Functional neurological disorders: an Australian interdisciplinary perspective

High prevalence and associated health care and social costs demand a change in health care paradigms for functional neurological disorders

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If legendary neurologist Professor Jean Marie Charcot worked in an Australian hospital in 2022, rather than in 19th century Paris, he might still be enthusiastic about at least one of his pet topics. The contemporary name for the neurological condition that Charcot called *l'hystérie* is "functional neurological disorder" (FND), a condition that is highly prevalent in neurology practice today, but also appears increasingly in popular culture. For example, the TikTok tic has recently generated both academic and popular debate,[1] and FND after vaccination for coronavirus disease 2019 (COVID-19)[2] is an increasingly familiar reason for neurology consultation to Australian emergency departments.

All practising doctors see somatic symptom (previously known as "somatoform") disorders in their patients, and most experience some discomfort in making a clear diagnosis and undertaking management. FND can be understood as somatisation presenting with neurological symptoms, and as with all somatic symptom disorders, the high prevalence and associated health care costs demand a change in the way we deal with patients with FND. In this perspective, we outline clinical, health resource and service delivery issues surrounding FND in Australia, and propose a way forward to improve the landscape for people experiencing FND and the clinicians who provide their care.

FND — Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5):[3] conversion disorder (functional neurological symptom disorder); International Classification of Diseases, 11th revision (ICD-11): F44 (dissociative neurological symptom disorder)[4] — is the occurrence of neurological symptoms due to malfunction, rather than neuropathology or neurological disease, of the nervous system. FND presents with various core neurological symptoms, often concurrently, and of duration varying from acute onset to decades. Core symptoms include seizure-like attacks, gait difficulties, tremor and other movement disorders, cognitive and speech issues, disordered vision, and abnormal function of other special senses. Patients with FND often report additional associated symptoms, including chronic pain, fatigue, and gut and respiratory symptoms, and although psychiatric comorbid conditions and psychological stressors are common, they are not universal.[5,6] FND can occur across the age spectrum and often coexists with other neurological conditions. Diagnosis, therefore, requires careful clinical assessment, but where possible should be made early by identification of typical FND clinical features and without exhaustive, prolonged and potentially harmful investigation in a futile quest to exclude rare organic disorders. For example, lower limb weakness due to FND may vary with distraction, posture or activity, and the often-cited Hoover sign may be demonstrable.[7] Australian neurologists are now encouraged to take a rule-in approach to FND diagnosis, aimed at minimising iatrogenic harm.[7,8]

Epidemiology of functional neurological disorders: a common problem with inadequate health funding

FND is a common neurological condition anecdotally. Even though the prevalence of FND in the Australian community is unknown, 74% of 152 general practitioners based in the New South Wales Hunter Region reported seeing patients with "neurological symptoms due to somatisation" at least monthly in a 2021 survey (unpublished data). The reported prevalence of FND in international neurology outpatient series varies by clinic characteristics and definition, with neurological symptoms either "not at all" or only "somewhat explained by organic disease" in up to one-third of patients.[8] One published Australian neurology clinic series reported FND in 15% of patients.[9] About 8% of acute stroke admissions may be due to FND,[10,11] and a recent report that FND represents 9% of neurology hospital admissions in New Zealand is consistent with anecdotal Australian public hospital neurology experience.[12] The NSW Health Admitted Patient Collection 2001–2016 includes an average of 566 patients with ICD code F44 per year for the entire state.[13]

The direct health care utilisation costs related to FND are high (eg, in 2019, the estimated cost in the United States was US$900 million),[14] with delayed diagnosis, recurrent health care visits and repeated investigations all contributing. Australian specific data on health care utilisation are sparse, but a Victorian cohort of patients with non-epileptic seizure (undergoing video electroencephalogram between 2009 and 2014) reported median pre-diagnosis health care utilisation costs per patient of AU$26 468.[15] To the authors' knowledge, only pilot data are available for Australian health care costs of FND more broadly (unpublished data).

At least as important are the hidden costs of FND, particularly, when not diagnosed and treated early, as FND can cause chronic and significant disability at any age. In the 2018 National Mental Health Commission-sponsored survey of 179 Australians and carers living with FND, around 50% reported quality of life as poor or worse, 70% were unable to work and the majority were struggling financially.[16] Many seek support from the National Disability Insurance Scheme and Centrelink.

Therapeutic communication of the diagnosis is key

Following assessment, we contend that the manner in which the FND diagnosis is presented to the patient strongly sets the scene for their future management and health outcomes.[7] This initial clinician–patient interaction is critical to empower patients to participate in a recovery model of care. A structured diagnostic explanation, providing opportunity and time to explore patient understanding and beliefs, can lay the foundation for a productive therapeutic relationship and facilitate effective health care utilisation and outcomes. The use of one such structured approach in a study of newly diagnosed patients with non-epileptic (functional) seizure showed an improvement in patient understanding and acceptance of the diagnosis while reducing negative emotions and symptom frequency in the short term.[17] Equally, a dismissive approach to communicating the diagnosis can jeopardise patient confidence in the validity of their illness experience, leaving them feeling angry, ashamed and strongly rejecting discussion of the diagnosis and treatment plan.[18] In our own clinical practice, there is a strong emphasis on fostering optimism and developing a collaborative and individualised management plan with the patient's illness narrative at the centre.

Multidisciplinary management is essential in functional neurological disorders

For the past half century, the clinical management of FND has been subject to a great deal of buck-passing between neurologists and psychiatrists, thanks in no small part to traditional models of service delivery shaped by notions of the presence or absence of organicity.[19] Fortunately, advances in evidence-based treatments and new pathophysiological models for FND have catalysed a shift in these outdated models, and consequent recognition of the need for truly multidisciplinary care is slowly changing the culture of FND care in Australia. Clinical formulations of FND genesis and maintenance have evolved from older notions of "psychic conflict" and "conversion" of psychological difficulties and prior traumatic events to consider a broader range of cognitive, emotional, physical and social factors.[20] The science behind these changes includes neurobiological experiments that suggest malfunction of unconscious predictive systems important to normal movement, sensation and cognition, and neuropsychological models emphasising abnormalities in higher order cognitive functions, particularly attention and agency (sense of control).[21]

A detailed review of the evidence base for treatment is beyond the scope of this article. Instead, we refer readers to recent reviews and consensus statements[22-24] and confine ourselves to emphasising the underpinning principles of treatment.

First, empathic and positive diagnostic explanation is fundamental to the success of all treatment that follows. Second, individualised, multidisciplinary treatment plans must address the most prominent presenting core and non-core symptoms for the individual patient. Third, the allied health team, including physiotherapists, occupational therapists and speech therapists, should base therapy on a biopsychosocial formulation addressing illness beliefs, symptom-focused attentional biases, aberrant movement patterns, and functional limitations. Finally, there is evidence for both psychodynamic and cognitive behavioural approaches in the management of FND, although the evidence for cognitive behaviour therapy is of higher quality.[24]

Developing responsive, resource-sensitive models of care for functional neurological disorders and the role of clinical consortia

The reported dissatisfaction with the experience of health care interactions by Australians with FND[16] is reflective of systemic problems in the clinical care pathways. We need to adopt a model of care for FND shaped by patient experiences. Best practice management includes neurology, psychiatry, general practitioners, emergency department and rehabilitation physicians as well as clinical psychologists and allied health practitioners, although not all may be required for every patient.[16] Effective communication between these stakeholders and the patient is essential to prevent the fragmented care and negative health care experiences that remain commonplace in FND. Given the current constraints around health care resources, we suggest the most pragmatic way forward will be to develop a stepped care approach, building capacity in primary and secondary care settings, with specialist FND clinics at the apex.[25] It is time, therefore, for FND to become everyone's business; all of us need to take responsibility for our own part in the health care journey of people with FND.

Investigator-led clinical consortia have the potential to promote health equity, set standards for care, promote sharing of knowledge and expertise, and foster the development of a cohesive translational research agenda.[26] An Australian consortium of FND clinics is needed to allow prospective collection of accurate epidemiological and resource utilisation data to inform health administrators and government bodies regarding the need for further investment to address ongoing gaps and inequities in FND care.

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