





## ORIGINAL ARTICLE

# International online survey of 1048 individuals with functional neurological disorder

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## Abstract

**Background and purpose:** Functional neurological disorder (FND) is common, and symptoms can be severe. There have been no international large-scale studies of patient experiences of FND.

**Methods:** A patient questionnaire was created to assess FND patient characteristics, symptom comorbidities and illness perceptions. Respondents were recruited internationally through an open access questionnaire via social media and patient groups over a month-long period.

**Results:** In total, 1048 respondents from 16 countries participated. Mean age was 42 years (86% female). Median FND symptom duration was 5 years, and median time from first symptom to diagnosis was 2 years. Mean number of current symptoms (core FND and associated) was 9.9. Many respondents had associated symptoms, for example fatigue (93%), memory difficulties (80%) and headache (70%). Self-reported psychiatric comorbidities were relatively common (depression, 43%; anxiety, 51%; panic, 20%; and post-traumatic stress disorder, 22%). Most respondents reported that FND had multiple causes, including physical and psychological.

**Conclusions:** This large survey adds further evidence that people with FND typically have high levels of multiple symptom comorbidity with resultant distress. It also supports the notion that associated physical symptoms are of particular clinical significance in FND patients. Dualistic ideas of FND were not supported by respondents, who generally preferred to conceptualize the disorder as one at the interface of mind and brain. The need for a broad approach to this poorly served patient group is highlighted. Potential selection and response biases due to distribution of the survey online, mostly via FND patient groups, are a key limitation.

## KEYWORDS

comorbidity, FND, functional neurological disorder, illness perception, survey

## INTRODUCTION

Functional neurological disorder (FND) constitutes symptoms of the voluntary motor or sensory nervous system which can be positively identified as being incompatible with recognized neurological diseases [1]. FND is common [2–4], and disability resulting from the condition is similar to other neurological diseases such as multiple sclerosis and Parkinson's disease [5]. Symptoms are often found to persist or worsen over time [4], particularly in the absence of treatment, and prognosis can be poor [6,7]. Healthcare costs of FND in the USA for inpatient treatment and emergency visits alone were calculated at \$1.2 billion for the year 2017 [8].

Functional neurological disorder can present with a number of neurological symptoms in varying combinations [9]. The Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) includes the following symptoms as part of the core features of FND: weakness or paralysis, abnormal movement (e.g., tremor, dystonia, myoclonus or gait disorder), swallowing symptoms, speech symptoms, attacks or seizures, anaesthesia or sensory loss, special sensory symptoms (e.g., visual, olfactory or auditory). There is also a diagnosis of 'mixed symptoms', appropriate for those with several simultaneous core symptoms [10]. The International Classification of Diseases 11th Revision (ICD-11) has an additional inclusion of a cognitive subtype of FND [11,12]. Specific epidemiological data in relation to symptom co-occurrence in FND are currently lacking.

Alongside the core neurological symptoms, associated physical symptoms (e.g., pain, fatigue, sleep disturbance, poor concentration, bladder and bowel dysfunction) as well as psychological symptoms (e.g., low mood, anxiety, panic, dissociative phenomena, and post-traumatic stress symptoms) are of particular clinical significance in FND patients [13–17]. These frequently co-occurring symptoms have been shown to negatively affect clinical outcomes [7,18], and are often at least as severe and disabling as the core features [13]. As well as this, co-occurring symptoms can adversely affect quality of life [19,20] and can be more strongly adversely correlated with quality of life than the primary FND symptom(s) [21,22]. Some authors have called for the incorporation of pain and somatic symptom subtypes of FND into future classification [23].

In this study, the aim was to understand the prevalence of core FND and associated symptoms, comorbidities, patients' own experience of their condition, as well as patients' own perceptions about FND in general. To achieve this, an online questionnaire was disseminated to an international sample of FND patients.

## METHODS

### Respondents

Respondents were those who self-reported a diagnosis of FND from a medical professional. Recruitment was facilitated via social media posts on Twitter, as well as by dissemination through patient support

groups (FND Hope, FND Action, FND Friends), who shared the online invitation on their websites and mailing lists.

### Design and materials

This was a cross-sectional observational survey design. An online questionnaire was created via the Qualtrics platform and shared open access over a period of a month from 12 September to 14 October 2019 inclusive. Questions were written using plain English, avoiding medical jargon where possible. Support from the charity FND Hope and FND Hope UK in the design of the study was gratefully received. The original questionnaire can be found in File S1.

Respondents were asked about basic demographics, current and past symptoms, treatments accessed, psychiatric comorbidities and illness perceptions. Questions were tick-boxes, visual analogue scales (VAS) or free-text fields. Where respondents were asked to rate the degree of their agreement, this was on a scale where 0 represented 'strongly agree', 50 represented 'neither agree nor disagree' (50/100), and 100 represented 'strongly agree'.

Questions on mood were adapted from the Maudsley three-item VAS which has been validated against the Quick Inventory of Depressive Symptomatology 16 item scale [24]. Where respondents were asked to rate their current mood over the past 2 weeks, this was on a scale of 1–100, where 0 represented 'extremely low mood', 50 represented a 'normal mood', and 100 represented 'extremely high mood'. Where respondents were asked to rate their ability to enjoy life activities that they were still able to do over the past 2 weeks (anhedonia), this was on a scale where 0 represented 'much less than usual', 50 represented 'the same as usual', and 100 'much more than usual'.

Respondents were asked questions from the Brief Illness Perception Questionnaire, a validated scale used to assess the cognitive and emotional representations of illness [25]. In this study, questions were modified to change the word 'illness' to 'FND symptoms' and respondents were asked to rank each answer on a VAS ranging from, for example, 0 = no control at all to 100 = full control. This section also included two free-text questions on respondents' perceived causes of their FND.

Respondents read the online information sheet which detailed the aims and scope of the study. Once respondents navigated to the study page, they were asked to read through terms and conditions and provide their consent for their data to be submitted anonymously. Respondents were clearly informed that they could withdraw from the study at any point without penalty. A single £50 voucher prize draw was offered to respondents who agreed to provide their email address (which was kept separate from the survey data); however, this did not affect data collection in any way.

### Data analysis

Data were analysed using IBM SPSS Statistics 26 and Python v3.9. Age was calculated as year of birth to survey year (2019); similarly,

length of symptoms and time since diagnosis were calculated as year of occurrence to survey year (2019). Unless otherwise stated, averages are presented as mean ( $\pm$  standard deviation). Where respondents were given the option to select more than one answer, mutually incompatible answers were both removed from analysis. Values were rounded to one decimal point. Descriptive statistics (i.e., frequencies, proportions/percentages, measures of central tendency and dispersion) were used to summarize the data. Kernel density estimates and conditional probability analyses and figures were constructed with custom Python scripts. Free-text responses were coded by AB-W, JB and SP using a thematic analysis approach.

## Ethics

The study conforms with the World Medical Association Declaration of Helsinki. The study was approved by King's College London Research Ethics Committee, Ethical Clearance (Ref: HR-18/19-11278).

## RESULTS

### Demographics

In total, 1162 international respondents participated in the study; 1048 of the respondents answered yes to the question 'Have you been diagnosed with functional neurological disorder by a medical professional?' Those who did not were excluded from further analysis. Of those who were diagnosed with FND, 88.9% ( $n = 914$ ) reported a diagnosis by a neurologist, 7.6% ( $n = 78$ ) by a psychiatrist (e.g., neuropsychiatrist) and 3.5% ( $n = 36$ ) by another type of doctor (unspecified). Some respondents only partially completed the survey; however, 909 (86.7%) completed every question.

The mean age of respondents was 42.5 years (SD 12.7). Females constituted 86.2% of included respondents. Most respondents ( $N = 851$ , 78.5%) resided in the UK; however, responses were received from respondents from all continents (Table S1). Most patients (96.2%) reported having completed compulsory education. Almost half (49.0%) were married, and there was a range of employment statuses, although unemployment was most common (Table 1).

### Symptoms

Self-reported symptoms, many of which co-occurred, are displayed in Table 2. Less than one percent (0.8%) of respondents indicated that they only had a single current symptom (4.5% had no current symptoms). More than half of respondents (50.1%) had  $>10$  current symptoms. Mean number of symptoms was 9.9 per respondent. Figures 1 and 2 display the conditional probability of currently experiencing a symptom if another symptom is reported (i.e., co-occurrence of symptom pairs in heatmap and pictorial form). There was a strong conditional probability between all FND symptoms and

**TABLE 1** Demographics of respondents from the study

	N	%
Gender <sup>a</sup>	1048	–
Female	903	86.2
Male	137	13.1
Age range	1046	–
18–25	126	12.0
26–35	208	19.9
36–45	229	21.9
46–55	316	30.2
56–65	144	13.8
$>65$	23	2.2
Level of education <sup>b</sup>	1045	–
Didn't complete mandatory education	40	3.8
Completed mandatory education	269	25.7
Completed higher education	359	34.4
Completed tertiary education/university	353	33.8
Marital status	1044	–
Single	302	28.9
Married	512	49.0
Divorced	69	6.6
Other	161	15.4
Employment status	1048	–
Full-time	143	13.7
Part-time	143	13.7
Self-employed	47	4.5
Unemployed	335	32.0
Student	77	7.4
Retired	93	8.9
Other	208	19.8

Note: The ratio of females to males is slightly higher than reported in clinical populations of FND patients.

<sup>a</sup>Three, 'other'; five, 'prefer not to say'.

<sup>b</sup>Twenty-seven, 'other'.

both memory difficulties and fatigue. Figure S1 displays the logarithmic relative risk of co-experiencing a pair of symptoms.

### Symptom duration

Mean overall duration from first FND symptom to survey was 8.7 years (SD 9.4) (median 5 years). Mean time from first FND symptom to FND diagnosis was 5.4 years (SD 8.6) (median 2 years) (Table S2). Years of symptoms prior to diagnosis by frequency are reported in Figure 3, and breakdown of age of first symptom (by gender) is reported in Figure S2.

Symptom	N	Currently (%)	In the past (%)	Never (%)
Core FND symptoms				
Altered bodily sensations (i.e., numbness/tingling)	1012	801 (79.2)	124 (12.3)	87 (8.6)
Loss of balance	1007	772 (76.7)	159 (15.8)	76 (7.5)
Difficulty walking	1011	766 (75.8)	158 (15.6)	87 (8.6)
Muscle jerks ('myoclonus')	1006	660 (65.6)	158 (15.7)	188 (18.7)
Difficulties talking, stuttering or changes in the speed of your talking	1011	655 (64.8)	200 (19.8)	156 (15.4)
Muscle spasms ('dystonia')	1005	652 (64.9)	155 (15.4)	198 (19.7)
Tremors	1004	609 (60.7)	183 (18.2)	212 (20.2)
Seizures (e.g., unawareness, shaking episodes)	1010	511 (50.6)	172 (17.0)	327 (32.4)
Vision problems or blindness	1005	457 (45.5)	190 (18.9)	358 (35.6)
Paralysis (of limbs or face)	1009	427 (42.3)	252 (25.0)	330 (32.7)
Trouble swallowing or a 'lump in the throat'	1002	412 (41.1)	245 (24.5)	345 (34.4)
Hearing problems	1000	375 (37.5)	138 (13.8)	487 (48.7)
Problems with your memory	1010	811 (80.3)	111 (11.0)	88 (8.7)
Associated symptoms				
Fatigue	1010	937 (92.8)	48 (4.8)	25 (2.5)
Headache	1007	706 (70.1)	156 (15.5)	145 (14.4)
Bladder symptoms	1048	457 (45.5)	183 (18.2)	364 (36.3)
Bowel symptoms	1003	387 (38.6)	174 (17.3)	442 (44.1)

Note: Respondents could select from 'yes, currently', 'yes, in the past' and 'no'.  
Abbreviation: FND, functional neurological disorder.

## Psychiatric comorbidities

Current self-reported psychiatric comorbidities, particularly anxiety and depression, were relatively common (Table S3), with most patients experiencing anxiety and/or depression at some point. Only 9.7% ( $n = 164$ ) of patients reported never having a psychiatric comorbidity.

## Management of symptoms

Respondents reported that they had received a range of treatments (Table S4). Overall, 112 (11.4% total) respondents indicated that they had not had any medically recommended treatments at any point.

Many respondents (66.8%) had been prescribed medication at some point. Only 38 patients indicated which medication they had been specifically prescribed; most of these respondents had been prescribed multiple medications. From 135 responses regarding prescribed medication, 32 (23.7%) were antidepressants such as fluoxetine, 14 (10.4%) benzodiazepines, 16 (11.9%) sleeping tablets, 20 (14.8%) opiates, 23 (17.0%) non-opiate analgesia and eight (5.9%) medicinal cannabis, and 22 (16.3%) other.

**TABLE 2** Breakdown of symptoms experienced

## Visual analogue scales

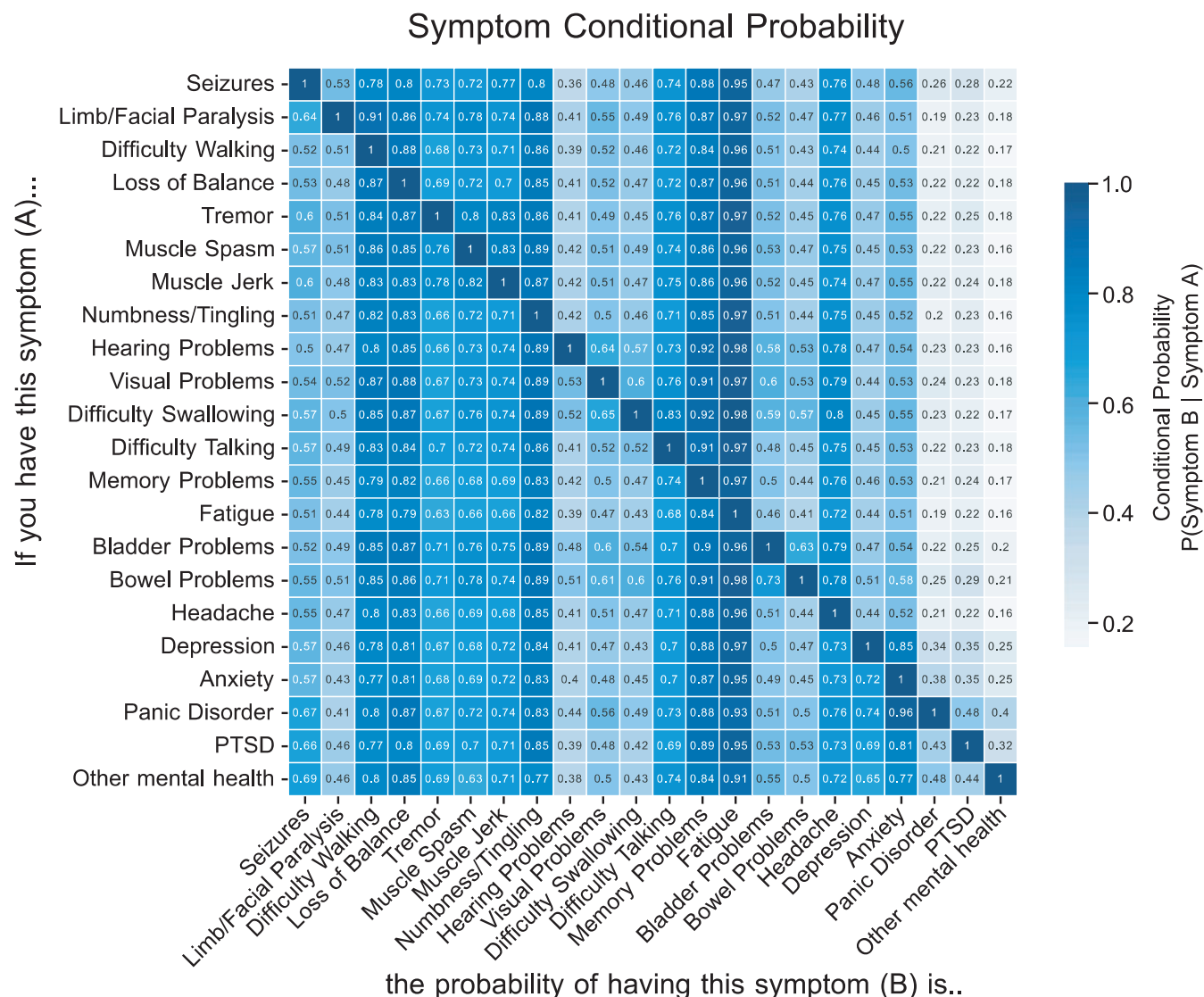
Results of the Maudsley three-item VAS and the Brief Illness Perception Questionnaire are summarized in Figure 4. The free-text responses offer a more detailed account of the perceived causes (Table 3).

## DISCUSSION

In this large survey of people with FND the aim was specifically to understand the frequency of functional neurological symptoms—core and associated—as well as comorbidities and illness perceptions. Previous studies have identified that patients with FND often present with multiple core FND symptoms (as well as other associated symptoms such as fatigue) in clinical settings [1,26,27]; however, to our knowledge this is the first to assess self-reported occurrence of multiple symptoms on a large scale.

## Demographic and illness characteristics

In this study, respondents had an average age of 42 years, which is in line with previous similar studies [1,5,9,27]. Females constituted 86% of respondents, which is a slightly higher proportion than in



**FIGURE 1** Matrix of current symptom co-occurrence. The probability of co-occurrence is represented in the colour of the square between symptoms—darker colours indicate stronger co-occurrence of a symptom on the x-axis with a symptom on the y-axis. The lighter columns above mental health problems indicate lower co-occurrence in relation to physical symptoms

other similar studies [1,5,9,27]. Our respondents on the whole were highly educated; around a third were not in work, which it is suspected may be due at least in part to the impairing effects of their FND symptoms. Our respondents had a median FND duration of 5 years, suggesting that chronic symptoms occur in many FND patients. This symptom duration is slightly higher than reported in previous studies [9]; this increased population-level symptom duration in our study may have influenced findings in other domains, for example the large number of coexisting symptoms. The median of 2 years of symptoms prior to diagnosis in this study is lower than in previous studies in motor FND [1] and functional seizures [28].

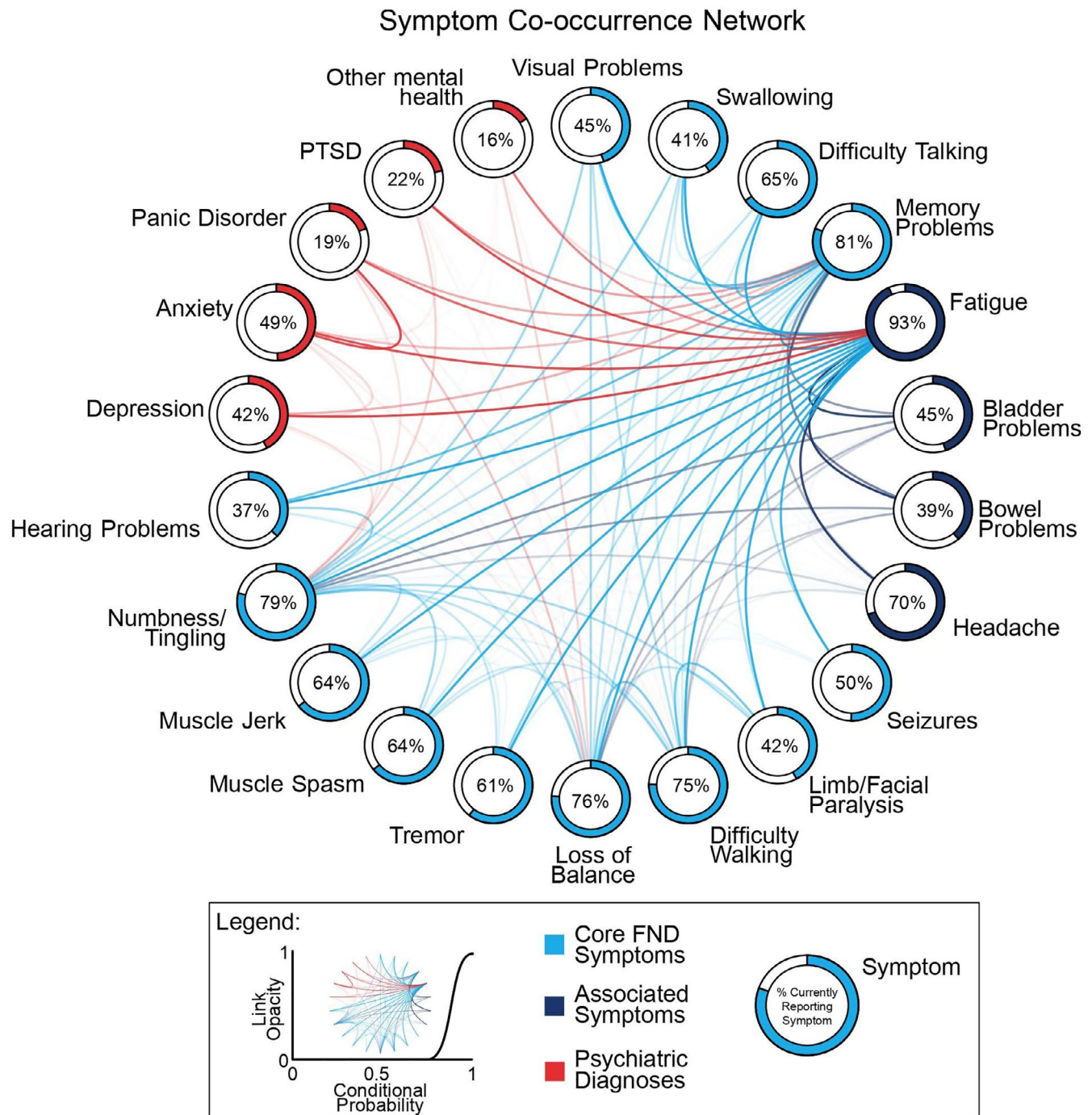
### Core FND symptoms

Self-reported co-occurrence of multiple FND and other physical symptoms was striking. More than 90% reported fatigue, and

more than two-thirds of respondents currently reported experiencing gait abnormalities, loss of balance and memory difficulties. Furthermore, over half of respondents reported currently experiencing seizures, tremors, dystonia or myoclonus, speech abnormalities and headache. Additionally, the majority had at some point in the past experienced limb or face paralysis, hearing abnormalities, visual problems or blindness, swallowing difficulties, or bladder and bowel symptoms.

Many respondents suffered with multiple co-occurring motor symptoms (difficulty walking, loss of balance, tremor, spasm and jerk), suggesting that patients with motor FND may be predisposed to multiple symptom manifestations. However, given the nature of the question asked, it is likely that at least some of this overlap may be due to interpretation of the questions; for example, people may interpret the phrases 'muscle jerks' and 'muscle spasms' in different ways or someone with functional leg dystonia is likely to have difficulties in walking.





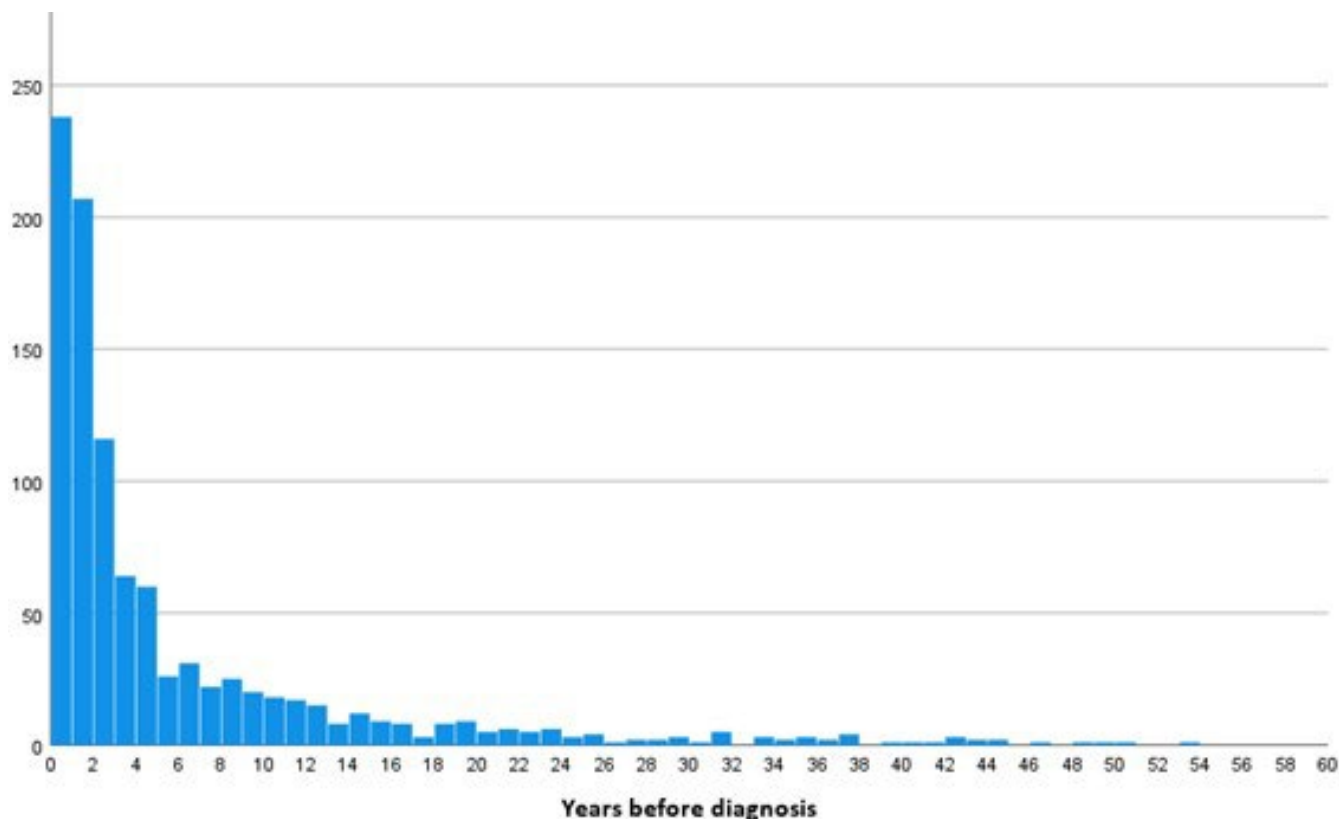
**FIGURE 2** Network of current symptom co-occurrence. The prevalence of each symptom is shown within the doughnuts whilst probability of co-occurrence is represented by the opacity of links between symptoms (see figure legend). Doughnuts and links are coloured according to symptom group. Fatigue and memory problems strongly co-occurred with many symptoms

### Associated physical symptoms

Our study indicated that many respondents had co-occurring somatic symptoms, for example headache and fatigue. It was also found that self-reported bowel and bladder symptoms were roughly as prevalent as anxiety and depression, and headache was more common than any self-reported psychiatric diagnosis. Our respondents very commonly reported fatigue associated with

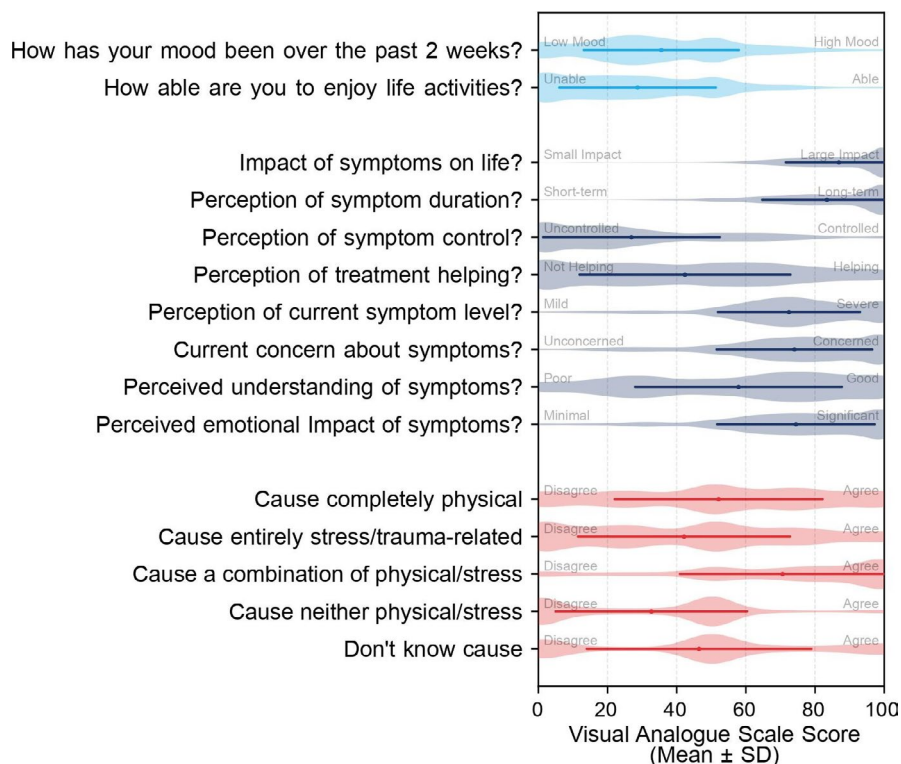
their FND; fatigue currently lies outside the core features of FND, and so may not be routinely explored during clinical assessments [9].

Our results support the notion that associated physical symptoms are of particular clinical significance in FND patients [13]; as has been shown previously, these symptoms negatively affect quality of life [19,20], as well as clinical outcomes [7,18], and are often as severe and disabling as the core features of FND [13]. Although pain



**FIGURE 3** Years of FND symptoms prior to diagnosis by frequency

**FIGURE 4** A violin plot of kernel density estimates and mean  $\pm$  SD visual analogue scale scores. The valence of each answer is displayed in word form at the extremes of each score. If a score equal to or above the 51st percentile is taken for 'agreement' with a particular viewpoint, then 51% of respondents agreed that FND is caused by completely physical factors, 43% agreed that FND is caused by completely stress/trauma related factors, and 77% agreed that FND is caused by a combination of both factors



is increasingly recognized as a common comorbid FND in some patients [29], this was not asked about, other than headache, which is a limitation of this survey. Given that somatic, sensory and cognitive

symptoms (e.g., memory problems [30]) can be common in the general population, further research could be undertaken to assess the rates of core and alternative symptom profiles in a related control

**TABLE 3** Proportion of patients who filled in the free-text responses who described causes in the following categories

Physical	65% (613)
Other physical causes	37% (346)
Neurological	21% (199)
Injury	16% (149)
Infection	9% (89)
Genetics	5% (45)
Other physical environmental	4% (34)
<b>Psychological, social and environmental</b>	60% (559)
<i>Psychological</i>	50% (469)
Stress, worry or feeling overwhelmed	40% (371)
Additional or untreated mental health disorders or symptoms	20% (188)
Personality and interpersonal styles	3% (25)
Emotional dysregulation or specific emotional difficulties	3% (24)
<i>Social and environmental</i>	26% (245)
Adverse life events, psychological or mental trauma	17% (159)
Long-term social/environmental adversity	14% (132)
<b>Mixed</b>	38% (357)
Medical treatment, negligence and lack of support	18% (165)
Unspecified trauma	16% (147)
Other functional neurological disorder symptoms	5% (50)
Others	5% (46)
<b>Uncertainty</b>	29% (270)
Responses indicating uncertainty about cause	29% (270)

Note: Responses could be coded in multiple categories.

clinical and healthy population, to compare with the self-reported rates from our FND survey.

## Associated psychiatric symptoms

Our survey also showed that respondents reported a high prevalence of current psychiatric comorbidities including depression, anxiety, panic disorder and post-traumatic stress disorder. Further analysis of the data suggested that there was a subset of patients who reported multiple psychiatric comorbidities, with many other respondents not reporting any mental health diagnoses; despite this, patients on average had modestly low mood and some degree of anhedonia. To date, studies have found variable rates of comorbid psychiatric conditions in people with FND, although they are often above rates in healthy populations [1,9,31]. This is perhaps unsurprising, given similar psychiatric comorbidities in many diseases associated with a high symptom burden and functional impairment, for example epilepsy [32], ischaemic heart disease [33] and diabetes [34]. Although the presence of a single psychiatric comorbidity was associated with co-occurrence of other psychiatric comorbidities, patients with psychiatric comorbidities endorsed similar levels

of both FND core and associated symptom co-occurrence as those with physical symptoms; to put it another way, the presence of psychiatric comorbidities was not associated with more FND symptoms (see Figure 1). Our data did not indicate how many respondents had a psychiatric diagnosis prior to developing FND.

Recognizing psychiatric comorbidities is important, not only in highlighting specific psychiatric treatments but also because of the possible ramifications on FND prognosis and quality of life. One study showed that depressive symptoms were independently related to worsening quality of life in patients with functional seizures [35]. The findings of this study, particularly in the high prevalence of both physical and psychiatric symptom comorbidity, highlight the need for management of FND which incorporates both physical and mental health interventions.

## Treatments accessed

The majority (89%) of respondents had accessed some form of treatment for their FND symptoms. The most common treatment was medication, and in many cases this was a number of medications, including antidepressants, benzodiazepines and opiates. Supportive evidence for pharmacological management of FND has not been borne out by data, although in at least some cases medication may have been prescribed for common associated comorbidities such as anxiety or pain [4]. Despite this, antidepressants [36], opiates and benzodiazepines are sometimes prescribed [37], and polypharmacy is common [38].

Many respondents in our study reported having received physiotherapy at some time since diagnosis. There is promising evidence that many patients with motor FND benefit from physiotherapy [39,40]; a large multicentre randomized controlled trial on the efficacy of physiotherapy in functional movement disorder is under way [41].

Cognitive behavioural therapy (CBT) had been accessed as a treatment method by almost half of our respondents. There is a developing evidence base for CBT in FND, and it is one of the treatment options most widely offered [42,43]. A recent large randomized controlled trial on CBT in functional seizures showed that CBT can improve the length of seizure-free periods as well as improve quality of life versus controls [44].

## Illness perceptions

In our survey, although there was wide variation, most respondents agreed that FND is a combination of physical and stress/trauma related factors (Figure 4). Figure 5, derived from free-text responses, illustrates that most respondents felt that FND had multiple causes, including causes which could not be categorized as either physical or psychological. This indicates a more nuanced and varied perception of FND. A number of previous studies have tended to show that only a minority of people with FND attribute their symptoms even in



part to psychological factors such as stressful life events, although in most studies a small group generally did [45–48]. This may reflect a number of issues including personal and societal stigma around the term ‘psychological’, and poor experiences with healthcare professionals presenting this model. Our data, from a larger dataset than is typical, indicates a more balanced view of causation than has been seen previously in the literature. Potential explanations for this difference from previous data include participant selection from support groups, and the representation of participants with longer symptom duration. Overall, older dualistic ideas of FND do not seem to be supported by our respondents, who generally preferred to conceptualize the disorder as one positioned at the interface of mind and brain.

In parallel, most assessments of clinician attitudes towards FND have suggested that the dominant view of FND is of a disorder in which psychological factors are dominant [49–52]. This is also reflected in the literature as, although the term ‘functional seizure’ is felt to be the most accepted and aetiologically neutral term [53] ‘psychogenic non-epileptic seizure’ (emphasizing a psychological aetiology) is most commonly used [54]. Despite this, as with these patient data, there are indications that clinician attitudes to FND are changing; for example, the view that FND was related to both neurological and psychological factors was the most popular choice in surveys of 450 clinicians in the Netherlands [55].

Previous studies have shown that an insufficient understanding of FND can lead to feelings of powerlessness over symptoms and a perceived lack of support [56–58]. In our survey, some respondents indicated a disagreement with their diagnosis of FND, which may result in feeling unsupported. However,

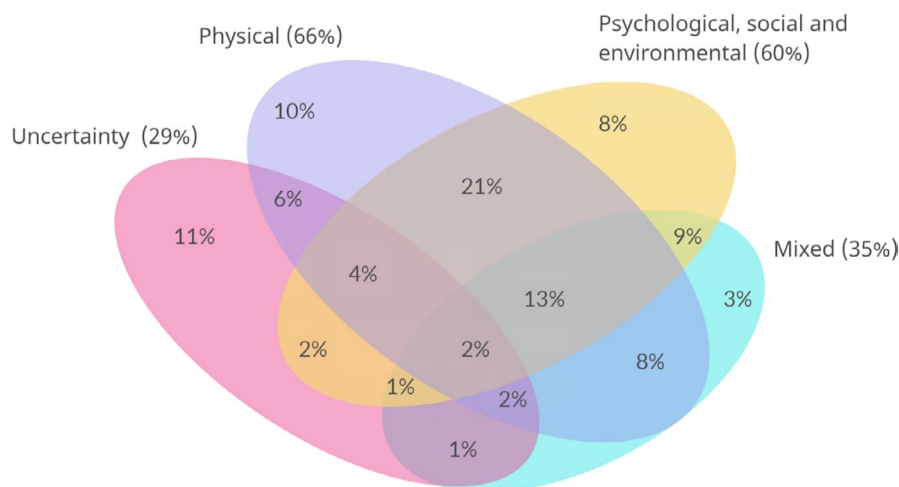
despite respondents indicating that they had a moderate understanding of their FND symptoms, blank space responses to barriers to recovery included medical treatment, negligence and lack of support.

Unsurprisingly, many respondents indicated that FND symptoms greatly affected their lives: many indicated that they were concerned about their symptoms and that they affected them emotionally to a significant degree. Despite the many advancements in FND research and advocacy, there remains a perception from some clinicians that ‘nothing is wrong’ with FND patients or that they are unconcerned by their symptoms [59]. It is likely that some of this limited FND understanding comes from clinicians’ stigma [60] or lack of confidence in explaining functional symptoms [51], supporting the notion that compassionate and thorough explanation of FND symptoms can in itself help improve patient care and quality of life [61]. It is hoped that the weight of data will contribute to the ongoing diminishment of these attitudes.

## STRENGTHS AND LIMITATIONS

### Strengths

The main strength of this study is the large sample of respondents, with many questions receiving over 1000 responses. The broad inclusion criteria mean that the results are likely to have greater external validity than more focused studies of clinical populations. Similarly, the fact that the study was completed online meant that it was possible to access patients who may not have been able to travel for research (e.g., due to symptom or financial barriers).



**FIGURE 5** Overlapping belief categories, derived from free-text data ( $n = 937$ ). ‘Physical’ includes the following categories: other physical causes, neurological, injury, infection, genetics and other physical environmental. ‘Psychological, social and environmental’ includes stress, worry or feeling overwhelmed, additional or untreated mental health disorders or symptoms, personality and interpersonal styles, emotional dysregulation or specific emotional difficulties, adverse life events, psychological or mental trauma, long-term social/environmental adversity. ‘Mixed’ includes medical treatment, negligence and lack of support, unspecified trauma, other functional neurological disorder symptoms and other causes. ‘Uncertainty’ includes all responses where respondents indicated they did not know the cause of their FND symptoms

## Limitations

There are several limitations to this study. First, there is a potential selection and response bias in patient participation in online surveys; our data may have over-represented those who are younger, online, well, more motivated and more educated [62]. As well as this, respondents were recruited through patient groups, members of which are more likely to be those with severe and enduring symptoms who are looking for alternative solutions for their symptoms.

Due to data anonymization issues, only years of birth, first symptom and diagnosis were collected, as opposed to specific dates. This means that conclusions on diagnostic delay and age at first symptom will lack complete accuracy. Respondents self-reported their diagnosis of FND, which was not clinically verified; it is also possible that, given the older terminology for FND (particularly conversion disorder) and international variance in the use of terminology, some patients may not have identified with the terminology used in the survey.

The validated Maudsley VAS was used; however, the third domain of suicidality or measures of anxiety were not included in our study. There are also inherent issues in the comparability and generalizability of results obtained from a VAS [63]. The Brief Illness Perception Questionnaire is a validated scale; however, in this study the terminology was changed slightly in order to make it relevant to patient groups after consultation with patient representatives when designing this study; it is not believed that these subtle changes significantly interfered with the validity of the scale in our survey. Finally, bodily pain was not asked about, which is one of the most important physical symptom comorbidities of FND.

## CONCLUSIONS

In this study, the aim was to understand the prevalence rates of core FND and associated symptoms, comorbidities and illness beliefs in a large online sample of FND patients. Patients' own views were explored to help elucidate experiences of living with FND at the group level. Overall, the study indicated a striking co-occurrence of multiple symptoms, core FND symptoms, associated physical symptoms and psychiatric comorbidities.

Our results also highlight that patients often have symptoms for many years, and some are not diagnosed until years after symptom onset. Despite perceptions of FND patients as opposing psychological models, our results indicate that patients have a balanced view on neurological and psychiatric aspects of the disorder. It is hoped that further research and clinical provision is provided to this patient group in order to improve diagnostic and treatment outcomes.

## ACKNOWLEDGEMENTS

The authors would like to express their particular thanks to all respondents to the survey. They would also like to express their gratitude to the charities FND Hope, FND Action and FND Friends in kindly assisting with the dissemination of the survey.

## CONFLICT OF INTEREST

JS reports independent expert testimony work for personal injury and medical negligence claims, he receives royalties from UpToDate for and runs a free non-profit self-help website, [www.neurosymptoms.org](http://www.neurosymptoms.org), for people with FND. He is on a medical advisory board for FND Hope UK. COMPASS Pathways PLC has paid for JR to attend trial related meetings and conferences to present the results of research using psilocybin. JR has undertaken paid consultancy work for Beckley PsyTech and Clerkenwell Health. Payments for consultancy work are received and managed by King's College London; JR does not benefit personally. JR has no shareholdings in pharmaceutical companies. The other authors do not report conflicts of interest.

## AUTHOR CONTRIBUTIONS

**Matthew Butler:** Conceptualization (equal); data curation (lead); formal analysis (equal); investigation (equal); methodology (equal); project administration (lead); visualization (supporting); writing—original draft (lead); writing—review and editing (lead). **Oliver Shipston-Sharman:** Data curation (equal); formal analysis (equal); investigation (equal); project administration (supporting); software (equal); visualization (lead); writing—review and editing (equal). **Mathieu Seynaeve:** Conceptualization (equal); formal analysis (equal); investigation (equal); writing—original draft (supporting); writing—review and editing (equal). **Jianan Bao:** Formal analysis (equal); investigation (equal); software (equal); visualization (equal); writing—review and editing (equal). **Susannah Pick:** Conceptualization (equal); formal analysis (supporting); investigation (equal); supervision (equal); visualization (supporting); writing—review and editing (equal). **Abigail Bradley-Westguard:** Conceptualization (equal); formal analysis (supporting); supervision (equal); writing—review and editing (equal). **Eveliina Ilola:** Formal analysis (equal); visualization (equal); writing—review and editing (equal). **Bridget Mildon:** Conceptualization (equal); methodology (equal); project administration (equal); writing—review and editing (equal). **Dawn Golder:** Conceptualization (equal); methodology (equal); project administration (equal); writing—review and editing (equal). **James Rucker:** Conceptualization (equal); methodology (equal); software (equal); supervision (equal); writing—review and editing (equal). **Jon Stone:** Supervision (equal); validation (equal); visualization (supporting); writing—review and editing (equal). **Timothy R Nicholson:** Conceptualization (equal); investigation (equal); methodology (equal); project administration (supporting); supervision (equal); writing—review and editing (equal).

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author (MB) upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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