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RESEARCH ARTICLE



# Physiotherapy management of functional movement disorders: the patient perspective

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## ABSTRACT

**Purpose:** People with functional movement disorders (FMD) are commonly seen in neurology clinics. Despite a recent increase in research, no standardised treatment pathway across the UK exists. Currently only a few qualitative studies in FMD with a focus on psychological aspects and diagnosis have been published. This study aimed to understand people with FMD perceptions of their physiotherapy treatment.

**Method:** Qualitative web-based interviews were conducted with seven participants and an interpretive phenomenological approach was used to identify themes from the data.

**Results:** Four themes were identified; 1) my brain, mind and body are all me, 2) physiotherapy; what helps and what doesn't, 3) what recovery is to me, and 4) barriers to treatment. Participants desired a combination of psychological and physical approaches, which were holistic, individualised, and delivered by experienced physiotherapists. Limited availability and funding of specialist treatments were barriers to recovery.

**Conclusion:** Holistic management combining psychological and physiological systems seems to be crucial for effective management of FMD. Large variations in physiotherapy treatment exist across the UK. It is hoped that increasing the understanding, amongst healthcare professionals will lead to the development of timely and appropriate pathways for patients that otherwise find themselves lost between medical specialities.

## ARTICLE HISTORY

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## KEYWORDS

Functional neurological disorder; functional movement disorder; qualitative; subjective experience; psychogenic; conversion disorder; physiotherapy

## > IMPLICATIONS FOR REHABILITATION

- Patients report more positive experiences when a combined and detailed psychological and physiological explanation to their symptoms is given.
- An individualised approach working with the patient on activities they find challenging is more preferable than group exercise or impairment based (e.g., strengthening/stretching) treatments.
- Having a physiotherapist who is experienced in treating functional movement disorders or prepared to learn and understand them helped with adherence to treatment.

## Introduction

Functional neurological disorders (FND) are characterised by the presence of motor and/or sensory symptoms associated with physical signs of internal inconsistency or incongruity with the normal rules of neurological disease [1]. Functional movement disorders (FMD) are a subcategory of FND, where patients present with motor symptoms such as weakness, tremor, gait-disturbances, abnormal postures, and seizures. These are caused by a disorder in the functioning of the nervous system rather than a known structural disease process and are distinct from malingering and fictitious disorders [2]. They are the second most common reason for referral to a neurology clinic with around 8000 new diagnoses a year in the UK [3,4]. Despite the high incidence of FMD, historically the condition has been neglected in terms of clinical research and service development, leading to the disorder being poorly understood by clinicians. However, a recent flourish in research has resulted in positive diagnostic criteria to help eliminate diagnostic uncertainty, and reduce the negative associations from patients and clinicians [5]. The increase in research has

enhanced the understanding of the complex aetiology of FMD [6] with a common theme of altered functioning, rather than structure, of the brain. This has helped to move the management of FMD away from purely psychodynamic trauma focused models, towards emphasising the importance of both physical and psychological influences [7]. Therefore physiotherapy treatment has now been recognised as a promising treatment choice, along with psychological therapies, leading to positive patient and therapist reported outcomes in measures of functional ability or quality of life [8–11].

Of these studies three considered the effects of a multidisciplinary team (MDT) approach which usually consists of physiotherapists, occupational therapists, neuropsychologists, and neurologists. Depending on the setting and the presenting symptoms, speech and language therapists and nursing staff may also be involved [8,9,11]. Although the studies produced encouraging results, the variety of approaches used and a lack of detail regarding the interventions limits their reproducibility into clinical practice. Descriptive physiotherapy consensus recommendations have been produced [12] from existing

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evidence and clinicians' experience, and are commonly referred to in practice. They are based on a biopsychosocial aetiological framework, with treatment focusing on addressing illness beliefs, self-directed attention and abnormal habitual movement patterns, through education, movement retraining and self-management strategies within a positive and non-judgemental setting [12].

The perceptions that patients have about their FND is recognised as one factor that influences prognosis, which is supported by the results of a 1-year prospective cohort study. The results identified that the patient's expectation of non-recovery was a strong predictor of a poor outcome alongside receipt of illness-related financial benefits [13]. The authors conclude that these factors are more useful in predicting poor outcome than the number of symptoms, disability, and distress a patient may have.

Previous qualitative research of people with FND, medically unexplained symptoms and non-epileptic seizures has predominantly identified their frustrations with service delivery and feelings of being misunderstood and abandoned by the current healthcare system [14–23]. Research has highlighted the negative attitudes and stigma, from both patient and clinician perspectives. Of these studies only three [17,22,23] specifically consider the person with FMD perspective's of their disorder, emphasising the importance of their relationships with clinicians and valuing the effect of feeling listened to and believed. One study [17] considered the perspectives of patients who were participating in a randomised control trial (RCT) of physiotherapy treatment. However the interviews were completed prior to them receiving treatment therefore the interactions with a physiotherapist was not exclusively reported. The above studies [17,22,23] give recommendations for treatment including one from a physiotherapy perspective, which recommended, careful communication with the patient, listening and helping them make sense of the disorder through the use of a biopsychosocial explanatory model [17]. The other two studies suggested the use of psychological interventions focused on self-compassion, acceptance, identity and empowerment to help reduce external and internalised stigma in order to increase their participation in management strategies [22,23]. None of the studies appeared to capture the components of treatments that people with FMD perceived as the most effective.

This study aimed to explore the understanding, encounters and expectations that people with FMD have of physiotherapy treatment. Furthermore, it aimed to gain an understanding of the participants' views of their recovery with the hope that the findings may provide insightful considerations for future treatment pathways.

## Methods

### Study design

A qualitative study design which used semi-structured interviews to gain an understanding of participants expectations and experiences of receiving physiotherapy.

### Sampling and recruitment

Participants were people with FMD who responded to study adverts placed on two FND charity websites and social media pages (FND Hope and FND Action) between March and July 2020. Participation was voluntary and subject to informed consent.

### Inclusion and exclusion criteria

Study participants were over 18 years old, had a diagnosis of a functional neurological disorder with motor symptoms and had

received physiotherapy treatment for their symptoms within the last five years. Participant's self-report of their diagnosis was accepted without further confirmation. To capture participants diverse experience, a specified amount or type of physiotherapy treatment was not stipulated.

Ethical approval was obtained from the University of Plymouth, Faculty of Health: Medicine, Dentistry & Human Sciences, Research Ethics, and Integrity Student Committee on 01/04/2020 (reference 19/20-579).

### Data collection

Semi-structured interviews were completed by the lead researcher (DZ), who is a physiotherapist with experience in treating patients with FMD, using a web-based video conferencing platform. DZ did not have any prior relationship with the participants, nor did she work in any setting where the participants had received treatment. The interviews followed a topic guide reflecting the aims of the study with the key questions displayed in Table 1 and the full topic guide available in the [online supplementary information](#). Interviews were audio recorded and transcribed verbatim (by DZ) within 24 hours. Identifiable information was fully anonymised, and participants given pseudonyms.

### Data analysis

A phenomenological approach using interpretive phenomenological analysis (IPA) was best suited to the study as it tries to understand how a person's world is experienced. Furthermore, (IPA) recognises the role and influence of the researcher in exploring the participants experience [24]. In IPA the enquiry starts from the researchers perspective, [25] and rather than setting aside assumptions and preconceptions, the researcher acknowledged their current understanding of FMD and took a sensitive and responsive approach during the data analysis, and was open to adjusting their preconceptions when data arose, as suggested by Smith et al. [26].

Data collection and analysis was conducted concurrently, allowing emerging ideas to be explored and the researcher to reflexively update the topic guide for future interviews. Analysis of each transcript was performed by DZ using an approach described by Braun and Clarke, [27] shown in Table 2.

Table 1. Primary questions from the semi-structured interview guide.

Topic	Suggested questions and prompts
Participants account	Please can you tell me about your FMD symptoms, from when they started and how they are now? Were you given any information about FMD, had you heard of it before you were diagnosed with it?
Experiences of physiotherapy	Please describe the physiotherapy treatment that you have received. When, how often, for how long? Inpatients/ outpatients? Was there anything that you found helpful/not helpful?
Expectations of treatment	Did you have any expectations of the physiotherapy treatment? Is there anything you would liked to have done differently in physiotherapy? Is there anything you feel that will help you get better or improve?
Recovery	What does recovery from FMD look like to you? Have you ever had any periods of time without your symptoms? What happened, how did this feel? (Like you had recovered or did you expect the symptoms to come back) Do you think your symptoms will go away?
Any other comments	Is there anything else you would like to mention about your experiences of FMD or physiotherapy?

**Table 2.** Description of the stages of interpretive phenomenological analysis.

Stage	Interpretative phenomenological analysis description
1	Data Preparation (transcription)
2	Reading and familiarisation, taking note of items of interest.
3	Coding – complete coding of one data item – providing a brief commentary on the data occurring at 3 main levels; 1. Descriptive comments, 2. Linguistic comments, 3. Conceptual comments
4	Developing emergent themes of that data item
5	Searching for connections across emergent themes and generating superordinate themes across the one data item
6	Producing a table/figure to represent the analysis
7	Repeat stages 3-5 with all other data sets
8	Identifying themes and superordinate themes across the datasets. Producing a table/figure to represent the complete analysis
9	Writing up and finalising the analysis

To ensure rigor all transcripts were re-read with the final themes in mind to check that the data and themes were aligned. The final stage of the analysis synthesised the themes into a table with the addition of notable quotations to reflect the participant voice. It was hoped that this would help the reader grasp the perceptions of the participants.

## Results

Seven people responded to the advert, met the inclusion criteria, and consented to participate in the study. Following the completion of seven interviews, the themes were reviewed and due to a lack of any new themes and a number of themes reoccurring, it was concluded that data saturation had occurred as suggested by Braun and Clarke [27]. The clinical and demographic data are represented in Table 3.

The analysis identified that people with FMD perceived an overarching relationship between the physical and psychological factors of the disorder. This relationship is embedded though all themes but discussed in more detail in theme 1. Other themes derived from the interviews are discussed below with some divided into subthemes where appropriate. All themes are supported by quotations to represent the participant voice.

1. My brain, mind and body are all me,
  - a. Giving me knowledge
  - b. Working together
2. Physiotherapy: what helps and what doesn't
  - a. Specialist versus non-specialist physiotherapy
  - b. Group treatment
  - c. The end of my physiotherapy and peer support
3. What recovery means to me
4. Barriers to treatment

### Theme 1: My brain, mind and body are all me

This theme provided the most data and will be divided into two parts.

#### Theme 1a. Giving me knowledge

Participants commonly perceived a separation of their physical symptoms and associated psychological explanations from clinicians, whether at the initial diagnosis or during treatment sessions. However, when the psychological and physiological approaches were combined, particularly in treatment sessions, they found it beneficial for the understanding of their symptoms.

The psychologists explained that you know, my body was shutting down trying to protect itself from any sort of thing that it perceived as a threat. So, if my body felt a little bit tired or a little bit achy from doing something physical that it was the similar sensation to what I'd experienced after [the accident] then my body went into protect mode ... just knowing that helped how we go forward with my physical therapy. Billy

All the participants discussed how important it was to gain an understanding of FMD when receiving the diagnosis and during their treatment. However, most participants stated they had a negative experience of this.

I didn't get a good explanation of what it meant basically and so it's a bit confusing, I was also told that although like it was positive because he said you should make some improvement like, he also said there was nothing else that could be done. So that was like really difficult. And there was no time scale on like how long it would take to get better... and I think you feel a bit of despair because they say that it's, it's a software problem like it's a good thing and, and you're still left sitting in a wheelchair. Delia

Two participants expressed that an increased understanding of FMD did not improve their symptoms alone but that it helped increase their awareness of symptom triggers, treatment techniques and motivated them to engage with clinicians.

A common topic was that participants wanted a more in-depth scientific explanation linking psychological triggers, physiological symptoms, and brain functioning, rather than simply being told that there was no structural cause. They wanted the information to be at an appropriate intellectual level as they found some of the discussions and resources condescending.

It helped an enormous amount for me personally to understand the amygdala to the CNS link and the, the jumbling of the signals and so on and being able to understand how I get twitches in the hand. The educational part, the way it was structured together we had the initial session with [psychologist and physiotherapist] they explained in some detail the neural pathway through the body in the fight and flight

**Table 3.** Demographic and clinical data of participants.

Participant pseudonym	Age	Gender	Duration of symptoms	Symptom onset to diagnosis	Symptoms	Type of treatment received
Adam	67	M	42 months	33 months	Weakness, seizures, tremor, loss of dexterity, loss of balance and falls	Specialist MDT programme (as outpatient), community physiotherapy
Billy	31	M	23 months	5 months	Spasms, shaking, pain, global dystonia	Outpatient physiotherapy, generic group exercise
Claire	31	F	Since toddler	27 years	Dystonia, paralysis, brain fog, pain, fatigue, sensory disturbance	Pain clinic, exercise on referral (group), outpatient physiotherapy, sports injury clinic, psychology
Delia	35	F	19 months	4 months	Shuffling gait, altered sensation, speech changes, brain fog	Neurological physiotherapy, community physiotherapy with some experience of FMD, physiotherapist led group exercise
Edwina	57	F	136 months	77 months	Muscle twitching, gait disturbance, sensory disturbance, pain, weakness	Inpatient general ward physiotherapy, community physiotherapy, specialist MDT programme (as inpatient)
Fatima	55	F	Since toddler	45 years	Dystonia, freezing, memory loss, word finding difficulties, dissociation	Community physiotherapy, private massage, acupuncture
Gemma	24	F	9 months	2 days	Paralysis, weakness, spasms reduced balance, numbness	Inpatient generic ward physiotherapy, community neurological physiotherapy

and freeze versus rest and digest.... All of these things together make great sense. So, when we came to the rather more practical matter of first learning to just stand up. I can't tell you what a boost it was. Adam

### **Theme 1b: Working together**

While the overall perception of physiotherapy treatment varied, all participants who received psychological interventions alongside physiotherapy reported a positive experience.

[The physiotherapist] listened to what the psychologists had to say... it was really crucial I guess, that they worked together, the psychologists couldn't have done that work with me like that, and the physio couldn't have [done the psychological work]. Yeah, it would, would have been like patching something up without actually getting to the root of the problem so yeah so working together it has just been really effective. Delia

Most participants reported both negative and positive experiences of physiotherapy treatment. Positive experiences tended to occur when they received their treatment in conjunction with another therapy, for example, psychology and/or occupational therapy. Combining therapies helped develop their understanding of the psychological techniques used when trying to move their body as intended. Participants also reported that discussing the link between physical and psychological aspects gave them more time to work on techniques simultaneously, rather than just trying to practice physical activities which sometimes made their symptoms worse.

It needs to be kind of a holistic approach and all of the different therapies kind of need to be working together, theory and practice at the same time. Instead of being taught all the theory and none of the practice and not being able to apply the theory to the practice.... or only being taught practice and not knowing why, I think knowing why is so important. Claire

When the participants were asked if their treatments enabled them to have more control of their symptoms, they unanimously described that they were not in control. However, some participants were able to reduce or prevent their symptoms from escalating by recognising early triggers, which they had been made aware of in therapy sessions. Other participants perceived that they were able to manage their symptoms using the techniques they had been taught. This gave them a sense of being in control of their symptoms, even if they were unable to stop them occurring in the first place.

I'd just been looking at the practical side and it wasn't until I was made aware that the amygdala doesn't just look after all the, the physical elements of the body like walking patterns, it also looks after the emotional. So, I had what I may describe as a road to Damascus experience of emotions, that suddenly, probably for the first time my life, I suddenly felt emotions it was colossal. And my wife had never seen me crying in thirty years... it's such a benefit to recognise these, there was a positive element in fact on my FMD symptoms. Controlling my emotion probably affected my ability to walk. Adam

In summary, participants described more positive experiences when they were provided with a detailed explanation of the link between their physical symptoms, psychological triggers, and perpetuating factors, and how these relate to the functioning of the brain. When the treatment incorporated physiotherapeutic techniques in combination with psychological approaches, participants described a positive shift in their symptoms, and they were more enthusiastic about the treatment.

### **Theme 2: Physiotherapy; what helps and what doesn't**

This theme focuses on the components of physiotherapy treatment that patients received, either standalone or within a MDT. The first subtheme reflects the perceptions of the participants having been seen by a specialist physiotherapist compared to a non-specialist physiotherapist in an outpatient clinic, ward, or community setting. Subtheme (b.) reflects the perceptions of the participants that attended a group compared to individualised treatment. The final theme acknowledges self-management strategies and other influences that the participants described when asked about their physiotherapy treatment.

#### **Theme 2a: Specialist versus non-specialist physiotherapy**

The importance of spending more time with a physiotherapist was a prominent feature when discussing the setting where their treatment was received. Importantly, participants perceived that neurological or FMD specialist clinicians had more time available to spend with them. Currently, there is no specific training requirement to become a specialist physiotherapist in the UK, instead physiotherapists tend to gain experience from working in a single specialist area. While additional courses are available, these are optional and from the participants perspective, they are not usually aware of the physiotherapists level of experience or additional training completed. The participants referred to physiotherapists as specialists if they worked in FMD specific centres or neuro physiotherapists who had specific knowledge of FMD.

It gave me confidence, after so many years of medical people saying well there's nothing I can do or it's up to you, to know that I was somewhere where they had a pathway. Moving forwards was such a relief, it gives you that confidence to know you can do it. Edwina

Several participants discussed that specialist physiotherapists provided them with the confidence to try things and the hope that they would improve. Many participants were set tasks to do in-between sessions to reinforce techniques that they had found beneficial.

I did have neurophysio in [a specialist FMD treatment programme]. And they got me walking, it's fantastic. What I feel is that what it gave me was the confidence to try by myself. Adam

Other participants mentioned negative effects of not having specialist physiotherapy.

Sometimes getting anything at all is better than nothing but there are other times where getting something completely inappropriate does more harm than good. I've had some extremely negative experiences with physio, but I've also had some like quite positive ones and, and I think it would be very easy that if all you had was negative experiences you then like shut down and refuse to engage with any further help if you did finally manage to get it. Claire

I feel that understanding's not there, they're [Sports physio] not willing to try and understand what's wrong with you and they disbelieve you and then they've got their standard treatments and they won't deviate even if they think they should but it doesn't say so in the book or they won't do further research themselves. Fatima

Many participants were not treated by a physiotherapist that specialised in FMD. However, those that were treated by a physiotherapist working in a neurology speciality, reported better outcomes than when they were seen in an outpatient or community-based setting or on a non-neurological ward.



Participants perceived that less effective treatments tended to be more impairment based e.g., addressing loss of strength or tightness in a particular muscle group, with less holistic focus on the many other factors that influence the symptoms of FMD.

The physio saw me he was like here's a new patient his leg's not working, what's weak, what's tight? Here's some exercises and stretch and that's all, I was basically left really it just made everything, made it all worse. Billy

However, not all positive experiences were from specialist physiotherapists, two participants recognised that their physiotherapists lacked expertise in FMD, but they were eager to learn about the disorder and were non-judgmental.

My physio has taken it upon herself to learn about FMD and she's very graciously allowed me to help educate her and she's done it herself and this is meant our sessions have been most enjoyable. Adam

I got a private neurophysio assessment as well and treatment, so that was really good, and I found the neurophysio very non-judgmental of my situation and even though he admitted that he didn't have that much experience with FMD. The neurophysio was very flexible as well with what we could do... I think it's really important as well just having somebody who's experienced and, I've been looking at some of the research papers and people say that the the treatment doesn't work but I, I just wonder like what treatment are people actually getting and is it 'go ahead and look at a website and whatever' that isn't good treatment. Delia

### Theme 2b: Group treatment

The most negative comments about physiotherapy came from three participants who attended generic exercise groups, two at a local gym (exercise on referral) and one in a physiotherapy outpatient department. Both of which were designed for a variety of different conditions with the aims of improving strength and cardiovascular fitness.

It's a really busy group setting and noisy environment, so you know, I got into the gym and, and I remember standing in the middle.... I stood in the gym and just the sound it just made me freeze completely, I couldn't move I was stuck. I didn't know where the instructor was and the, the music was just so loud and I, I just didn't go back it was just so distressing. Delia

Basically, I could not keep up with the pensioners and what they were doing in the classes.... the dystonic twisting really started as a result of being in that place and being made to do completely inappropriate types of exercise for recovery from specific things that were not what I had. Claire

Some explanations provided for the negative perceptions of these group sessions were related to the setting itself, being overstimulating and fast paced. While other explanations for the distress are reflective of the general lack of understanding of FMD by the people running the groups, for example, not being provided with an explanation of why they were doing certain exercises, impairment-based exercises which targeted increasing strength and cardiovascular fitness rather than helping to improve motor control and function.

None of the participants had attended a physiotherapy group that specialised in FMD, however, two had attended a specialist FMD treatment programme. These participants reflected on their positive experiences of being around other people who experienced similar problems to them.

Knowing you're not alone, you're not like Frankenstein's monster the only one ever created there is somebody else who understands how you feel and that's the FMD guy next to you. Adam

I had the month inpatients stay, yeah unbelievable, brilliant. The best things were meeting other people like me. Edwina

### Theme 2c: The end of my physiotherapy and peer support

All the participants recognised the benefits of peer support, and although many participants attributed an improvement in their symptoms to the therapy they received, some also acknowledged that there were other contributing factors. Some participants discussed that accessing peer support increased their motivation to continue with physiotherapy when improvements were slow, and others found it reassuring to know they are not alone.

It takes much longer than you'd expect but it does improve and there is support out there. Like for me I had no idea there was all of these charities out there that support it because obviously it was such an unknown thing to me, there's things like Facebook groups where there's lots of people with FMD who all come together and it's brilliant. Gemma

In peer support groups, which I feel are wonderful, there are people there who know so much more than a lot of, of the doctors, psychiatrists and so on. Adam

At the time of the interviews most of the participants had finished their physiotherapy treatment and there were mixed perceptions of this ending. There were conflicting views about the use of self-management strategies and a couple of participants perceived feeling abandoned. Others wanted to utilise self-management strategies but required more holistic guidance rather than just a single task-based exercise.

I think I maybe expected more exercises or more advice rather than just we'll set these goals of how long I can walk and then gradually increase it. I don't know what exactly but I, I think maybe there would be a bit more than just exercises that I could do at home. Gemma

In summary the participants expressed a preference for specialist individualised physiotherapy treatment targeted on regaining control of their movement as opposed to building strength and cardiovascular fitness. They recognised that this was achieved when physiotherapy was provided in collaboration with techniques predominantly associated with occupational therapy or psychology but not exclusive to them, e.g., breathing control work, pacing, and recognising and understanding their individual factors driving their FMD. All the participants described variable experiences of physiotherapy treatment; most positive experiences were when they had received treatment from a physiotherapist knowledgeable in FMD. All the participants that received non-specialist group physiotherapy treatment reported negative experiences. None of the participants had received specialised FMD group therapy, however, all of them had accessed a peer support group.

The final aim of the study was to increase understanding of the participants ideas of recovery.

### Theme 3: What recovery is to me

All participants acknowledged that recovery was a slow process. Some did not think that they would recover from FMD but recognised that learning to manage their symptoms better was crucial rather than getting rid of them altogether. Three participants had been told, by a clinician, that they could not recover from FMD and many participants also held this belief.

My expectation is I am always going to have to manage this carefully. I don't see that as an impossible task. I see that as a very achievable thing. I'm just not quite there yet. Claire

And as long as I don't compare me to normal back in [prior to symptoms], then I can bear it, it's not that I'm better it's just that I'm phenomenally better at managing it. I think it's that combined thing because I manage it better I am also, I am recovering as well. Fatima

Now I have been told it is not possible to recover but it's possible to go into remission, and so on. I think that can be redefined as recovery and that is recovery, that's all right by me. Adam

The three participants who were told that they could not recover also perceived this 'feedback' and the clinicians' knowledge of FMD recovery, as barriers to receiving treatment and therefore a barrier to recovery itself. The final theme briefly discusses participants' perceived barriers accessing treatment and their recovery.

#### **Theme 4: Barriers to physiotherapy treatment**

Many participants were aware of the specialist FMD centres or clinicians, however, they reported long waiting lists and that the centres were too far away for them to travel.

I do feel that [the neurologist] has a two-year waiting list and to see me again is maybe holding up someone else's slot. Fatima

Another barrier was the lack of service for people with FMD, with three of the participants being told that they couldn't be seen by a clinician as they had a diagnosis of FMD. Many had been passed between neurology and psychology clinics leaving the participant feeling that neither speciality wanted to see them. This bouncing between services often prevented a timely referral to physiotherapy.

You just don't fit into the little tick box that that you need to be in, I guess it's funding and it's so frustrating, from both sides, really frustrating. One of the things about FMD is that it's just so isolating I found the whole NHS system really isolates people with their funding completely and there was just every door closed, you know, you don't tick any the boxes so you can't use their services so it's it's so demoralising when that happens it really really is it's, it's horrible. Edwina

I didn't fit in the box, so I, I couldn't get any further follow up appointments and [the physio] said all she could see me for was for my sprained ankle. Delia

Many participants attributed these challenges to the rigid way in which the NHS is funded and to the geographical location where they lived. For some there was no access to specialist FMD services or even neurological physiotherapy in their area, others felt their GPs were not prepared to refer them.

It was very lucky that actually there was a physiotherapist in that [outpatient] department who was interested in building FMD treatment pathways and do neuro rehab physio, so I like I got to see them. But it was, it was honestly just sheer luck it wasn't like I was specifically referred to neuro-rehab physiotherapy because I don't know that we even actually have that here, technically I think it's just this one person. Claire

Some of the participants felt there was a lack of understanding of their condition from the physiotherapist's perspective and that this could be overcome by increased training about FMD. The participants that attended an accident and emergency department reported feelings of being dismissed by the physiotherapist once FMD was diagnosed, whether this diagnosis was relayed to the participant or not. Two participants described being sent home in a wheelchair or severely disabled, unable to manage

independently and were not provided with any follow-up support. Other participants were admitted and provided with physiotherapy on the ward, but they felt that it was not helpful and sometimes felt harmful.

I was taken to the hospital in an ambulance and then had a CT scan that day which was clear, so I got discharged from hospital same day and so yeah that, that's when it, that was my trigger, that's what started it. So that day I wasn't able to walk out the hospital, so I went out in a wheelchair. Delia

[On being walked up and down the ward between two physiotherapists] in one of the beds opposite there was a retired nurse and she said that's not physiotherapy, that's torture, and she was not wrong. Edwina

All participants described negative initial interactions with various healthcare professionals regardless of the setting, which led to the perception that these interactions often resulted in them not being referred to specialist physiotherapy. However, for those who went on to receive more specialist treatment, they were more positive about their experiences. Often there was a long timeframe before receiving treatment; however, one participant presented to a hospital which had a specific FMD pathway in place. She reported a positive experience, being quickly referred to a knowledgeable clinician and seeing a physiotherapist with experience in FMD.

## **Discussion**

This study offers further insight and understanding of the management of FMD from the perspectives of the seven participants. Participants perceived that their poor experiences often resulted from a lack of understanding about the importance of an integrated approach (rather than separate physical and psychological treatments) when managing their condition. This has been previously described as a 'crisis for neurology' where people with FMD fell into a gap between psychiatry and neurology [28] and is reflected throughout participants narratives.

When asked to describe how their motor symptoms, for example weakness or spasms, felt, participants struggled to articulate these physical experiences. Rather than use descriptive words to explain their physical sensations they were experiencing they reported frustrations at being unable to do certain tasks. Rawlings and Reuber, [29] similarly noted less description of participants symptoms of non-epileptic seizures when compared to those participants with epilepsy and they attributed this to maladaptive coping mechanisms. This highlights the difficulty in separating the physical and psychological aspects of FMD.

Participants desire for an in-depth explanation of how these two areas are linked is supported by an earlier qualitative study that theorises the 'mind-body dualism' being reinforced by giving an overly simplistic psychological explanation for patients' physical symptoms [17]. Separating these factors in a dualistic way of thinking now appears obsolete, and the participants accounts support the growing literature for the need to change how the diagnosis is delivered [30]. Therefore, receiving combined physiotherapeutic and psychological treatment was associated with more positive narratives and perceived outcomes, which is supported by research conducted within an MDT approach. One study showed positive outcomes from a 1-week MDT inpatient program that combined rehabilitation strategies with psychological approaches and mental imagery training [8]. Similar improvements in function were seen in other studies of specialist MDT programmes that lasted several weeks [9,11]. The studies used psychological approaches such as, cognitive behaviour therapy,



mental imagery and relaxation techniques embedded within the physical activity sessions, as well as separate sessions with therapists and the use self-management strategies. The researchers concluded that an MDT approach was important to ensure that the positive effects seen post-treatment are maintained following discharge.

Due to the nature of these studies, it is difficult to decipher if there are any components or specific treatments within the MDT based approach that contribute to the improved outcomes, or if it was due to the participants receiving specialist treatment or individualised programmes, such as those valued by the participants in this study. The outcomes used were either self or clinician reported measures or measures of functional independence.

Physiotherapy treatment has been recognised as having a significant role in the management of people with FMD as with many patients, including some in this study, it is the only treatment they are offered. However, the most successful treatments incorporate psychotherapeutic modalities such as cognitive behavioural, psychoeducation and stress reduction techniques, emphasising the importance of addressing brain and behavioural elements of the disorder [2]. Providing a holistic approach is sometimes achievable with physiotherapy alone. A possible explanation for the positive perceptions of FMD specialist or neurophysiotherapy treatment experienced by participants in this study may be due to specialist therapists being more likely to incorporate the psychotherapeutic modalities into their holistic treatment programmes. Participants perceived this favourably, compared to the traditional view of physiotherapy treatment, where they receive an impairment-based approach. Another possible explanation is that neurophysiotherapists may have more time to spend with their patients rather than physiotherapists working in an acute setting or a musculoskeletal outpatient clinic. The perception that a specialist physiotherapist is able to spend more time with them links closely to a reoccurring theme in other qualitative research, that is 'being listened to and believed' [17].

There are several similarities between the findings of this study and those of another recent study, which utilised focus groups of health professionals who had experience of treating people with FMD [31]. The authors identified that a trusting relationship between the clinicians and patients was a key aspect for knowing when and how to encourage patients to move forwards in their rehabilitation journey. Moreover, alongside the findings of this study the authors recommend that patients with FMD should be accessed and treated by healthcare professionals that have experience of working with people who have FMD. This finding may be partly explained by staff having more positive attitudes towards this stigmatised patient group, than those who lack clinical experience [32].

The detrimental and traumatising experiences expressed by participants who attended a group physiotherapy session may be more reflective of a lack of specialist input than the group setting itself. Those who attended specialist programmes where they met other patients with FMD reported positive experiences. An opinion-based report [33] of a specialist FMD service in Germany describes the benefits of groups, in which they convey a clear biopsychosocial model of the disorder through psychoeducational, cognitive behavioural and emotional regulation techniques. Joos et al. [34] suggest patients express a sense of relief when meeting others with FMD, and in discussion find their uncertainty about the aetiology is reduced considerably. There are also other benefits of belonging to a condition specific group such as cohesion, interpersonal learning, catharsis, activation of resources and a validation of symptoms [34]. Group sessions may also be

considered to help overcome some of the aforementioned barriers, for example, as groups are a more cost-effective way of delivering specialist treatment this could help reduce waiting times for treatment. More research into the feasibility and clinical effectiveness of group therapy for people with FMD needs to be conducted, as group therapy could provide a challenge to the individualistic nature of treatment that participants desire.

Due to the heterogeneity between people with FMD, a one-size-fits-all approach to treatment is not appropriate or desirable [35]. Within the UK there are no formal evidence-based guidelines or pathways for the management of FMD, however, the consensus recommendations for physiotherapy [12] sets out treatment principles that could be adapted for an individual basis. Having an individualised treatment plan may help demonstrate to the patient that they are being listened to and that their symptoms are being taken seriously.

Studies that have incorporated specialist treatment programmes for people with FMD generally have patients attend for periods between one week and a month [9–11,36]. These programmes are time-limited and are designed to give patients the tools they need to continue with progress after the cessation of specialist input.

Self-management strategies are also endorsed in the physiotherapy, occupational therapy and the more recent speech and language therapy consensus recommendations [12,37,38]. The recommendations suggest including strategies and exercises that the patient has found useful as well as teaching techniques such as pacing to help prevent the return to unhelpful behaviours. Many of the participants in this study report that they would like more information on what they can do to help themselves and in the event of symptom relapse and setbacks.

Some participants were told that FMD was something to live with, rather than recover from, suggesting that these views of healthcare professionals may be based upon the poor prognosis commonly cited in the literature [6]. Interestingly more favourable results are being presented following specific physiotherapy and MDT interventions highlighting that this is something that needs to be considered when discussing the prognosis with patients [9,11,36,39]. Although the positive improvement in symptoms remained to some extent after a follow-up period, the cited studies do not report complete recovery, which is similar to participant experiences reported in this study. It is hoped that with a better understanding of the disorder and increased awareness leading to a quicker diagnosis as well as, access to effective treatment, more patients will be seen to recover from FMD.

Interestingly participants that had the onset of their symptoms more recently reported more positive experiences from healthcare professionals, suggesting that this may be due to the increased awareness of FMD, contributing to patients being diagnosed more quickly [32].

Despite this, the education of health professionals in FMD remains an area that requires attention, as evidenced in by a recent survey [34] of health professionals in Australia, who did not feel well educated in FMD.

This study supports recent research [23] which offers a perspective on how the current healthcare system is inequitable for people with FMD depending on, their geographical location, which medical department they are referred and the views of the treating clinician. The participants have suggested ways to overcome these barriers; increased staff training and greater awareness of FMD. The authors contend that the management of people with FMD could be facilitated by a dedicated pathway within the healthcare system. Interestingly, one participant initially seen somewhere that has a specific pathway for people with FMD,

appeared to have made the most recovery and had the shortest duration of symptoms.

Aybek et al. [40] acknowledges that a lack of necessary experience and resources in some community and hospital-based rehabilitation services leads to a problem in providing specialist centres to help patients with FMD. To overcome this, they suggested developing an outreach service to support community services, thereby improving the skills and confidence of staff. A recent pre-and post-course survey of healthcare professionals who completed an educational course on FMD, reported an increase in the knowledge and confidence in their assessment and management skills that was maintained at six-month follow-up [41]. This demonstrates that it is possible to increase the knowledge of healthcare professionals with a time limited, low-cost educational intervention that could improve patient care in areas that do not have access to specialist FMD treatment centres.

### Strengths and limitations

A strength of this study was that it provided an insight into the perceptions of people with FMD have about specific components of the treatment they received which has not been previously reported. Several participants found the interview beneficial for their own understanding and positive feedback about the study aims was given after the interview had finished.

However, this study is not without its limitations; all participants were recruited *via* social media platforms and the websites of two charities, narrowing the pool of people with FMD. Moreover, the recruitment process was less likely to reach people who had a resolution of their FMD symptoms as the participants were all active users of the social-media pages which provides guidance for people with the condition. The recruitment method was a convenience sample with those who responded first, subject to inclusion criteria and informed consent, enrolled on the study. It is likely that this resulted in participants who were more motivated and/or who had strong opinions. Another limitation is that the participants were aware of the researcher's profession, and this may have influenced their discussion.

### Implications for practice and further research

The findings from this study make several contributions which support the current literature, and it is hoped that together they will help highlight the need for specialist FMD services across the UK. As previously discussed, common themes correspond to the way people with FMD are received across a range of encounters with healthcare professionals. Increasing the awareness of FMD and challenging the negative attitudes of clinicians will have a positive impact on the perceptions people with FMD have of their disorder [17,23]. Participants perceived more positive outcomes when treatment was delivered by clinicians who were experienced in treating FMD or were keen to learn and understand this complex diagnosis. Therefore, continued efforts are needed to increase the awareness of FMD amongst all healthcare professionals and educate them on the influence they have on the patient's recovery trajectory. A greater focus on creating a pathway for FMD patients who present at primary or secondary care may improve patient outcomes and prognosis. Further studies are required to investigate the effectiveness of such a pathway, specialist MDT treatment programmes and the use of specialist group therapy sessions.

### Conclusion

Based on the perceptions of people with FMD, this study identified areas of practice which could be improved to enhance the treatment of people with FMD. People with FMD may see an improvement in their symptoms with effective treatment that is individualised, timely and enables them the opportunity to self-manage their symptoms.

Suggestions for clinical practice and future research have been made to benefit people with FMD and the NHS to ensure a clinically and cost-effective management programme can be accessible to people with FMD from all areas of the UK.

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