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

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# ABSTRACT

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

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

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

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

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

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

# Introduction

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

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

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

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

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

# Method

## Study Design and Setting

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

## Sampling and Recruitment

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

The eligibility criteria for the feasibility study from which participants were recruited are reported in full elsewhere [16]. In brief, the key inclusion criteria were a clinically established diagnosis of FMD according to Fahn-Williams criteria [18]; age 18 years or older; diagnostic investigations had been completed; and they accepted the diagnosis on the balance of probability (i.e., we did not exclude patients who continued to express some doubt over the diagnosis). We excluded patients if pain or fatigue was judged to be the primary cause of disability; if they had clinically evident anxiety or depression that we considered required assessment before starting physiotherapy treatment; or they had a high level of disability that prevented participation in an outpatient/day hospital environment.

## Data Collection

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

## Data Analysis

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

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

# RESULTS

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

*Insert table 1 about here*

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

* The burden of living with FMD
* Nobody knew what was wrong
* Dissatisfaction with psychological explanations
* Patients feel abandoned
* Iatrogenic harm
* Powerlessness

## The burden of living with FMD

Functional motor disorder had had a substantial negative impact on the participants’ lives, causing significant physical and emotional burdens. The extent of the physical burden varied amongst participants. Most described experiencing mobility restrictions, as well as limitations in their ability to complete activities of daily living such as washing, dressing, preparing meals, parental duties and sustaining employment. The emotional burden was expressed as distress and frustration related to coping with symptoms, distress associated with not understanding what was wrong, the unknown prognosis and a perceived lack of support from HCPs.

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

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

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

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

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

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

## Nobody knew what was wrong

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

Lack of confidence in the doctors’ understanding was often reinforced by the experience of a protracted diagnostic period involving multiple medical investigations, such as MRI and nerve conduction tests, that failed to identify a cause for their symptoms. Rather than being reassuring, receiving normal test results was sometimes frightening, as it was interpreted as meaning that the cause for their illness remained mysterious and unknown.

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

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

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

## Dissatisfaction with psychological explanations

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

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

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

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

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

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

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

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

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

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

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

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

(6) Finally, some participants described how there was a potential danger in being diagnosed with a psychological problem. The most prominent concern was that doctors jumped to the conclusion that symptoms were psychogenic which prevented them from adequately assessing the problem and therefore potentially missing an underlying sinister disease. Some participants reported having been subjected to undesirable treatments, such as being “locked” in a psychiatric hospital ward and the prescription of sedating and addictive medication, whilst being excluded from what they perceived to be potentially helpful physical treatments such as “physiotherapy” and “botulinum toxin”.

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

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

## Patients feel abandoned

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

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

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

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

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

## Iatrogenic harm

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

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

## Powerlessness

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

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

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

# DISCUSSION

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

The study participants generally felt that most HCPs had misunderstood their problem and they lacked confidence in the ability of these individuals to help them. This perception of HCPs was related to the common experiences of diagnostic tests that did not identify a specific cause; a diagnosis reached through exclusion of disease; and explanations for symptoms focusing on psychological mechanisms. These findings support clinical recommendations that emphasise the importance of carefully communicating the diagnosis to patients as a first step in the treatment of FMD [20]. In particular, it has been recommended that clinicians should describe to the patient the clinical features of their symptoms that are diagnostic for FMD, rather than relying on negative test results or the presence of psychiatric comorbidity to explain the diagnosis [17,20].

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

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

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

Finally, an interesting finding associated with suggestions about a psychological causation was that some participants felt that attribution of their movement problem to psychological causes left them vulnerable to missed diagnoses, undesirable treatments and exclusion from potentially helpful treatment.

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

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

# CONCLUSIONS

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

# DECLARATION OF INTERESTS

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**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 |

**Implications for rehabilitation**

Careful communication is required to help patients understand and accept the diagnosis of functional motor disorder.

It is important to listen to the patient’s narrative in order to help them make sense of their illness experience.

A nuanced biopsychosocial explanatory model is needed to help patients understand how psychological factors can be relevant to physical symptoms and symptoms that are often perceived to be precipitated by a physical event.

A lack of understanding and acceptance of the diagnosis may leave patients vulnerable to iatrogenic harm and powerless to help themselves.

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**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**

1. What are the different symptoms that you experience?
2. 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
3. Which are the most disabling symptoms?
4. 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**

1. Tell me about receiving the diagnosis of FMD
2. How did they come to the conclusion that your diagnosis was FMD
3. How did they explain the diagnosis
4. Was any treatment offered?
5. What do you think is causing your symptoms?

**4. Treatment**

1. Tell me about what treatments you have had prior to this programme
2. What has been helpful so far,
3. What has been unhelpful
4. What do you think you need to get better?
5. What are your expectations about this physiotherapy programme?

**5. Recovery**

1. What would getting better look like to you?
2. What is realistic to expect – from this programme? With recovery in general?
3. What would you like to change / be able to do?
4. Who is important in your recovery?

**6. Psychological & Emotional factors**

1. 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….”**

1. Were these feelings present prior to experiencing symptoms

**Update: This question did not appear to be relevant and was not asked**

1. 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?