

## **A Qualitative Study of the Experiences and Perceptions of Patients with Functional Motor Disorder**

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1 **ABSTRACT**

2 **Background:** Patients with functional motor disorder are perceived as difficult by health care  
3 professionals, but we know very little about the patients' perspective. Understanding the  
4 experiences and perceptions of patients could help to improve clinical services and patient  
5 outcomes.

6 **Purpose:** To explore the experiences and perspectives of patients with functional motor disorder  
7 using qualitative research methods.

8 **Methods:** This qualitative study was embedded within a feasibility study of specialist physiotherapy.  
9 Eleven patients with functional motor disorder participated in semi-structured qualitative interviews  
10 prior to receiving treatment. The interview transcripts were subjected to an inductive thematic  
11 analysis.

12 **Results:** The data were arranged into six themes: (1) the burden of living with functional motor  
13 disorder; (2) nobody knew what was wrong; (3) dissatisfaction with psychological explanations; (4)  
14 patients feel abandoned; (5) iatrogenic harm; and (6) powerlessness.

15 **Discussion and Conclusion:** The study participants experienced substantial physical and emotional  
16 burdens associated with functional motor disorder. They were generally dissatisfied with  
17 psychological explanations for their symptoms and commonly felt misunderstood and abandoned by  
18 health care professionals, which appeared to leave them vulnerable to iatrogenic harm. A lack of  
19 understanding of functional motor disorder left participants feeling unable to help themselves. This  
20 research highlights a number of inadequacies within current clinical services for patients with  
21 functional motor disorder.

22

23 **Key Words:** Functional, Neurology, Psychogenic, Conversion Disorder, Qualitative, Subjective  
24 Experience

## 1 INTRODUCTION

2 Patients with functional motor disorder (FMD), also known as conversion disorder, typically present  
3 with weakness, tremor, gait disturbance and abnormal postures. These symptoms are not caused by  
4 a known structural disease process and they are distinct from malingering and factitious disorder [1].  
5 The diagnosis is usually made by a neurologist, but treatment has traditionally been considered the  
6 realm of psychiatry and psychology, although in recent years a role for physical rehabilitation has  
7 been increasingly recognised [2–4]. FMD is a problematic diagnosis amongst health care  
8 professionals (HCPs). Surveys and interviews have found that many clinicians endorse negative  
9 statements about FMD and clinicians often suspect patients of feigning illness [5–7]. It is perhaps  
10 unsurprising that prognosis is considered poor [8]. While there have been a number of studies  
11 investigating the clinicians' point of view, we know very little about the patient's perspective. This is  
12 despite recognition that, at least to some extent, clinical outcome is related to the patient's illness  
13 beliefs, expectations and satisfaction with treatment [8–10].

14 Research conducted by Nettleton et al (2005)[11] provides some of the only qualitative data on FMD  
15 from the patient's perspective. This study used narrative analysis, a qualitative approach, in a sample  
16 that included patients with FMD. The participants were defined as having unexplained neurological  
17 illness, which included individuals with motor symptoms (spasms, paralysis, shaking, and limited  
18 mobility) and individuals with non-motor symptoms. A key finding was that participants commonly  
19 perceived that HCPs considered their symptoms to be feigned, which was often associated with  
20 receiving psychological explanations for such symptoms. The participants felt they had been  
21 marginalised from medicine and unable to access ongoing medical and social support.

22 The related condition of dissociative (non-epileptic) seizures has been studied more extensively with  
23 patient focused qualitative research. The findings from this research may be relevant to patients  
24 with FMD, due to the presumed aetiological relationship between the diagnoses [12,13]. Rawlings  
25 and Reuber (2016)[14] produced a narrative systematic synthesis of 21 qualitative studies including  
26 220 patients with dissociative seizures. Key themes included that patients often expressed  
27 dissatisfaction with psychological explanations for their symptoms; patients felt isolated; they  
28 usually described an inability to work and often felt a sense of loss.

29 The illness beliefs of patients with FMD have been explored quantitatively using the Illness  
30 Perception Questionnaire [9,15]. Findings include that patients lack understanding of their illness;  
31 they often perceive their illness to be permanent rather than temporary; and they commonly feel  
32 that psychological factors are unrelated to their symptoms.

1 Thus, the existing small body of research shows that patients with FMD often have difficulty  
2 understanding their diagnosis and often express dissatisfaction with psychological explanations for  
3 their symptoms. There is however little data to suggest why patients may hold these particular  
4 points of view and how their beliefs and experiences influence their interaction with HCPs. A better  
5 understanding of the perspective of patients with FMD could help to inform improvements to  
6 clinical services, which may lead to more satisfactory patient-clinician interactions and improved  
7 clinical outcomes. Therefore the aim of this study was to explore the experiences and perceptions of  
8 patients with FMD, using semi-structured qualitative interviews.

## 9 **METHOD**

### 10 **Study Design and Setting**

11 This qualitative study was embedded into a randomised feasibility study of specialist physiotherapy  
12 for FMD [16], which was conducted at the National Hospital for Neurology and Neurosurgery, Queen  
13 Square, London. We used semi-structured interviews to explore the experiences and perceptions of  
14 patients before and after receiving specialist physiotherapy treatment. Here we report the data from  
15 interviews conducted prior to treatment. Ethics approval for this research was obtained from the  
16 National Research Ethics Service Committee London–City Road & Hampstead (14/LO/0572). All  
17 participants gave written informed consent.

### 18 **Sampling and Recruitment**

19 Participants were selected from the intervention group of the feasibility study of specialist  
20 physiotherapy for FMD. Purposive sampling was employed to ensure representation of common  
21 symptom phenotypes (tremor, gait disturbance, weakness, mixed movement disorder); symptom  
22 duration (less than 18 months, 18 months to 5 years, more than 5 years); gender and age. Age  
23 brackets were chosen to represent early adulthood (18-29), mid-adulthood (30-59), capturing  
24 participants who may have dependents, and mature adulthood (60+), capturing participants who  
25 may be in or approaching retirement. Prior to recruitment into the study, participants attended a  
26 consultation with the study neurologist and co-author (MJE) where the diagnosis of FMD was made  
27 and comprehensively explained following a standardised approach [17].

28 The eligibility criteria for the feasibility study from which participants were recruited are reported in  
29 full elsewhere [16]. In brief, the key inclusion criteria were a clinically established diagnosis of FMD  
30 according to Fahn-Williams criteria [18]; age 18 years or older; diagnostic investigations had been

1 completed; and they accepted the diagnosis on the balance of probability (i.e., we did not exclude  
2 patients who continued to express some doubt over the diagnosis). We excluded patients if pain or  
3 fatigue was judged to be the primary cause of disability; if they had clinically evident anxiety or  
4 depression that we considered required assessment before starting physiotherapy treatment; or  
5 they had a high level of disability that prevented participation in an outpatient/day hospital  
6 environment.

## 7 **Data Collection**

8 Participants were interviewed by the first author (GN) approximately four weeks after their initial  
9 consultation with the study neurologist and prior to receiving the study intervention. Interviews  
10 were conducted in an outpatient clinic room. Partners were asked to leave the room during  
11 interviews. The interviews were semi-structured, following a topic guide (see supplementary  
12 material), which was updated iteratively during the data collection period in response to ideas that  
13 were generated. The topic guide explored 7 key topics: (1) the patient's narrative; (2) the illness  
14 experience; (3) receiving the diagnosis; (4) previous treatment; (5) recovery; (6) psychological and  
15 emotional factors; and (7) free comments. We chose from the outset to explore the participants'  
16 perception of the role of psychological factors in their movement problem as we were aware from  
17 clinical experience and the previous literature that this is reported as a topic of concern amongst  
18 many patients. The interviews were audio recorded and transcribed verbatim (by GN). We had  
19 planned to interview a minimum of 10 participants and review the need for further interviews.

## 20 **Data Analysis**

21 Data were analysed using inductive thematic analysis. Analysis was conducted concurrently with  
22 data collection, allowing themes to be explored inductively as they emerged. Analysis was  
23 performed by a multidisciplinary group consisting of a medical sociologist (FS), an academic GP (MB),  
24 and a physiotherapist (GN). The analysis process was informed by the approach described by Braun  
25 and Clarke (2006) [19]. Key steps were: (1) familiarisation with the data; (2) generating initial codes;  
26 (3) refining initial codes to develop a coding framework by consensus agreement of the analysis  
27 group; (4) coding transcripts according to the coding framework; (5) analysis of coded data to  
28 identify themes and subthemes by consensus agreement of the analysis group; (6) reviewing original  
29 transcripts to ensure the themes were an authentic representation of the data; and (7) examining  
30 un-coded text for disconfirming evidence. Analysis was conducted with the aid of computer software  
31 NVIVO for Windows, version 10. The first author led the analysis, generating the initial codes which

1 were then discussed in intensive data analysis meetings held regularly over the data collection and  
2 analysis period until the group were happy with the coding and themes generated.

3 Data collection and analysis was approached with critical reflexivity in order to reduce the risk of  
4 bias. The lead author continually reflected on his role as a physiotherapist with a clinical and  
5 research interest in rehabilitation of people with FMD. The team worked to ensure the analysis was  
6 grounded in the data. The multidisciplinary team involved in the analysis helped to minimise the risk  
7 of bias due to occupational experience and vested interest by challenging each other's assumptions  
8 and interpretations.

## 9 **RESULTS**

10 From a pool of 29 participants who had been allocated to the intervention group of the feasibility  
11 study, 11 fitting the purposive selection criteria were invited to participate in the qualitative study.  
12 All invited participants agreed to take part and there were no dropouts. We reviewed the data after  
13 11 participants and determined that further recruitment would be unlikely to produce any new  
14 ideas. Interviews ranged in length from 27 to 66 minutes. Clinical and demographic characteristics of  
15 the cohort are presented in table 1. Participants are identified by assigned pseudonyms.

16 *Insert table 1 about here*

17 Following the analysis the data were arranged into six themes, which are presented below and  
18 illustrated with representative quotes:

- 19 • The burden of living with FMD
- 20 • Nobody knew what was wrong
- 21 • Dissatisfaction with psychological explanations
- 22 • Patients feel abandoned
- 23 • Iatrogenic harm
- 24 • Powerlessness

### 25 **The burden of living with FMD**

26 Functional motor disorder had had a substantial negative impact on the participants' lives, causing  
27 significant physical and emotional burdens. The extent of the physical burden varied amongst  
28 participants. Most described experiencing mobility restrictions, as well as limitations in their ability  
29 to complete activities of daily living such as washing, dressing, preparing meals, parental duties and  
30 sustaining employment. The emotional burden was expressed as distress and frustration related to

1 coping with symptoms, distress associated with not understanding what was wrong, the unknown  
2 prognosis and a perceived lack of support from HCPs.

3 I've been off [work] for the last 13 months... it has drastically affected my life over the  
4 last 13-14 months. I've lost virtually a year of my life because of my condition...  
5 It's not knowing whether you're going to get better or not. It's, it's not in the back of  
6 your mind it's in the front of your mind. [Michael, age 46]

7 [It affects me] quite a lot and it's pretty horrible. It stops me doing a lot of things. And  
8 it does get me down quite a lot, not being able to work. [Megan, age 22]

9 Social isolation and loneliness was another prominent and distressing consequence of living with  
10 FMD. This was particularly a problem for those who had left work or education due to ill health.  
11 Isolation was associated with exclusion due to difficulty accessing some environments, withdrawing  
12 from social activity due to pain or fatigue, and avoiding going out in public due to the  
13 embarrassment caused by prominent symptoms.

14 Friends, as I've said, I've cut a lot of them off... So as time goes by, out of sight, out of  
15 mind. So it's like they think, oh he'll get in touch when he's ready, so you hear less and  
16 less and less from people. [James, age 36]

17 A number of participants reported that FMD caused strain to their interpersonal relationships. This  
18 was often blamed on significant others being unable to relate to the experience of living with FMD.

19 R: It's, it's made a severe impact on the quality of the relationship I have with my wife.  
20 She gets very, very impatient at times. She gets, it's more annoyed and distressed I  
21 would say, more than anything else. My 15 year old at times would like me to be able  
22 to do more things. ...a lot of the times I have to say I'm sorry girls I'm just not well  
23 enough. [Michael, age 46]

#### 24 **Nobody knew what was wrong**

25 It was common for participants to express a belief that HCPs did not understand their problem,  
26 which caused additional distress. This was despite most participants having undergone multiple  
27 medical consultations with GPs, neurologists, other specialist physicians and allied health  
28 professionals.

29 Lack of confidence in the doctors' understanding was often reinforced by the experience of a  
30 protracted diagnostic period involving multiple medical investigations, such as MRI and nerve  
31 conduction tests, that failed to identify a cause for their symptoms. Rather than being reassuring,

1 receiving normal test results was sometimes frightening, as it was interpreted as meaning that the  
2 cause for their illness remained mysterious and unknown.

3 Because I went for the DaTSCAN, then I went to see the consultant. And he showed  
4 me the brain results on his screen and told me what the normal levels should be. And  
5 said well you don't have Parkinson's disease, but I don't know what it is that's wrong  
6 and then he said you don't look very happy. But it was plunging at the unknown then  
7 as I hadn't a clue what the diagnosis was. [Julie, age 50]

8 Several participants had previously been diagnosed with FMD before seeing the study neurologist.  
9 There was a tendency to feel unconvinced by this diagnosis when it was perceived to have been  
10 made based on exclusion of disease by negative investigations.

11 Ahh I, I took it as bullshit really. I just thought, you're putting me in a, you can't find  
12 anything specifically wrong with me. My brain MRI is clear. There's no lesions showing  
13 on my brain. My spinal MRI is clear. All the other tests are clear. The EMG's are clear.  
14 So it has to be a functional neurological disorder. Because we can't find anything else  
15 wrong with you. [Michael, age 46]

## 16 **Dissatisfaction with psychological explanations**

17 Prior to their consultation with the study neurologist, most participants had received a psychological  
18 explanation for their problem. For example, some were told that they had conversion disorder,  
19 which was caused by recent or past stressful events. Participants generally expressed dissatisfaction  
20 with these types of psychological explanations for their symptoms. Several acknowledged having  
21 been affected by psychological problems or psychological trauma (which included anxiety,  
22 depression, bipolar disorder, and an abusive relationship); however they felt these issues were not  
23 directly related to their movement problem.

24 I've seen a psychologist for the pain, because that's part of the pain management. And  
25 there are issues, underlying issues, you know from getting over my dad's death and  
26 different things like that. But I think that's separate. I think this [the movement  
27 problem] is something different. [Julie, age 50]

28 We all have stress, we all have anxiety and it all depends how we deal with it and how  
29 we are in that mind-set... But I'm not sure that's relevant to me. I do get stressed, I do  
30 worry [have] anxiety, which we all do. I don't think I'm overly stressed or anxious.  
31 [Amy, age 43]

1 Not all participants were completely opposed to the idea that psychological factors were relevant to  
2 their movement problem and some participants described feeling that psychological factors were  
3 part of their problem, but that they were not on their own explanatory.

4 I do think, I do think looking back now, maybe it was stress, I don't know. I don't know  
5 and that's the honest answer. I do think stress can factor into a part of it. [James, age  
6 36]

7 Psychological factors definitely make it worse. But I don't think they're a trigger for it.  
8 [Deborah, age 58]

9 There appeared to be several reasons why participants were dissatisfied with psychological  
10 explanations for their movement problem:

11 (1) Participants commonly perceived that their movement problem had been precipitated by an  
12 injury or illness. Psychological explanations, such as stress, were seen to be inconsistent with the  
13 physical precipitating event.

14 (2) Physical symptoms and psychological explanations were often seen in a mind-body dualistic way  
15 as separate issues and therefore mutually exclusive.

16 (3) Most participants interpreted psychological explanations as meaning that the doctor did not  
17 believe their problem to be real or worthy of concern.

18 (4) Some participants associated psychological explanations for their symptoms with pejorative  
19 stereotypes of people with mental illness. Examples included; that psychological problems are trivial  
20 and could be overcome if the person really wanted to get better, that the patient is at fault, and that  
21 mental illness is a character flaw. Participants either endorsed these views or projected them onto  
22 others, leading them to distance themselves from such stereotypes. For example, some commented  
23 that they were "not that type of person".

24 (5) Negative attitudes of HCPs towards what they perceived as psychogenic problems (i.e. having a  
25 psychological basis), may have played some role in the participants' dissatisfaction with receiving  
26 psychological explanations for their problem. It was common for participants to describe  
27 experiences of poor treatment and negative interactions with HCPs only after a psychogenic  
28 diagnosis was made.

29 (6) Finally, some participants described how there was a potential danger in being diagnosed with a  
30 psychological problem. The most prominent concern was that doctors jumped to the conclusion that

1 symptoms were psychogenic which prevented them from adequately assessing the problem and  
2 therefore potentially missing an underlying sinister disease. Some participants reported having been  
3 subjected to undesirable treatments, such as being “locked” in a psychiatric hospital ward and the  
4 prescription of sedating and addictive medication, whilst being excluded from what they perceived  
5 to be potentially helpful physical treatments such as “physiotherapy” and “botulinum toxin”.

6 And I saw another consultant after that who more or less told me it was psychological.  
7 Um, that because I had a history of, I’d had stress and depression in the past. And he  
8 sort of honed in on that and because of that, it’s just psychological your symptoms  
9 and we don’t think that there’s anything wrong. [Julie, age 50]

10 Because that’s what it feels like, psychological feels like it should mean, it’s literally  
11 you are making it up. It’s all in your head, there’s nothing wrong with you at all.  
12 [Megan, age 22]

### 13 **Patients feel abandoned**

14 Interactions with HCPs were often negative experiences for the participants in this study. Anecdotes  
15 describing conflict with HCPs and perceived poor treatment featured prominently in their narratives.  
16 These experiences had a powerful and lasting impact, leaving many with a sense of shame and a  
17 feeling that they had been abandoned by doctors and let down by the health care system.

18 Yeah, he said you haven’t got a, you haven’t got a brain tumour and you haven’t got  
19 cancer, I’ve got other patients. Like, he said like, because I didn’t have cancer he didn’t  
20 want to help me. [Sarah, age 21]

21 So I was always led to feel almost, ah, I don’t want to, I don’t know embarrassed but,  
22 quite shamed, in that that was the reason. That’s how I always felt, in that I was  
23 contributing or a contributory to my condition. Um, without anyone actually coming  
24 out and saying that, that was kind of how I was always left to feel. [Lisa, age 43]

25 In contrast, one participant described only positive experiences of interacting with HCPs, although  
26 most participants had encountered at least one clinician who they considered praiseworthy. The  
27 characteristics commonly associated with these clinicians were that they listened, they believed the  
28 participant, and they were open minded.

29 I’ve got a very good doctor and he’s been looking it up. And he’s been very supportive.  
30 [Amy, age 43]

1 **Iatrogenic harm**

2 Six out of the 11 participants reported being given inappropriate treatment that they believed made  
3 their problem worse. These treatments included medication for a presumed diagnosis of Parkinson's  
4 disease, prescription of escalating doses of benzodiazepines, medication side effects that went  
5 unnoticed, being given the wrong type of physical therapy and advice to use alcohol to control a  
6 tremor.

7 One of the consultants recommended that I took a glass of wine every evening. And it  
8 did relax me instantly. And even that if I took a glass of wine it would stop it, you  
9 know, for a while. But of course once you start you need more and more. Your body  
10 becomes reliant on it and I'm afraid I did become an alcoholic. [Mary, age 67]

11 **Powerlessness**

12 It was common for participants to describe feeling stuck because they did not know what was wrong  
13 and therefore they did not know how to help themselves. Feeling powerless was compounded by  
14 their perception of abandonment by HCPs.

15 And I quite understand going to the doctors and they not understanding what it is. Ok,  
16 you don't understand what it is, but you must have an indication of roughly what it is.  
17 Refer me on! Do something. Don't just allow me to stay at home and do nothing.  
18 [Lynn, age 56]

19 I just can't control my head or my hands or my legs at all. I'm trying to tell them to  
20 stop. They won't stop. Um, it gives me headaches. I get a lot of pain, I end up going to  
21 bed early. [Amy, age 43]

22 **DISCUSSION**

23 This qualitative study found that patients with FMD experience a substantial physical and emotional  
24 burden. Interactions with HCPs were often difficult experiences and an additional source of distress.

25 The study participants generally felt that most HCPs had misunderstood their problem and they  
26 lacked confidence in the ability of these individuals to help them. This perception of HCPs was  
27 related to the common experiences of diagnostic tests that did not identify a specific cause; a  
28 diagnosis reached through exclusion of disease; and explanations for symptoms focusing on  
29 psychological mechanisms. These findings support clinical recommendations that emphasise the  
30 importance of carefully communicating the diagnosis to patients as a first step in the treatment of  
31 FMD [20]. In particular, it has been recommended that clinicians should describe to the patient the

1 clinical features of their symptoms that are diagnostic for FMD, rather than relying on negative test  
2 results or the presence of psychiatric comorbidity to explain the diagnosis [17,20].

3 It is widely recognised that psychological factors are an important part of the aetiology of FMD [20],  
4 yet most participants in this study described feeling dissatisfied with psychological explanations for  
5 their movement problem. Rejection of psychological explanations by patients with functional  
6 symptoms is widely reported in the literature, backed by evidence from qualitative studies [11,14],  
7 illness belief questionnaires [21], and anecdotal evidence from neurologists [22]. The results of our  
8 analysis identified several potential factors that may help us understand why many patients with  
9 FMD are opposed to psychological accounts of their movement problem:

10 First was the perceived incompatibility between physical problems (such as tremor, weakness and  
11 gait disturbance) and psychological mechanisms. This mind-body dualistic way of thinking is not  
12 special to patients with functional symptoms but is embodied in society in general, including  
13 amongst health care professionals [23]. Mind-body dualism amongst the study participants may  
14 have been reinforced by being given overly simplistic psychological explanations (e.g. FMD is caused  
15 by stress) and explanations that failed to take physical precipitating events into account when they  
16 were an important part of the participant's narrative. These findings point to the importance of  
17 listening to the patient's story and the need for an integrated biopsychosocial explanatory model to  
18 help the patient make sense of their illness experience.

19 The stigma associated with mental illness was another important factor contributing to participants'  
20 dissatisfaction with psychological explanations and they commonly distanced themselves from  
21 pejorative stereotypes of people with mental health problems. In addition, there was some evidence  
22 to suggest that participants picked up on negative attitudes held by some clinicians towards  
23 psychological problems. Such negative attitudes have been previously reported in clinician surveys  
24 [5,6], although this finding in our study should be read with caution as it relies on our interpretation  
25 of the participants' subjective account. Replicating the findings of other qualitative studies in  
26 functional neurological disorders, we found that suggesting a psychological causation led some  
27 participants to feel ashamed and disbelieved [24]. The attitudes and prejudices of both patients and  
28 clinicians towards mental illness may help to explain the reluctance of some patients to consider  
29 psychological factors as part of their movement problem.

30 Finally, an interesting finding associated with suggestions about a psychological causation was that  
31 some participants felt that attribution of their movement problem to psychological causes left them

1 vulnerable to missed diagnoses, undesirable treatments and exclusion from potentially helpful  
2 treatment.

3 Conflict with HCPs was common and a perception of having been abandoned by the health care  
4 system was a prominent theme. Nettleton et al (2005)[11] used the term “medical orphans” to  
5 describe a similar situation in patients with “unexplained neurological symptoms” who felt they  
6 had been marginalised from medicine. Feeling marginalised contributed to the emotional burden  
7 of FMD and was a source of significant distress for several participants. In addition, marginalisation is  
8 likely to be a significant factor in our finding that several participants in this study considered they  
9 had been subjected to iatrogenic harm. There are other reports in the literature that this group is  
10 particularly vulnerable to iatrogenic harm [28]; however objective data are scarce. Several common  
11 experiences reported by participants in this study may increase the risk of exposure to iatrogenic  
12 harm. These are: (1) delayed diagnosis may leave patients at risk of receiving inappropriate  
13 treatment; (2) failure to find support from the conventional health care system (perceived  
14 abandonment) may lead patients to seek help from less reputable sources; and (3) lack of  
15 understanding of the problem by HCPs (as perceived by patients) may lead to poor clinical decisions.  
16 Further evidence is needed to support these hypotheses.

17 This study has a number of limitations that must be considered alongside the findings. The findings  
18 represent the views of a relatively small sample, and crucially participants were restricted to patients  
19 meeting the selection criteria for the physiotherapy clinical trial [16]. Excluded from this group were  
20 patients who were not accepting of the diagnosis, those who declined participation in the study, and  
21 those who were deemed inappropriate for physiotherapy. Participants were aware that they had  
22 been randomly allocated to the intervention group of a clinical trial, which may have influenced their  
23 expectations and motivation. The interviewer’s (GN) identity as a physiotherapist may have led to  
24 bias during data collection and may have influenced how participants responded to the interview  
25 questions. Transferability of the data may be limited by the specially selected participant group, the  
26 clinical trial context of the interviews, and the specialist tertiary centre in which participants were  
27 recruited. Those unaccepting of the diagnosis were excluded and they may have been more troubled  
28 by their journey to diagnosis and treatment. A strength of this study was the mixed disciplines and  
29 backgrounds of the analysis group. Another strength was that there was representation of different  
30 symptom durations, phenotypes, and different age groups; in addition the cohort was restricted to  
31 patients with functional motor symptoms, which makes this study unique. Future studies should  
32 seek to explore the views of a greater diversity of people with FMD, with consideration of age,

1 gender, ethnicity, cultural background, socioeconomic status, and people with FMD who do not  
2 meet the eligibility criteria of the current study.

### 3 **CONCLUSIONS**

4 The findings of this study highlight the substantial burden of living with FMD. Patients often struggle  
5 to get answers that fit with their understanding, and feel they have been misunderstood and  
6 abandoned by HCPs. This may leave them vulnerable to iatrogenic harm and without resources to  
7 help themselves. Overly simplistic psychological explanations may leave patients feeling  
8 misunderstood or disbelieved, which suggests a more sophisticated biopsychosocial explanatory  
9 model is needed to help patient's make sense of their illness experience. This research has  
10 highlighted a number of inadequacies within the service provision for patients with FMD, which  
11 could be addressed with better education of HCPs and the availability of responsive, appropriate and  
12 patient-acceptable treatment pathways. This in turn may help to reduce the stigma attached to the  
13 diagnosis of FMD.

14

### 15 **DECLARATION OF INTERESTS**

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25 Neurology and Neurosurgery for supporting this research.

1 **Table 1.** Demographic and clinical characteristics of the study participants

Pseudonym	Sex	Age	Symptom Duration (years)	Symptom
Amy	F	43	2	Head & upper limb tremor
Michael	M	46	2	Mixed movement disorder
Julie	F	50	6	Upper limb tremor & gait
Lynn	F	56	4	Gait disturbance
James	M	36	1	Mixed movement disorder
Mary	F	67	10	Head tremor
Nicole	F	45	4	Gait disturbance
Deborah	F	58	5	Mixed movement disorder
Sarah	F	21	1	Left sided weakness
Megan	F	22	1	Weakness
Lisa	F	43	30	Weakness

## REFERENCES

- 1 Stone J, Carson A. Functional neurologic disorders. *Contin (Minneapolis Minn)* 2015;**21**:818–37. doi:10.1212/01.con.0000466669.02477.45
- 2 Nielsen G, Stone J, Edwards MJ. Physiotherapy for functional (psychogenic) motor symptoms: A systematic review. *J Psychosom Res* 2013;**75**:93–102. doi:10.1016/j.jpsychores.2013.05.006
- 3 Jordbru AA, Smedstad LM, Klungsøyr O, et al. Psychogenic gait disorder: A randomized controlled trial of physical rehabilitation with one-year follow-up. *J Rehabil Med* 2014;**46**:181–7.
- 4 Nielsen G, Stone J, Matthews A, et al. Physiotherapy for functional motor disorders: a consensus recommendation. *J Neurol Neurosurg Psychiatry* 2015;**86**:1113–9. doi:10.1136/jnnp-2014-309255
- 5 Ahern L, Stone J, Sharpe MC. Attitudes of neuroscience nurses toward patients with conversion symptoms. *Psychosomatics* 2009;**50**:336–9. doi:10.1176/appi.psy.50.4.336
- 6 Evans RW, Evans RE. A survey of neurologists on the likeability of headaches and other neurological disorders. *Headache* 2010;**50**:1126–9. doi:10.1111/j.1526-4610.2010.01708.x
- 7 Kanaan R, Armstrong D, Barnes P, et al. In the psychiatrist's chair: how neurologists understand conversion disorder. *Brain* 2009;**132**:2889–96. doi:10.1093/brain/awp060
- 8 Gelauff J, Stone J, Edwards MJ, et al. The prognosis of functional (psychogenic) motor symptoms: a systematic review. *J Neurol Neurosurg Psychiatry* 2014;**85**:220–6. doi:10.1136/jnnp-2013-305321
- 9 Sharpe M, Stone J, Hibberd C, et al. Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict 1-year outcome. *Psychol Med* 2010;**40**:689–98. doi:10.1017/S0033291709990717
- 10 Edwards MJ, Adams RA, Brown H, et al. A Bayesian account of 'hysteria'. *Brain* 2012;**135**:3495–512. doi:10.1093/brain/aws129
- 11 Nettleton S, Watt I, O'Malley L, et al. Understanding the narratives of people who live with medically unexplained illness. *Patient Educ Couns* 2005;**56**:205–10. doi:10.1016/j.pec.2004.02.010

- 12 World Health Organisation. ICD-10 Chapter V Mental and behavioural disorders: F44 Dissociative [conversion] disorders. 2016.<http://apps.who.int/classifications/icd10/browse/2016/en#/F40-F48> (accessed 6 Mar2017).
- 13 American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: : American Psychiatric Publishing 2013.
- 14 Rawlings GH, Reuber M. What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies. *Seizure*. 2016;**41**:100–11. doi:10.1016/j.seizure.2016.07.014
- 15 Stone J, Warlow C, Sharpe M. The symptom of functional weakness: a controlled study of 107 patients. *Brain* 2010;**133**:1537–51. doi:10.1093/brain/awq068
- 16 Nielsen G, Buszewicz M, Stevenson F, *et al*. Randomised Feasibility Study of Physiotherapy for Patients with Functional Motor Symptoms. *J Neurol Neurosurg Psychiatry* 2017;**88**:484–90. doi:10.1136/jnnp-2016-314408
- 17 Stone J, Edwards MJ. Trick or treat? Showing patients with functional (psychogenic) motor symptoms their physical signs. *Neurology* 2012;**79**:282–4. doi:10.1212/WNL.0b013e31825fdf63
- 18 Fahn S, Williams DT. Psychogenic dystonia. *Adv Neurol* 1988;**50**:431–55.
- 19 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101. doi:10.1191/1478088706qp063oa
- 20 Espay AJ, Aybek S, Carson A, *et al*. Current Concepts in Diagnosis and Treatment of Functional Neurological Disorders. *JAMA Neurol* Published Online First: 2018. doi:10.1001/jamaneurol.2018.1264
- 21 Binzer M, Eisemann M, Kullgren G. Illness behavior in the acute phase of motor disability in neurological disease and in conversion disorder: A comparative study. *J Psychosom Res* 1998;**44**:657–66. doi:10.1016/S0022-3999(97)00289-4
- 22 Kanaan RA, Armstrong D, Wessely SC. Neurologists' understanding and management of conversion disorder. *J Neurol Neurosurg Psychiatry* 2011;**82**:961–6. doi:10.1136/jnnp.2010.233114
- 23 Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. *Clin*

- Rehabil* 2017;**31**:995–1004. doi:10.1177/0269215517709890
- 24 Karterud HN, Risør MB, Haavet OR. The impact of conveying the diagnosis when using a biopsychosocial approach: A qualitative study among adolescents and young adults with NES (non-epileptic seizures). *Seizure* 2015;**24**:107–13. doi:10.1016/j.seizure.2014.09.006
- 25 Ludwig L, Pasman JA, Nicholson T, *et al.* Stressful life events and maltreatment in conversion (functional neurological) disorder: systematic review and meta-analysis of case-control studies. *The Lancet Psychiatry* 2018;**5**:307–20. doi:10.1016/S2215-0366(18)30051-8
- 26 Stone J. Functional neurological disorders: the neurological assessment as treatment. *Pr Neurol* 2016;**16**:7–17. doi:10.1136/practneurol-2015-001241
- 27 Adams C, Anderson J, Madva EN, *et al.* You've made the diagnosis of functional neurological disorder: now what? *Pract Neurol* 2018;**18**:323 LP-330.<http://pn.bmj.com/content/18/4/323.abstract>
- 28 Espay AJ, Goldenhar LM, Voon V, *et al.* Opinions and clinical practices related to diagnosing and managing patients with psychogenic movement disorders: An international survey of movement disorder society members. *Mov Disord* 2009;**24**:1366–74. doi:10.1002/mds.22618

## Supplementary Online Information: Interview Topic Guide

### PATIENT INTERVIEW TOPIC GUIDE

Patient Experiences of diagnosis and treatment of FMD

Interviewer: Glenn Nielsen

Version 2, 8/03/2014

### INTERVIEW ONE: PRE-TREATMENT

[Introductory Script]

Thank you for your time and agreeing to talk to me about your experiences and for me to record this interview. I'm part of a research team investigating functional motor symptoms. We would like to learn about how it feels to be diagnosed with FMD, how they affect your life and what experiences you have had with treatment – specifically physiotherapy. We are interested in both positive and negative experiences. All information you provide me will remain anonymous. I have to let you know that if you disclose information about risk of harm to yourself or others, I am obliged to let the relevant authority know. If you would like to pause the interview at any stage, let me know and if you would like to stop the interview at any stage, that is fine.

#### 1. Patient Narrative

- a) Could you start by telling me your story?
- b) When did you first become unwell?
- c) How was your health before these symptoms started?

#### 2. Illness Experience

- a) What are the different symptoms that you experience?
- b) How do they affect your everyday life?
  - What do you need help with
  - Sleeping
  - Work
  - Looking after yourself and others
  - What would you like to be able to do
- c) Which are the most disabling symptoms?
- d) Do you have any control or influence over your symptoms?

**Update to topic guide: The impact of living with FMD on relationships emerged as an important theme and was explored. Participants were asked to expand on the impact of their symptoms on their relationship with partners, children and friends and acquaintances.**

#### 3. Receiving the diagnosis

- a) Tell me about receiving the diagnosis of FMD
- b) How did they come to the conclusion that your diagnosis was FMD
- c) How did they explain the diagnosis
- d) Was any treatment offered?
- e) What do you think is causing your symptoms?

#### 4. Treatment

- a) Tell me about what treatments you have had prior to this programme
- b) What has been helpful so far,
- c) What has been unhelpful

- d) What do you think you need to get better?
- e) What are your expectations about this physiotherapy programme?

#### 5. Recovery

- a) What would getting better look like to you?
- b) What is realistic to expect – from this programme? With recovery in general?
- c) What would you like to change / be able to do?
- d) Who is important in your recovery?

#### 6. Psychological & Emotional factors

- a) How does it make you feel to have FMD  
**Update: some participants had difficulty describing feelings and answers were often lists of symptoms. The following prompts were therefore often used: “Can you tell me about a time when you experienced...”**
- b) Were these feelings present prior to experiencing symptoms  
**Update: This question did not appear to be relevant and was not asked**
- c) Some people believe that psychological factors such as low mood or anxiety have a part to play in this diagnosis. How do psychological factors relate to your symptoms?  
**Update: Participants’ views about being given psychological explanations and attitudes towards mental health problems emerged as important themes early in the data collection period. This question was explored in greater depth using prompts to encourage participants to expand on their thoughts (e.g. “Can you tell me why you think that?” or “What do you think the doctor meant when s/he said that”)**

#### 7. Free comments

Do you have anything you would like to say about your experiences?