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2 **Iatrogenic harm in functional neurological disorder**

3 Caoimhe Mcloughlin, Wei Hao Lee, Alan Carson and Jon Stone

4 **Abstract**

5 Functional Neurological Disorder (FND) is continuing to gain increasing recognition globally
6 as a valid and potentially treatable disorder. Iatrogenic harm towards patients with FND is
7 significant however, and has been around for centuries. Despite advances in our understanding
8 around the aetiology, pathophysiology, and treatment of FND, many aspects of such harm
9 continue to persist. Avoidance of iatrogenic harm has been highlighted by clinicians as one of
10 the most important therapeutic considerations in FND, however, the sources and range of
11 potential harms, or indeed ways to mitigate them, have not been previously summarised. Using
12 a combination of clinical and research experience and scoping review methodology, this review
13 aims to describe the main sources of iatrogenic harm towards patients with FND, including
14 harm from misdiagnosis, delayed diagnosis and treatment, direct harm from professional
15 interactions, other stigma-related harms, harm related to diagnostic overshadowing and over-
16 diagnosis of FND. We also describe some potential ways to address and prevent such harms,
17 such as ways to reduce misdiagnosis with a focus on rule in signs, optimising teaching and
18 communication, ensuring parity of FND with other medical conditions, and continued
19 integration of patient and professional organisations.

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5

6 **Keywords:** functional neurological disorder; conversion disorder; iatrogenic harm;
7 misdiagnosis; stigma

8 **Running title:** Iatrogenic harm in FND

9

10 **Introduction**

11 *“I will use treatment to help the sick according to my ability and judgment, but never*
12 *with a view to injury and wrong-doing”*. -Translation of Hippocratic Oath.¹

13

14 Functional Neurological Disorder (FND) is now recognised as a common, valid and treatable
15 disorder² with population studies suggesting a prevalence of 50–100 cases in 100 000². FND
16 typically affects women with a female preponderance of 60-80% across studies, though the
17 gender gap narrows with increasing age³. It remains, however a neglected condition, influenced
18 by outdated misperceptions and attitudes, and inadequate knowledge and training.⁴⁻⁶ Though
19 newer developments aim to address this, (for example the FND Society and patient-led FND
20 charities) the consequences of this systemic neglect are far-reaching, and continue to cause
21 harm to patients with FND.

22 Iatrogenic harm refers to harm experienced by patients resulting from medical care, and is a
23 concept that will be familiar to every practicing physician. We acknowledge that iatrogenic
24 harm is a complex issue, can be difficult to avoid, and often occurs in the context of intended
25 broader benefit to the patient – the side effects of chemotherapy or antibiotics for example.
26 Some of these harms are unavoidable, an inevitable consequence of the advance in medical
27 treatment – so-called “diseases of medical progress”.⁷ It is hoped in most cases, that treatment
28 is given in the knowledge of weighing up potential risks and benefits. With FND however,
29 there have been centuries of harm towards patients, that have persisted despite patients and
30 professionals highlighting such issues and ways to alleviate them. The repercussions of such

1 harm span a wide spectrum – and are driven by historical inaccuracies, failure to recognise
2 FND as a valid condition, and indifference in training and service development.

3 A large survey of neurologists from 92 countries showed that 58% of clinicians considered
4 avoidance of iatrogenic harm the most important therapeutic action in FND,⁸ but the range of
5 potential harms has not been previously summarised. This paper aims to review eight main
6 sources of such iatrogenic harm related to FND, and considers potential ways to address such
7 harms (Table 1 and 2).

8

9 **Literature search**

10 We used a combination of scoping review methodology, and clinical and research knowledge
11 to inform our search and construction of themes. The process of doing a recent review on the
12 topic of stigma in FND⁹, led us to recognise that iatrogenic harm in FND is a topic that has not
13 been collated and described in an organised way in the literature. Informed by some of the
14 themes from this systematic review, and using the expertise of the two senior authors (JC, AC),
15 who have been working clinically and conducting research in the field of FND for over 25
16 years, we developed core themes that we considered relevant to iatrogenic harm, namely:
17 misdiagnosis, delayed diagnosis, direct harm/assault, and stigma. These themes were expanded
18 upon in detail by the authors (CM and WL) who conducted a scoping review of these topics on
19 the main databases – Medline, PsycInfo, Embase and Google scholar. This search was
20 conducted in line with scoping review methodology in accordance with the five-step
21 framework proposed by Arksey and O'Malley¹⁰. We decided on a scoping review because it
22 allows for a broad literature search, and for the organisation of a heterogeneous literature base.
23 This process resulted in themes related to harm sources 1-5, outlined in Table 1.

24

25 After conducting this scoping review of the initial five themes we realised that there are further
26 sources of harm that were not easily found or described in the literature, which informed the
27 remainder of the sources of harm (sources 6-8 in Table 1). We wrote about these, and the
28 mitigating factors (Table 2) from a mixture of our clinical and research experience, augmenting
29 with current relevant literature from the area.

30

1 **Unnecessary treatment from misdiagnosis of FND as** 2 **another condition**

3 Regarding misdiagnosis, this is not unique to FND and is an inevitable part of practicing as a
4 clinician. We acknowledge the harm experienced by patients described in the following
5 scenarios is at times unavoidable and arises in the context of well-meaning attempts to treat
6 and prevent illness.

7 FND should be diagnosed by inclusion, and not by ‘ruling out’ other explanations. However,
8 there remain many who are concerned about missing a diagnosis of another neurological
9 condition such as epilepsy, stroke or multiple sclerosis (MS), which might be perceived to be
10 a larger clinical error than missing FND. Any misdiagnosis is likely to cause harm to some
11 extent. However, evidence shows that misdiagnosis of another neurological condition as FND
12 occurs no more commonly than the baseline for many neurological conditions.¹¹⁻¹³
13 Misdiagnosis of someone who really *does* have FND as another neurological condition, may
14 even be more common than the other way round¹⁴ and certainly appears to be the case for
15 epilepsy and functional seizures.¹⁵ It is important to note the question of misdiagnosis is not a
16 binary one since FND is also commonly comorbid with other neurological conditions such as
17 MS, Parkinson's and epilepsy.^{13,16} FND can occur subsequently, as commonly occurs with
18 epilepsy,¹⁷ simultaneously, or, in the prodrome, as occurs in Parkinson's disease.^{18, 19}

20 **Misdiagnosis of functional seizures as epilepsy**

21 *“But for some or other reason the pills made me sicker, not better... I think the medication*
22 *was the worst...because it makes you feel really clumsy and confused” - Patient with*
23 *functional seizures, South Africa.*²⁰

24 The frequency of “false positive” diagnosis of epilepsy has been reported to range from 2-71%,
25 with functional seizures (also called dissociative or non-epileptic seizures) being one of the
26 most common final diagnoses.²¹ There is substantial evidence in the literature describing
27 patients misdiagnosed in “status epilepticus” when they were in fact having prolonged
28 functional seizures.¹⁵

29 Many have been administered repeated doses of anti-epileptic medications in the emergency
30 setting, often on multiple occasions, including children.²²⁻²⁴ Other sequelae from this

1 misdiagnosis include unnecessary invasive major vessel venous access, Intensive Care Unit
2 (ICU) admission and assisted ventilation/intubation, and even anti-convulsant induced
3 respiratory arrest.²⁵⁻²⁸ One study evaluated 80 patients admitted via the emergency department
4 with a diagnosis of functional seizures without comorbid epilepsy, finding that 15% of these
5 patients underwent intubation, with 65% (n=31) of the non-intubated patients receiving anti-
6 epileptic mediations in the Emergency Department (usually intravenous benzodiazepines).²⁸
7 Several of these patients had prolonged length of inpatient stays and went on to develop further
8 iatrogenic complications such as hypotension requiring vasopressors, and nosocomial
9 infection. A more recent study evaluated 980 inpatients aged eight and above, finding that 8.1%
10 (n=79) of patients initially thought to have status epilepticus had a final diagnosis of functional
11 seizures, and this risk was highest in children and young adults. Furthermore, respiratory
12 intubation and ICU admission were documented in a substantial portion of this group.²⁹ The
13 above studies show that vulnerable populations such as those with learning disability and
14 children appear particularly at risk from this misdiagnosis.

15 In addition to “status”, there are less acute but nonetheless harmful implications of being
16 misdiagnosed as epilepsy. For example, there are reports of patients, including women and
17 young children, remaining on potentially teratogenic and toxic medications in the longer term
18 even after the diagnosis of epilepsy was retracted, in absence of another clear indication such
19 as bipolar affective disorder or chronic pain.^{30, 31} In a study of 288 patients with functional
20 seizures, 154 (53%) patients were being treated with anti-epileptic medications despite a much
21 smaller number (n=32 /11%) having comorbid epilepsy.³²

22 A small proportion of patients are likely prescribed anti-epileptic medications for other
23 indications such as mood stabilisation or pain – though these scenarios would be rare in
24 children. Such regimes may perpetuate further confusion and harm.³³ Furthermore, one study
25 found that 13 patients were implanted with a vagal nerve stimulator for “intractable seizures”
26 later found to be exclusively functional seizures, diagnosed with video-EEG.³⁴

27 An important cohort study showed the mortality rate in patients with functional seizures is 2.5
28 times higher than the general population, and at a risk comparable to drug-resistant epilepsy,³⁵
29 and a further Danish study found that mortality was three times higher in patients with
30 functional seizures compared with matched controls.³⁶ It is important to recognise there are
31 many potential reasons for this – such as issues related to physical and psychiatric
32 comorbidities, including suicide.³⁷ However, there is suggestion among experts that iatrogenic
33 harm from misdiagnosis of epilepsy may be an important contributory factor to mortality.^{29,38}

1 Concerningly, antiepileptic medications have been used in suicide attempts in children who
2 were referred to a tertiary centre for epilepsy treatment and diagnosed with functional
3 seizures.³⁹ Elderly patients are also at particular risk of unnecessary iatrogenic harm given the
4 increased propensity for falls and delirium with antiepileptic medications, as a recent case in
5 the literature reported.⁴⁰

6 We recognise these risks are not unique to FND and epilepsy. Suicide attempts can occur with
7 any medication, whether or not it is prescribed inappropriately, and elderly patients are more
8 likely to suffer the risks associated with side effects and polypharmacy in general. However,
9 prescribing central nervous system agents that have high potential for lethality, falls, cognitive
10 difficulties and subsequent complications, in the absence of a clear indication for their use,
11 carries a particularly high potential for harm in these more vulnerable groups. We do also
12 recognise however, that there are cases where a diagnosis is difficult, and the risks of untreated
13 epileptic seizures may outweigh the risk of a trial of medication while ongoing efforts occur to
14 clarify a diagnosis.

16 **Misdiagnosis of FND as stroke, multiple sclerosis, myasthenia,** 17 **autoimmune encephalitis and dementia**

18
19 Functional motor symptoms such as weakness and tremor are one of the most common types
20 of FND presentation² but can also go misdiagnosed as other neurological conditions such as
21 stroke, Parkinson's disease or MS, with iatrogenic harm complications. A large-scale study
22 spanning 43 countries showed that FND has shown to be a common cause of a "stroke mimic"
23 presentation given intravenous thrombolysis.⁴¹ Thrombolysis appears to be a low-risk
24 intervention in people without acute stroke and carries considerable potential benefit so
25 therefore this is a calculated risk. Nonetheless, it is one that could be mitigated even more with
26 optimal knowledge of the distinguishing semiological features of FND.⁴²

27 In another study of 320 people with motor FND, 238 (74%) received one or more initial
28 misdiagnoses of a different neurological diseases such as Parkinson's disease, cerebrovascular
29 disease, essential tremor, epilepsy or neuroinflammatory disease, with a diagnostic delay of
30 about six years. Importantly, during this period of misdiagnosis, these patients were not being

1 offered the correct services, delaying treatment.^{19,43} There have also been case reports of deep
2 brain stimulation mistakenly given for FND, with potential adverse effects.⁴⁴

3 A survey of 122 North American MS specialists found that FND, fibromyalgia and other related
4 disorders were common reasons for misdiagnosis among an estimated 598 patients, with
5 around half of those taking a disease modifying therapy.⁴⁵ Another study of 110 patients
6 misdiagnosed with MS recorded 12(11%) of patients had FND and another 16 with
7 fibromyalgia. 70% were given disease modifying therapy, 21 of these for over 10 years.⁴⁶ A
8 study of 8 people misdiagnosed with myasthenia gravis found that 4 had FND who were
9 exposed to unnecessary surgery and immunosuppression.⁴⁷ FND was the commonest final
10 diagnosis (25%) in another study of 107 people misdiagnosed with autoimmune encephalitis,
11 with exposure to heavy duty immunosuppression.⁴⁸

12 Functional cognitive symptoms are characterised through their typical clinical features, and
13 people with these symptoms are sometimes misdiagnosed as dementia given the high rate of
14 these presentations to memory clinic.⁴⁹ There is potential in such scenarios that inaccurate
15 treatments are offered, in addition to the potential psychosocial harm of a dementia diagnosis,
16 though data on treatments in this group are lacking.⁵⁰

17

18 **Psychosocial harm from misdiagnosis of FND as another** 19 **condition**

20 *“[I] felt suicidal and unprepared for this diagnosis. All at once a lot of significant*
21 *information that had affected my career prospects and decisions not to have children*
22 *was given to me. I felt I had been cheated and wanted my life back again” – Patient*
23 *with a diagnostic change from epilepsy to functional seizures.⁵¹*

24

25 There are psychological and social repercussions from misdiagnosis of FND as another
26 condition. Many patients have reported feelings of confusion, anger, uncertainty and mistrust
27 when their diagnoses were changed from epilepsy to functional seizures.⁵¹⁻⁵³ For many, the
28 unique identity associated with having that illness may have formed a big part of their life, such
29 as belonging to a patient group or charity. It may also have impacted people’s decisions around
30 starting a family, or career prospects.⁵¹

1 Having to tell people that you no longer have epilepsy or MS may feel embarrassing or hard to
2 explain, especially when it is hard for people to communicate the diagnosis of FND to family,
3 friends or work.⁵³ Neurologists have reported reluctance to “undiagnose” MS, and the role of
4 family members and practical issues like welfare benefits may make it even more difficult.^{45,54}
5 Being mislabelled can affect how others perceive an individual also – one study examining
6 paediatric coding of functional seizures found that 17 different diagnostic ICD-10 codes were
7 used by 61 paediatricians and, somewhat bizarrely, the most common code fell under “F91.8 -
8 Other Conduct Disorders”.⁵⁵ This is likely to have significant consequences on how these
9 children are perceived both in and outside clinical settings, given how Conduct Disorder
10 manifests with anti-social and aggressive characteristics, and deceitfulness.⁵⁶ On this point of
11 coding, a United States study demonstrated that neurologists, after diagnosing FND, selected
12 FND-related ICD-10 codes in only 22.8% of consultations. The biggest predictor of noncoding
13 was the belief that FND was a “diagnosis of exclusion”.⁵⁷

14 In addition, there is self-stigma that comes with the “status loss” of not having a more well-
15 known neurological illness. Studies have reported feelings of shame and self-blame when
16 diagnoses were changed, as if the situation was now somehow the individual’s fault.^{51-53,58} On
17 a more practical social note, they may have lived with the influence of restrictions imposed by
18 the wrong diagnosis for several years, having had unnecessary driving restrictions or other
19 social and lifestyle constraints.

20 There are identity issues with being labelled with FND also, especially after a previous more
21 socially acceptable, credible diagnosis and this likely affects treatment engagement.^{51,52,59,60}
22 This self-stigma may lead to some not disclosing their true diagnosis,⁶¹ or pretending they don’t
23 have FND, maintaining they had “epilepsy”⁶² or “brain injury”.⁶³

24

25 **Iatrogenic harm from delayed diagnosis and treatment**

26 *“You just don’t fit into the little tick box that that you need to be in, I guess it’s funding and*
27 *it’s so frustrating, from both sides, really frustrating. One of the things about FMD is that*
28 *it’s just so isolating I found the whole NHS system really isolates people ... there was just*
29 *every door closed, you know, you don’t tick any the boxes so you can’t use their services so*
30 *it’s so demoralising when that happens” - Patient with functional motor disorder, UK.⁶⁴*

1 The wait time for a diagnosis of FND has been shown to be particularly long compared with
2 other neurological conditions.⁶⁵⁻⁶⁷ A study comparing diagnostic delay for patients with FND
3 with other neurological disorders, showed a longer diagnostic delay in the FND group
4 compared with the other neurological disorders group (median=48 months versus median=12
5 months), with diagnostic delay correlating significantly with total costs in the entire sample,
6 more strongly in the group with FND.⁶⁵ In a service evaluation study comparing MS and FND,
7 those with FND reported significantly longer waiting times for diagnosis and specialist care.⁶⁶
8 Furthermore, in this study, significantly more reported that they felt they were not treated with
9 respect and dignity, compared with almost no patients with MS feeling they were not treated
10 with dignity and respect by professionals.⁶⁶ A significant issue that often co-occurs with this is
11 that with many patients remain on incorrect, harmful treatments whilst awaiting confirmation
12 of their diagnosis,⁶⁸⁻⁷¹ coupled with the added harm of not getting treatment for the correct
13 diagnosis.

14 For functional seizures, the mean time from symptom onset to diagnosis in published studies
15 ranges from three years to nearly nine years.^{69,72,73} Some factors associated with delay in
16 diagnosis include being female⁷⁴; being prescribed anti-seizure medication^{68,70,71}; and history
17 of physical abuse⁷¹ and in children, a history of psychological abuse.³⁹ These delays have been
18 described as source of distress and dissatisfaction,^{62,75} and as health professionals describe, are
19 “costly and time consuming”.⁷⁶

20 Taking a broader view, the lack of available treatment in many areas causes harm – a global
21 problem that is worse in low-income countries.⁷⁷ A study of healthcare professionals from 92
22 countries revealed that 48% of respondents indicated that low availability of services to refer
23 to was one of the factors considered as ‘often’ or ‘always’ limiting patient management.⁸ In a
24 report of 360 healthcare professionals from 17 countries, only one-third stated they follow-up
25 patients with functional seizures.⁷⁸ A survey of professionals from 63 countries revealed that
26 “stigma/lack of awareness” was the main barrier to the diagnosis and treatment for functional
27 seizures in 70% of countries.⁷⁷ This lack of follow up translates to patients feeling rejected and
28 dumped⁷⁹⁻⁸² and is likely to affect clinical outcomes. A 14-year study looking at the long-term
29 prognosis for patients with FND causing limb weakness showed that 80% still had the symptom
30 at follow up, with outcomes worse for those with long duration of symptoms, and better for
31 those with early diagnosis and treatment.⁸³

32 It is important to note that delayed diagnosis of FND is not the case everywhere, and the tide
33 is changing in many institutions. However, this discomfort and reluctance to manage this group

1 means patients are unable to access clinical services – with FND itself reported as an “exclusion
2 criterion” in many services.^{84,85} This has a direct impact on the future generation of health
3 professionals who can develop an interest in and treat FND.

5 **Direct harm and assault in medical settings**

6
7 *“She then bent a pillow around my face, again to try and get a response... put me in a*
8 *wheelchair with force and started shouting at me and pushing my shoulder and head back*
9 *into the chair. I was very woozy and didn't understand what was happening...” – Patient*
10 *with functional seizures, UK.*⁸⁶

11
12 Some publications describe disturbing episodes of maltreatment of people with FND, often in
13 emergency settings. Some examples include being unnecessarily pierced with needles, covered
14 with a pillow or pushed violently in a wheelchair.⁸⁶ One study reported a perception of being
15 deliberately hurt during treatment with physiotherapy.⁶⁴ Some harm may have been driven by
16 cultural perceptions of illness; *“when I went to the emergency room, for example, the nurses*
17 *grabbed me, they told my mother to go to an exorcist. Those things hurt me”*.⁸⁷ Some tests
18 described for FND involve potential injury to patients. The ‘arm drop test’ involves dropping
19 a weak arm over a patient's face to see if they hit themselves. It has been suggested that people
20 with FND don't hit themselves if they have limb weakness or are in the middle of a seizure
21 whereas people with other causes of weakness or epilepsy do. A test designed to allow a patient
22 to hit themselves, is in our view unethical and has been described as unreliable.⁸⁸ Assessing
23 response to painful stimulation can be a legitimate part of the assessment of a comatose patient,
24 but we are aware of it being performed in a needlessly harmful, arguably vindictive way in
25 people with functional seizures.

26 Deceptive strategies – such as telling people with FND undergoing rehabilitation falsehoods
27 such as: “failure to recover was definitive proof of a psychiatric aetiology”⁸⁹– have
28 intermittently been promoted as part of the treatment of FND, in a way that is at variance with
29 usual healthcare. The arguments made for this, similar to the use of deceptive placebo in the
30 diagnosis of functional seizures, is that deception is a lesser harm than not benefiting from
31 treatment or being admitted to intensive care for seizures. However, honesty is a core and

1 paramount component of a health professional relationship with a patient, and deception like
2 this violates patient autonomy.⁹⁰ In addition and importantly, such deceptive practices have not
3 been proven to achieve better outcomes compared with practices using a transparent approach.

4 Anecdotally, the authors continue to hear of people being injected with large boluses of
5 unnecessary intravenous saline, and still having their arms dropped on them, particularly in
6 emergency care settings. Jokes by health professionals at the expense of patients with FND
7 have been frequently observed anecdotally, and also reported in the literature.⁹¹

9 **Psychological harm through the stigma of being labelled,** 10 **dismissed and doubted**

12 **Labelling**

13 *“Up to that time, hysteria had been the ‘bête noire’ of medicine. The poor hysterics,*
14 *who in earlier centuries had been burnt or exorcized, were only subjected, in recent,*
15 *enlightened times, to the curse of ridicule; their states were judged unworthy of clinical*
16 *observation, as being simulation and exaggerations”.- Sigmund Freud 1888⁹².*

18 “Labelling” patients is a way of “categorising” an individual, and usually has an intended
19 meaning above and beyond the term. There is evidence that labelling leads to medical
20 stereotyping and harm from healthcare rejection.^{93,94} For FND, terms like “hysteria” and
21 “pseudo” have negative connotations, as well as likely reinforcing stereotypes about
22 individuals with FND being non-genuine or out of control. Despite clear evidence of prejudice
23 and use of the label hysteria to dismiss patients, especially women, the term was only removed
24 from the DSM-III and from ICD-9 in the eighties, but has been continued to be used in research
25 papers.

26 Other terms are not only misleading, but have shown to be perceived as offensive, and linked
27 to treatment expectation.⁹⁵⁻⁹⁷ In a study of a healthy population of 87 adults ranking their
28 preferred terms, pseudoseizures, conversion disorder, and hysteria were the three least
29 preferred terms. These three terms were also the most offensive (with functional non-epileptic
30 attacks the most preferred term), and interestingly in this study, the terms pseudoseizures,

1 psychogenic seizures, and hysteria linked with expectations of non-recovery from treatment.⁹⁵
 2 In a mixed method study exploring this issue (39 patients), pseudoseizures and hysteria were
 3 the least preferred terms.⁹⁶ Though it is less mainstream now, “pseudo” continues to be
 4 used,^{98,99} perpetuating the myth that FND is fake and imagined, despite clear evidence to
 5 support the contrary.¹⁰⁰ The term ‘psychosomatic’, historically associated with FND, originally
 6 meant to describe bidirectional disorders of mind and body, but its use has become problematic
 7 and stigmatising for patients.¹⁰¹ This mode of usage has even extended to a recent Lancet
 8 editorial where the author implies that “psychosomatic” conditions should not be taken
 9 seriously.

10 *“...long COVID is often easily dismissed as a psychosomatic condition. Given what we*
 11 *now know about the effects of long COVID and its biological basis, it must be taken*
 12 *seriously.”¹⁰²*

13 Moreover, the multitude of names that exist for FND is likely to add confusion during clinical
 14 communication or when individuals with FND or their caregivers are seeking information
 15 about the condition.

17 **Dismissal**

18
 19 *People’s attitudes towards these patients is often really negative and dismissive, [...] not*
 20 *really giving them the time of day, being annoyed that they’re there really, if I can be frank,*
 21 *and just wanting them out - Speech and language therapist, UK.¹⁰³*

22
 23 The literature is rife with several examples of how many healthcare professionals still consider
 24 these patients the “*bête noire*’ of medicine”. Dismissal and prejudice towards patients range
 25 across a spectrum of mild disregard to more overt rejection and derision.^{79-81,104,105} Emergency
 26 care services, often the first port of call for patients with worrying symptoms have been
 27 described as more outright and explicit in their dismissal.^{86,106} A large survey of healthcare
 28 professionals from 92 countries showed that 29% reported somewhat or very much disliking
 29 seeing patients with FND.⁸ In an Australian study 39% of healthcare professionals (n=516)
 30 agreed they found patients “demanding and difficult to deal with”.⁶ In an Israeli study, 62%
 31 agreed that these patients arouse anger among staff, 60% agreed this group were treated with

1 disrespect, and 50% agreed patients misuse medical resources, with no correlation with
2 professional speciality or seniority.¹⁰⁷ One might argue that dismissive attitudes do not
3 necessarily equate to iatrogenic harm, however, these attitudes have been shown to affect
4 treatment.

5 In a recent study examining professional attitudes of “legitimacy” towards FND and MS,
6 professionals displayed stronger explicit attitudes that FND is illegitimate (doctors more than
7 psychologists), with less favourable attitudes negatively associated with referral to
8 physiotherapy.¹⁰⁸ Patients and professionals have noted that anticipated stigma from
9 professionals impacts motivation to seek help.^{76,79} It has been noted that patients are not
10 received well in outpatient clinics “*nobody wants to deal with them*”.¹⁰⁹ Furthermore, stigma
11 impacts on wellbeing and has been shown to correlate with patient quality of life in FND.^{110,111}

12

13 **Doubted - feigning and voluntary control**

14 *“Doctors in general [...] have been dismissive, rude and talked about me as if I wasn't*
15 *there... I heard the paramedics discussing [...] "Yeah, I don't want to explain how you*
16 *lost [the medication] and she's faking anyway." From there I don't recall exact words,*
17 *but they went on to degrade me as a person. They were wheeling me into the ER as they*
18 *were continuing their derogatory conversation, the ER staff joined in ...”* Patient with
19 functional seizures.⁸⁶

20

21 There are several reports outlining how healthcare professionals across every relevant
22 discipline consider at least some patients with FND to be feigning or have voluntary control
23 over their symptoms.¹¹²⁻¹¹⁶ A range of clinical and neurophysiological data indicates why
24 feigning is rare and not a good explanation for FND.¹⁰⁰

25 In a survey of 159 and emergency physicians and GPs, 38% believed that functional seizures
26 were “*voluntarily induced (patients are fakers)*”, with emergency physicians more likely to
27 consider this.¹¹⁷ One study of speech and language therapists revealed some clinicians thought
28 malingering and functional stroke were interchangeable terms, with patients again being called
29 “*fakers*”.¹⁰³ In a recent survey of 152 psychiatrists, (34%) agreed that they were “*often worried*
30 *patients were actually malingering/faking/feigning*”.¹¹⁸ Studies examining differences in illness
31 perceptions indicate that doctors perceive patients to have more voluntary control over their

1 symptoms in FND than those with epilepsy^{119,120} – the latter study finding emergency care staff
2 more likely to attribute functional seizures to “*alcohol or behavioral issues*”. These
3 misperceptions were quite prominent in the paediatric realm also.^{121,122}

4 From the patient perspective, this obviously has harmful repercussions. Patients are aware that
5 other people think they are faking their seizures.^{52,80} whether it was felt implicitly, or more
6 explicitly being told they were making it up.^{20,60,81,87} It is likely that such patients will be less
7 likely to seek help for troubling symptoms, leading to worse prognosis. It may also impact on
8 self-stigma, confidence and trust in others. These harmful interactions have led to humiliation
9 and shame for many.^{63,86,123}

10

11 **Misuse and misinterpretation of the concept of a functional** 12 **disorder**

13

14 FND undoubtedly carries with it the burden of its history and the ideas associated with it. In a
15 modern clinical neuroscience era when it has been reformulated as disorder of mind and brain,
16 many clinicians still incorrectly associate the term functional to mean “psychological in
17 origin”,¹²⁴ or symptoms with “no obvious organic origin”¹²⁵ – often with a poorly concealed
18 view that this is an imaginary and a lesser illness. The implications are that the symptoms can
19 be controlled, and the patient is not as deserving as those with “real biological” disorders.

20 As long as “mental health issues” or “psychological issues” are artificially separated and
21 viewed dualistically, it is likely these issues will continue to affect FND. Recognising the
22 stigma around mental health is a necessary part of understanding the stigma that patients with
23 FND face. FND defies dualistic models of health and illness¹²⁶ and is conceptualised as a
24 disturbance in areas involved in cognitive, emotional, interoceptive and motor overlapping and
25 interrelated domains. Moving away from outdated dichotomous models will require continuous
26 challenging of traditional belief systems about mind, brain and body by clinicians, patients and
27 carers in the FND community.

28 Some consider that using the term functional neurological disorder is an unhelpfully agnostic
29 position, negates important psychological components and may even promote an overly
30 ‘neurocentric’ view of the condition.^{127, 128} We acknowledge that “functional neurological
31 disorder” is not a perfect term and it is likely that no term will be, given the historical and

1 linguistic challenges. We agree with Scamvougeras & Castle¹²⁸, that to tackle stigma around a
2 condition it is not enough to change a term, but to face the challenge misconceptions and
3 promote treatments for the condition itself. A monistic view of brain, mind and body may be
4 most helpful when considering FND.

5 In the online public domain, the term “functional disorder” has been widely and inaccurately
6 depicted as a synonym for clinicians meaning “it’s not real” or “dustbin diagnosis”, “you’re
7 imagining it”,¹²⁹ when that is far from its intended meaning. This inaccurate misperception has
8 extended into the conversation around other disorders, where FND symptoms may occur
9 comorbid to the presentation, such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
10 (CFS/ME) or Long Covid syndrome.¹³⁰⁻¹³³ There have been reports of patients feeling stigma
11 and shame when trying to obtain information about their FND diagnosis and encountering such
12 negative material:

13 *“It wasn't until I started reading [online] oh my god, oh my god that's when I just lost*
14 *all respect, all my self-respect...just reading things like you're nuts basically...do you*
15 *know what was very unhelpful recently... ..from a COVID group...eh and basically it*
16 *was to do with FND research being led by [name removed] basically he is a fraud, they*
17 *are all frauds uhm... that just set me back just all the way” – Norah.¹³⁴*

18 Researching pathophysiological processes in functional disorders is essential and welcomed.
19 Studies on structural and functional neuroimaging, the immune system, endocrine dysfunction
20 and genetics all form part of the modern portfolio of FND research.¹³⁵⁻¹³⁷ However, the trend
21 of using discoveries that are considered more biomedical in nature to “prove it’s a real illness,
22 not psychological” as is common in the Long Covid and ME/CFS literature, introduces a
23 layered helping of stigma for patients, and prevents an integrative and constructive approach
24 when researching, diagnosing and treating these conditions.

26 **Diagnostic overshadowing – overinterpretation of** 27 **investigations and under-investigation in established FND**

28
29 When one form of diagnosis unduly influences the clinical assessment, it is called diagnostic
30 overshadowing. FND is a clinical diagnosis, but people with it usually require investigations,
31 to assess for comorbid neurological and other medical conditions, which are common and

1 easily overlooked. In this context iatrogenic harm may result from an inappropriate diagnostic
2 weighting or communication of investigations without considering their relevance or frequency
3 in the general population. For example, degenerative abnormalities appear in everyone as we
4 age such that 60% of the population over the age of 50 have “disc bulge”, with little evidence
5 that these correlate at a population level to spinal pain, or even predict future spinal pain.^{138,139}
6 “High signal change” and “white matter change” on an MRI brain scan may be within normal
7 limits for age, but given undue weight in a clinical assessment or miscommunicated as evidence
8 of stroke or possible multiple sclerosis. The mild incidental abnormality on a scan may be
9 emphasised much more than the clinical diagnosis. Electroencephalography (EEG) is often
10 used to distinguish between epilepsy and functional seizures but many normal EEG findings
11 can, in some cases, be misinterpreted as epilepsy.¹⁴⁰

12 Conversely, harm can also occur to people with established FND when they present with new
13 symptoms and are insufficiently investigated, another consequence of diagnostic
14 overshadowing. FND is usually a polysymptomatic disorder and often when new symptoms
15 arise, they are a consequence of the same condition. However, people with FND may have
16 separate new conditions which require investigation in their own right. A balanced approach is
17 needed not to over or under-investigate new symptoms on their own merits. The tendency for
18 people with FND to feel that new symptoms are not being taken seriously is not unique to this
19 condition, and is experienced by people with other long-term conditions that have multiple
20 symptoms such as MS and systemic lupus erythematosus.¹⁴¹

21

22 **Harm related to misdiagnosis of other conditions as FND** 23 **and overdiagnosis of FND**

24 The studies that we have of long-term diagnostic change in FND suggest that it is misdiagnosed
25 no more than other neurological or psychiatric disorders.¹⁴ However, if there is greater
26 awareness of the disorder, especially with a lack of understanding of how it should be
27 diagnosed, then this may lead to an increase in misdiagnosis of people who have other
28 neurological conditions and are wrongly told they have the condition.

29 Our personal experience is, over the last few years, of an increase in premature and
30 inappropriate diagnosis of FND, especially in emergency and acute settings, by health
31 professionals without specific neurological training. Common reasons for incorrectly

1 diagnosing FND include assumptions made based on the presence of comorbid psychiatric
2 disorder, making a diagnosis because tests are negative, or because a symptom is unusual or
3 not previously encountered.^{142,143}

4 We also notice a trend for overdiagnosis in hyperacute settings when it would be more
5 appropriate to wait and see if symptoms become persistent, or in situations where someone has
6 a functional neurological symptom such as mild leg weakness, which is occurring in the context
7 of a more obvious major condition such as chronic pain, neurodevelopmental condition or a
8 psychiatric disorder. There should be room for people to have functional neurological
9 *symptoms* as well as a *disorder*. Furthermore, as with any medical condition, rule in clinical
10 signs must consider the whole presentation and its context, as opposed to blindly or in isolation
11 – for example motor inconsistency can be found in other disorders such as paradoxical kinesis
12 in Parkinson’s Disease.¹⁴⁴

13 The term ‘disorder’ can in itself be harmful and unwanted by some patients, even though it is
14 appropriate and helpful for others. Inappropriate use of the term functional neurological
15 disorder, when a more specific one such as functional seizures, or functional cognitive disorder,
16 can also lead to harm because clinicians may assume someone has one kind of symptom when
17 they have another. The term FND is appropriate in our view for people with severe or multiple
18 symptoms but usually benefits from clarification of main subtype or subtypes.

19

20 **Five potential ways to address and mitigate effects of** 21 **iatrogenic harm**

22

23 **Reduce risk of misdiagnosis –make FND a diagnosis of inclusion**

24

25 We acknowledge that misdiagnosis is an inevitable part of medicine. Some of the time, though,
26 inappropriate diagnoses are a result of lack of knowledge and interest in FND. We are aware
27 that in many settings clinicians are still stuck with an outdated idea that FND needs to be
28 diagnosed by exclusion, rather than by inclusion of typical diagnostic features. Enhancing the
29 visibility of FND at an early stage in core curricula across disciplines may help combat this.
30 Rule in signs for functional motor symptoms include discrepancy between voluntary and

1 automatic movements as evidenced by Hoover sign, hip abductor sign and the tremor
2 entrainment sign, as well as functional seizure signs such as long duration of events and closed
3 eyes during the event – there are many more rule-in signs described in detail elsewhere.²

4 We recognise that some of the features of status epilepticus and functional seizures are hard to
5 distinguish especially in the absence of specialised training, that status epilepticus is life-
6 threatening, and it's rare for the above risks to be ill-intended. However, the risks could be
7 mitigated with optimal knowledge around semiology of differentiators between the two
8 conditions.⁴² Maintaining high awareness of other neurological comorbidity may help to
9 prevent some misdiagnoses. Simple educational interventions may help reduce iatrogenic harm
10 – one study found that rates of benzodiazepine use dropped from 78% to 41% after an
11 educational session to emergency physicians about the features differentiating epileptic and
12 functional seizures.¹⁴⁵

13 It is also worth pointing out that diagnosing FND may carry a certain level of uncertainty at
14 different points throughout the patient journey – for example it may range from possible,
15 probable, clinically-established, to documented. We argue this is no different to other
16 diagnostic journeys in the field of medicine and employing the same strategies as you would
17 with any other disorder will help confirm if FND is present – such as comprehensive history
18 taking, clinical examination, collateral history, video if available, investigations to look for
19 comorbidity, and follow up in clinic to monitor illness course, while always appropriately
20 assessing new symptoms or changes to presentation.

21

22 **Introduce FND early in the differential and contextualise** 23 **investigations**

24 Perhaps as a consequence of the idea of 'diagnosis of exclusion', FND is often not considered
25 by clinicians until later in the diagnostic process. At an early stage, an open mind about the
26 spectrum of possible diagnoses, is important, but adding 'functional' to a list of other diagnostic
27 categories such as 'inflammatory, neoplastic, metabolic, genetic' would help. Conversely,
28 clinicians, especially more junior trainees should not be in a rush to diagnose FND after just
29 one meeting of the patient, especially if the symptoms are new and acute.¹⁴³

30 Investigations are usually an essential part of the assessment of someone with FND, partly
31 because neurological comorbidity is so common, and clinical evidence of comorbid conditions

1 may be mild. The message therefore should not be to avoid investigations but do them and
2 communicate them in a way that is least harmful to patients. Anticipating a possible ‘normal
3 for age’ result before the investigations are done has been shown to reduce anxiety while
4 waiting for results.¹⁴⁶ More can be done to educate health professionals about the importance
5 of casual phrases which they may consider innocuous but could have nocebo consequences
6 like ‘wear and tear’ or ‘vascular changes in the brain’. Furthermore, in cases where there is
7 confidence about the FND diagnosis, it has been shown that something as simple as
8 documenting it, and referring to neurology have been shown to be associated with reduced ED
9 reattendance, likely reducing iatrogenic harm from multiple emergency presentations and
10 treatments.⁶⁷

11

12 **Teaching: with a focus on communication and stigma**

13

14 There is insufficient teaching and representation of FND in core undergraduate and
15 professional curricula.^{5, 104, 147, 148} It would be helpful to ensure FND is a core requirement in
16 training curricula internationally from an early stage in training, for all disciplines involved in
17 the care of patients with FND. This has recently happened with the UK and European
18 Association of Neurology training curricula.^{149, 150} It could be worth educating professionals
19 involved in FND formally or informally on how common stigma is for patients and the potential
20 influence of stigma on patient outcomes.¹¹⁰ The “hidden curriculum”¹⁵¹ is a more subtle method
21 of learning outside formal curricula, which includes informal conversations and role modelling
22 – and has been found to be a means of perpetuating stereotypes, but also more positive attitudes.

23

24 **Parity for FND services and research**

25 Many healthcare professional studies have described how they feel poorly resourced to
26 diagnose and treat patients with FND.^{8, 77} People with FND are routinely excluded from both
27 physical rehabilitation services (“mental health problem”) and mental health services
28 (“neurological problem”). Achieving parity of services for FND, especially in deprived areas
29 would help. Treatment of FND, like many other conditions is most beneficial when there is
30 interdisciplinary expertise available for the patient and their family. This does not just include
31 neurology and psychiatry but a range of specialisms including psychotherapy, general

1 practitioners, occupational therapy, nursing, physiotherapy, speech and language therapy and
2 rehabilitation medicine among many others. Equipping all specialisms with the skills to
3 confidently treat patients with FND will improve parity of care for this group. Further,
4 incorporating an understanding of all aspects that influence illness, outside just the biomedical
5 model – for example social aspects such as environment, family dynamics and culture is
6 important not just for FND but for all illness presentations, and such aspects could be
7 emphasised in training. Patients with FND should be prioritised for early access to treatment,
8 (just like any other medical condition), which would go some way to reducing harm from
9 chronicity and deconditioning, the distress of uncertainty and unnecessary investigations and
10 treatments. On the topic of treatment, research funding for FND treatments could be improved
11 - at the time of writing, there were less than 20 trials actively recruiting for FND compared
12 with hundreds for epilepsy, MS and Parkinsons.¹⁵² However, many positive things are
13 happening with regard to research and service development, and FND is now occupying a more
14 mainstream position in many areas.^{149,153,154}

15

16 **Ongoing promotion and integration of patient and professional** 17 **organisations**

18

19 Patient organisations such as fndhope.org and fndaction.org.uk,^{155,156} as well as patient
20 advocates on social media continue to draw attention to this neglected condition, reducing
21 stigma, challenging old paradigms, and working closely with professionals and
22 governments for improved research and service development for FND. Professional
23 organisations and platforms are also playing a role in enhancing the visibility of FND, changing
24 old paradigms, furthering education and research.^{157,158} Ongoing development and integration
25 of these groups will continue to play a role in addressing some of these harms.

26

27 **Limitations**

28 We are aware of some limitations to this review. It was not feasible to search the topic using
29 systematic review methodology and some of the harms we report, such as overdiagnosis of
30 FND arise from clinical experience rather than existing literature. It is possible that these views

1 are not representative of other clinicians in the field. We also only included topics in the English
2 language and so may have missed other relevant papers.

3

4 **Conclusion**

5 Undoubtedly there have been advances in many areas with regards to FND, and patient
6 involvement has been integral to driving progress. That said, it continues to be the
7 professional's job to reduce iatrogenic harm, and more can be done to mitigate and address this
8 issue. It is important that we continue to learn from the history of this common and treatable
9 condition, and use this knowledge in an adaptive way for the benefit of patients with FND and
10 their carers.

11

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17

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21 website, www.neurosymptoms.org, for patients with Functional Neurological Disorder. He is
22 president-elect of the FND society, and is on the medical advisory board of FND Hope UK and
23 FND Action. Alan Carson reports being a paid editor of the Journal of Neurology,
24 Neurosurgery and Psychiatry, is past President of the FND Society, is the director of a research
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28

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26 **Table I Eight sources of iatrogenic harm in FND**

Sources of harm	Example
Unnecessary medical treatment from misdiagnosis of FND as another condition	Misdiagnosis of FND as epilepsy can cause harm from unnecessary (often teratogenic) medications, and, in cases of presumed “status”, harm can occur as a result of unnecessary intubation and its sequelae.
Psychosocial harm from misdiagnosis of FND as another condition	Having a diagnosis changed - for example from Multiple Sclerosis to FND - can have psychological and social repercussions, such as impacting on identity, causing feelings of shame or unjustifiable responsibility for symptoms, or influencing relationships with caregivers and work.
Harm from delayed diagnosis and treatment	Patients often wait much longer for a diagnosis of FND compared with other disorders, delaying access to treatment and potential recovery.

Direct harm and assault in medical settings	There are reports of patients with FND being unnecessarily pricked with needles, being pushed forcefully in wheelchairs in an effort to stop their functional seizures, or ridiculed.
Psychological harm through the stigma of being labelled, dismissed and doubted	Terms such as “pseudo” have led clinicians to associate FND symptoms as fake, and patients have been accused of faking their symptoms for attention. Studies from the perspective of both patients and clinicians outline how patients can be treated in dismissive, rejecting and derogatory ways when they seek help.
Misuse and misinterpretation of the concept of a functional disorder	The term functional disorder (including FND) is often misunderstood, and has been widely and inaccurately depicted as a synonym for clinicians meaning “it’s not real” or “dustbin diagnosis”, “you’re imagining it”. This leads to doubt and worry when patients are researching their condition, particularly online.
Diagnostic overshadowing: overinterpretation of investigations and under-investigation in established FND	Overinterpretation of common signs such as ‘normal for age’ white matter change or degenerative changes on MRI may be given undue weight when FND is the actual diagnosis. Conversely, harm can also occur when patients with FND develop new signs that are not investigated properly as clinicians do not look past the patient’s existing FND for a cause.
Harm related to misdiagnosis of other conditions as FND and overdiagnosis of FND	Premature or misdiagnosis of FND, based on, for example, an unusual presentation or a psychiatric comorbidity, without an adequate period of assessment or investigation can lead to harm. In addition, the use of an FND ‘disorder’ diagnosis may not be appropriate for someone with mild symptoms, or where a more specific term, such as functional cognitive symptoms may be better.

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Table 2 Five potential ways to address and mitigate harm

1.	Reduce risk of misdiagnosis – make FND a diagnosis of inclusion
2.	Introduce FND early in the differential and contextualise investigations
3.	Teaching: with a focus on communication and stigma
4.	Parity for FND in service development and research
5.	Ongoing promotion and integration of patient and professional organisations

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