to access resources."

Data from multiple other chronic disorders (e.g., diabetes, cardiovascular disease, respiratory disease, and depression) support the utility of a comprehensive multidisciplinary approach, which can reduce care fragmentation and improve health care outcomes at an acceptable cost.³⁴ Although similar data do not exist for such a model in FND, the potential clinical, financial, and functional benefits makes the proposed approach worth exploration.³²

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TAKE-HOME POINTS

- FND is a highly disabling disorder.
- Healthcare costs in patients with FND is high.
- A stepped approach to care with a coordinated comprehensive team for the more chronic patients could help bridge gaps in care, potentially improve functional outcomes and limit costs.

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Mary O'Neal, MD	Brigham and Women's Hospital, Boston, MA	Drafted the manuscript
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