**What is the role of a specialist assessment clinic for FND? Lessons from three national referral centres**.

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**Abstract**

Background: A growing interest in Functional Neurological Disorder (FND) has led to the development of specialized clinics. However, there is little information about their structure and role.

Methods: We collected data as part of routine clinical practice from three national referral centres, two specifically for motor FND and one for FND in general. 100 consecutive patients in UK, 302 in Switzerland and 90 in Canada were referred over a 9-15 month period. Data included: subtype and duration of symptoms, co-morbid pain and fatigue, disability and treatment recommendations. Descriptive data are presented.

Results: Most patients (72% females, mean age 44 years) had a prolonged motor FND (6y) with 35% not working due to ill-health, 26% receiving disability benefits and up to 38% requiring a carer. In Switzerland, 30% were diagnosed with other somatic symptom disorder and in UK and Canada significant co-morbid pain (68%) or fatigue (48%) was reported. Most patients were triaged to physical rehabilitation (53%) while referral to neuropsychiatry/psychology differed across centers (32-100%).

Conclusion: Based on this experience we propose 4 lessons to consider when establishing an FND clinic: 1) FND specialty clinics have an important role in establishing the correct diagnosis/diagnoses and triaging into appropriate treatment; 2) Most patients with motor FND require specialized neurophysiotherapy as part of their treatment; 3) Patients readily accept an integrated neuropsychiatric approach; 4) FND clinics closely collaborating with acute neurology facilities might improve early detection of FND and could improve outcomes.

**Introduction**

Recent years have seen a resurgence in interest in functional neurological disorder (FND), fueled by the recognition of their frequency and profound disability{[1](#_ENREF_1)}. Increased understanding of the underlying neurobiology {[2-4](#_ENREF_2)} has developed hand in hand with new clinical management strategies and a growing evidence base for rehabilitative treatments{[5](#_ENREF_5), [6](#_ENREF_6)}. Yet, a gap exists in clinical practice as only a few clinical facilities{[7-9](#_ENREF_7)} worldwide have dedicated expertise and resources to coordinate the diagnosis and treatment of FND within a specialist service.

This report explores the utility of specialist FND clinics, based on experience from programs recently developed in the UK (2008) Switzerland (2016) and Canada (2018), and offers a critical view on how such services may be optimally developed in the future.

**Experience from 3 new referral centers:**

**United Kingdom**

Our specialist functional movement disorder (FMD) neurology-led clinic (first established at the National Hospital for Neurology and Neurosurgery, now relocated to St George’s University Hospital) is a tertiary service, with most referrals coming from other neurologists. The primary aims of the clinic are: 1) to provide a second opinion where there is diagnostic uncertainty; 2) to provide patients and their families with information and education about the diagnosis; and 3) to triage patients into appropriate treatment services depending on their symptoms and co-morbidities. Over time, the clinic has expanded to include 4 neurologists, and direct links to an FND-specialist neurophysiotherapy program, outpatient neuropsychiatry, clinical psychology and inpatient multidisciplinary rehabilitation (MDT). We aim to offer a follow up appointment after completion of treatment, and then will try to arrange local follow up in primary care, general neurology and/or local mental health services depending on need. In practice we often struggle to discharge patients from our service as they report benefit from ongoing contact with us, even if we are not providing active treatment. We are currently developing a specialist nurse role to aid transition back to local services. This person could also provide a point of contact for patients/local care providers in times of crisis or to deal with queries which do not require face-to-face follow up.

**Switzerland**

On the background of a merger of the Psychosomatic Unit within the Neurology Department, we opened a new out-patient service at Bern University Hospital, a bilingual tertiary center receiving referrals from all Switzerland. Neurologists and general practitioners were informed that they could refer suspected FND cases for diagnosis and treatment. Three neurologists receive the new referrals to 1) confirm the diagnosis and 2) offer interdisciplinary treatment. They also do in-house consultation for people suspected of having FND cases that are hospitalized. Interdisciplinary treatment consists of follow-up appointments (1h) with the neurologist alone or in joint-sessions together with the psychologist, offering cognitive behavioural therapy (CBT) based on published workbooks specific for FND{[10](#_ENREF_10)}. In parallel individual sessions with a physiotherapist and individual or group sessions with an occupational therapist (OT) are organized. A weekly interdisciplinary meeting allows all disciplines to share information in order to set goals and milestones for patients following therapy and plan discharge. When long-term psychotherapy is needed, patients are further referred to private practice psychologists/psychiatrists as they are informed from the beginning that we do not have capacity for long-term treatment. Bi-annual Neurology follow-up is systematically proposed after discharge. A close collaboration with the local pain clinic, psychosomatic medicine specialists and with rehabilitation hospitals allows referral of patients with somatic symptom disorder co-morbities or those in need of prolonged in-patients integrated care.

**Canada**

On the background of a long history of experience with FMD at the Toronto Western Hospital Movement Disorders Clinic, a dedicated treatment program was started for this patient population. This is a tertiary referral center with most referrals coming from community neurologists. The treatment program coincided with the recruitment of an academic neuropsychiatrist dedicated to motor FND. Prior to this, the role of the clinic was in 1) diagnosis of FND and 2) referral to community physiotherapy, neuropsychiatry within the same institution, or instructions for local referrals for physiotherapy by the primary care physician. In April 2018 an Integrated Clinic was started to develop an approach that replaced this referral-based model. In this clinic the patients are treated simultaneously by the neurologist, neuropsychiatrist and physiotherapist in a rehabilitation-based model for 6 visits in bi-weekly 45-minute duration appointments. All patients undergo a neuropsychiatric evaluation after diagnosis and prior to beginning therapy, reflecting an integrated approach.

**Information gathered from the 3 centers**

**Methods:**

We conducted retrospective data collection from clinical notes. Details of data collection are presented in Table 1.

**Results:**

Demographic and clinical data are presented in Table 2. We included 492 patients (UK:100; Switzerland:302; Canada:90; mean age of 44yr) with a female predominance (72%). The socio-economic impact of the cohort is notable with a mean of 35% of patients not working due to their health condition and 26% receiving disability benefits. In addition, a proportion of patients (10% -38%) needed a care provider for daily activities.

The mean symptom duration was 6 years across all centers with local differences: a mean of 6.7 and 7.4 years for UK and Canada respectively, but 4.8 for Switzerland.

The clinics in the UK and Canada were set up specifically for movement disorders (including limb weakness). The Swiss cohort, which included also non-confirmed suspected FND, had greater diversity of dominant symptom, although 61% had a motor dominant presentation. Pain (68%) and fatigue (48%) were common in the UK and Canada. In the Swiss cohort, 34% received a primary diagnosis other than FND and among them pain, fatigue or other somatic symptom disorder were the main complaints (68%). Also the Swiss cohort had 13% of individuals diagnosed with PNES.

Regarding treatment, many patients (53%) were offered physiotherapy either alone or as a component of a multidisciplinary program: 48% in the UK (specialized physiotherapy following consensus recommendations{[11](#_ENREF_11)} for 22% and within a multidisciplinary program for 24%), 43% in Canada, and 71% in Switzerland.

Recommendation for psychotherapy was more variable. In the UK, 8% were referred for psychotherapy as a stand-alone treatment and 24% as part of MDT rehabilitation (total 32%). In Switzerland 65% were referred to psychotherapy, either stand-alone or part of a MDT program. In Canada, all patients were referred to neuropsychiatry, a proportion (12%) of whom participated in the Integrated Clinic (for multidisciplinary treatment). Another 10% had a preexisting psychiatrist that they continued to follow-up with for treatment of comorbid psychiatric conditions and not specifc for their FND.

**Discussion and Lessons learned**

**Lesson 1: FND is a syndrome with multiple comorbidities where specialized neurological evaluation is useful in specific patients.**

* As FND is highly prevalent {[12](#_ENREF_12)}, all neurologists need to be familiar with and effective at making the diagnosis, discussing it with the patient and offering appropriate treatment. Local policies should be established to recommend which patients need to be referred to specialized FND clinics.
* One key role of FND clinics is to help resolve diagnostic uncertainty {[13](#_ENREF_13)}, especially in cases of co-occurrence of FND with other neurological disorders (particularly epilepsy and movement disorder).
* FND clinics can provide additional time and expertise for diagnostic explanation. This can be a useful service for patients who are uncertain about the diagnosis after initial neurological consultation {[14](#_ENREF_14), [15](#_ENREF_15)}. Many patients seemed to hear a clear diagnosis for the first time in our clinics and often expressed relief, which highlights difficulties among neurologists in delivering the diagnosis {[16](#_ENREF_16)}.
* FND clinics can also provide time and expertise to triage patients into appropriate treatment, paying attention to who have comorbidities such as fatigue and pain - which have a worse prognosis {[17](#_ENREF_17)}.

**Lesson 2: A high percentage of patients require physical rehabilitation and there is a need for specialized services**

* More than half of our patients (53%) were triaged to receive physiotherapy (alone or as part of a multidisciplinary treatment) reflecting evidence that physical rehabilitation can be effective for a proportion of people with motor FND{[18](#_ENREF_18)} without prominent comorbidities {[19](#_ENREF_19), [20](#_ENREF_20)}.
* The practicalities of where and how this treatment is delivered is still a challenge as some community and hospital-based rehabilitation services may lack the necessary experience and resources to help patients with FND{[21](#_ENREF_21)}.
* Developing specialist allied health services for FND will help provide outreach and support to community services, thereby improving skills and confidence in treating people with FND.

**Lesson 3: There is a need for neuropsychiatric evaluation and treatment specific to FND**

* Different data regarding triage to neurpsychiatry/psychology were found in our three centers.

The UK clinic policy is that neurologists ask patients about their psychiatric history and current mental health, but not all patients are referred to see a psychiatrist. This reflects the aim of trying to maintain efficiency within the service by avoiding a “one size fits all” pathway. This flexibility in how treatment is delivered is important to optimise outcomes and engagement. Some patients who are initially reluctant or skeptical about psychological treatment may be more amenable after starting physiotherapy.

In Switzerland a high percentage of patients accepted referrals to psychotherapy which might be explained by 3 factors; 1) the diagnosis of FND and proposal to see a psychologist was made by neurologists dual trained in neurology and psychosomatic medicine (psychosomatic medicine training targets mostly interpersonal communication techniques); 2) it was explained that the aim of seeing a psychologist was to start treatment (CBT-inspired therapy) and not to look for a psychiatric diagnosis that could explain the symptoms; and 3) the psychologist was integrated in our team and joint sessions were offered with both the neurologist and the psychologist to avoid the implicit message that the neurologist is passing off the patient to psychology.

In Canada all patients accepted referrals to neuropsychiatry. Therapeutic delivery of a clear diagnosis by the neurologist with an explanation of the neuropsychiatrist as a clinic-affiliated FND treatment expert likely facilitated this very high acceptance rate. Neuropsychiatric assessment and subsequent treatment involved framing of FND as a complex illness in which brain, body and mind represent an integrated whole, readily influenced by internal factors and the outside environment, rather than a manifestation of a ‘psychological problem.’ Psychiatric comorbidities and relevant psychosocial or physical stressors were appropriately managed but were considered perpetuating rather than causal factors for FND.

* There is a need for integrated neuropsychiatric skills - for both diagnostic and treatment purposes{[22](#_ENREF_22)}. Referral to an external psychiatric/psychology facility reinforces a dualistic view that the condition is not neurological but rather psychiatric, and increases the possibility of misunderstanding and poor uptake of potentially useful treatment.

**Lesson 4: There is a need for earlier detection and treatment of FND**

* Patients with long illness duration (6 years) were seen in our clinics, with high socio-economic impact. The Swiss cohort tended to have patients with shorter duration of symptoms (median of 2 years) which might reflect inclusion of patients being hospitalized in the acute phase of their symptom, when the UK and Canada clinics were based on out-patients referrals only.
* The understanding of the diagnosis was often poor, which may play a role in the fact that patients have prolonged symptoms/long illness duration (perpetuating factor). Even if it appeared clear from the notes that referring practitioners had already made and communicated diagnosis, the patient had often not understood the diagnosis except in a negative way – “They told me it was all in my head…”. One factor that may be important in this negative impression of previous consultations, is that often patients were not offered any treatment after diagnosis, perhaps contributing to the impression that healthcare services did not believe that there was anything seriously wrong.
* There is a need for FND clinics to work closely with acute neurology services and/or to accommodate early consultation for patients with recent onset of symptoms. Improving the way the diagnosis is communicated within the emergency department and implementing a liaison team from the FND clinic to see patients while they are in the emergency department could improve diagnostic understanding, help flag up specific patients for treatment and could improve attendance rates to FND clinic or other treatments {[8](#_ENREF_8)}.

The data presented in this report have a number of limitations including retrospective design, different inclusion criteria across centers, and treatment recommendations biased towards local availability and expertise.

**Conclusion**

Prospective and outcome data need to be collected to better refine the goals and added value of FND clinics in international health care systems. However our retrospetive data and clinical experience suggest that specialized FND clinics integrated in Neurology Departments are needed and will help improve the clinical care of FND patients.

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Table 2: Demographic and Clinical Data



*FND: functional neurological disorder, PNES: Psychogenic non-epileptic seizure, MDT: multidisciplinary treatment*