




What is it like to live with a functional movement disorder? An interpretative phenomenological analysis of illness experiences from symptom onset to post-diagnosis

Mandip Dosanjh^{1,2}, Jane Alty^{3,4}, Carol Martin¹, Gary Latchford^{1,2}
and Christopher D. Graham*⁵ 

¹Leeds Institute of Health Sciences, University of Leeds, UK

²Department of Clinical and Health Psychology, Leeds Teaching Hospitals NHS Trust, UK

³Department of Neurosciences, Leeds Teaching Hospitals NHS Trust, UK

⁴College of Health and Medicine, University of Tasmania, Hobart, Tasmania, Australia

⁵Department of Psychology, Queen's University Belfast, Northern Ireland

Objectives. With few empirically supported treatments, functional movement disorders (FMD) can be challenging to manage. To enable service providers to better support people with FMD, this study sought to understand the lived experience of FMD: to gain insight into how individuals make sense of their experience from symptom onset through medical evaluation and diagnosis to post-diagnostic adaptation.

Design. An interpretative phenomenological analysis (IPA) of patient accounts of living with FMD.

Methods. Eight participants were recruited from a UK teaching hospital adult neurology service: seven females, varying in age (20s–70s), FMD symptom type (tremor, dystonia, and tics), and time to diagnosis (10–192 months). Semi-structured interviews facilitated participant accounts of key events. Interviews lasted 75–125 minutes and were transcribed verbatim.

Results. Three super-ordinate themes were apparent. The first covered the experiences of onset ('Something is wrong with me'), including loss of control - with the affected body part often described as a separate entity - threats to identity and disturbance in relationships. 'At last! What now?' outlined the bittersweet experience of diagnosis and of treatments. Third, 'Living my life with it' incorporated ongoing experiences of coping with symptoms. While some continued to struggle with the emotional impact of symptoms, others developed a compassionate relationship with their self and maintained satisfying activities.

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*Correspondence should be addressed to Christopher Graham, Department of Psychology, Queen's University Belfast, David Keir Building, Belfast BT7 1NN, Northern Ireland (email: christopher.graham@qub.ac.uk).

Conclusions. FMD has a significant impact on patients' relationships with themselves and others, which in turn affects well-being. These findings suggest some nuanced additions to interventions (diagnosis, psychotherapy, physiotherapy, public education.)

Statement of contribution

What is already known on this subject?

- Quantitative studies found reduced quality of life and poor well-being in functional movement disorders (FMD).
- Current expert clinical opinion recommends early positive diagnosis of FMD and multi-disciplinary interventions.
- A qualitative study within a trial of physiotherapy found that FMD has an emotional impact and that patients often struggle with psychogenic explanations and feel misunderstood by health care professionals.

What does the study add?

- People with FMD experience multiple losses – movement control, roles, identity, credibility – resulting in anger, sadness, confusion, self-doubt, self-criticism, self-blame, and shame.
- Absence of diagnosis affects interpersonal relationships; people with FMD fear they are not believed by family, friends, and doctors. Yet, diagnosis is bittersweet: validation brings relief, but the lack of cure is frustrating.
- There is a divergence in well-being following diagnosis: while symptoms persisted for all, some continued to grieve their losses and remained self-critical; others developed compassionate relationships with their new selves and reported functioning well.

Background

Functional neurological disorders comprise a range of neurological symptoms not explained by known neurological disease pathologies, forming one of the commonest presentations to neurology services (Ahmad & Ahmad, 2016; van der Hoeven et al., 2015). Functional movement disorders (FMD) are a sub-category, involving tremor, dystonia, paresis, tics, and gait disorders (Edwards & Bhatia, 2012). FMD are associated with significant functional impairment, mood disturbance, and poor quality of life (Anderson et al., 2007; Vroegop, Dijkgraaf, & Vermeulen, 2013). While some experience symptom remittance, for many symptoms become chronic (Gelauff, Stone, Edwards, & Carson, 2014).

Clinical management is required for FMD (LaFaver, 2020; Jon Stone, 2009) but there is limited evidence supporting the application of any treatments (Luciana Ricciardi & Edwards, 2014). Consequently, management may be informed by the clinician's understanding of FMD pathophysiology and available treatment options. While progress is being made (Edwards, Adams, Brown, Pareés, & Friston, 2012; Edwards & Bhatia, 2012; LaFaver, 2020), the exact pathophysiology of FMD remains unclear. Historically, psychogenic explanations have predominated, for example conversion or illness behaviour theories (Wilshire & Ward, 2016). The first deems that FMD are due to a response to an emotionally traumatic event after which the resulting distress is converted into physical symptoms, which are maintained by sub-conscious processes; the second that symptoms represent illness behaviours driven by aberrant illness beliefs or interpersonal needs, for example attachment, and the reinforcing responses of others. Ergo, clinical management often primarily involved psychiatric or psychological interventions aimed at remediating the underlying psychological processes responsible

for symptoms. These included psychodynamic therapies for addressing subconscious conflicts (Kompoliti, Wilson, Stebbins, Bernard, & Hinson, 2014), cognitive therapies to modify unhelpful illness beliefs (Dallochio, Tinazzi, Bombieri, Arnó, & Erro, 2016; LaFrance & Friedman, 2009) and behavioural therapies to alter the reinforcers of illness behaviour (Shapiro & Teasell, 2004).

There has been growing interest in biopsychosocial explanations (Edwards et al., 2012), and corresponding acknowledgement of the heterogeneity in causal and maintaining factors for symptoms (Parees et al., 2014). In alignment with this, current guidelines and expanding treatment options mean that people with FMD should expect a carefully communicated 'positive' diagnosis (Stone, Carson, & Hallett, 2016; Stone & Hoeritzauer, 2019) and, depending on the presentation, consideration of referral to physiotherapy or occupational therapy (Gardiner, MacGregor, Carson, & Stone, 2018; LaFaver, 2020; Nielsen et al., 2015). Psychotherapies might be used to improve well-being or reduce symptom interference (Graham, Stuart, O'Hara, & Kemp, 2017) and are included within multi-disciplinary approaches (Demartini et al., 2014; Jacob, Kaelin, Roach, Ziegler, & LaFaver, 2018; LaFaver, 2020).

One further means to enhance treatment is to gain insight into the patient experience of managing their condition. For example, in support of self-management interventions, qualitative studies consistently evidence that effective long-term management of neurological conditions involves navigating the impact of symptoms on social and occupational functioning alongside regulating emotions like fear, shame and embarrassment and threats to identity (Graham, Simmons, Stuart, & Rose, 2015; Hammond, Farrington, Kilinc, 2019; Kilinc, Erdem, Healey & Cole, 2020; Kulnik, Hollinshead, & Jones, 2019). To date, there has been one qualitative study with people with FMD (Nielsen, Buszewicz, Edwards, & Stevenson, 2019), which used thematic analysis on accounts drawn from people with FMD participating in a RCT of physiotherapy. Among other themes, participants described living with FMD as a burden, dissatisfaction with psychogenic explanations for symptoms, and frustration at clinicians' lack of understanding of the condition. In their reflections on the clinical implications, the authors suggested that clinicians should listen carefully to patient narratives and offer appropriately nuanced biopsychosocial explanations for symptoms. While this study offered helpful insights into patients' perceptions of treatment, it was limited to the illness experiences of a specific sub-set of patients – those who were appropriate for, and volunteered into, a trial of physiotherapy. This sample may have had a different lived experience of FMD from the wider patient population, with symptom presentation and patient understanding perhaps more clearly suited to physiotherapy.

Qualitative analytic methodologies with a focus on the lived experience of people with FMD might allow further understanding of how to support patients. Interpretative phenomenological analysis (IPA) (Brocki & Wearden, 2006; Smith, 2011) is widely used within health psychology research to explore illness experience (Brocki & Wearden, 2006), facilitating detailed examination of the unique life experiences of individuals as well as pointing to broader themes. Commensurate with the context of FMD, IPA is well suited to making sense of complex subjective and emotionally laden phenomena (Smith & Osborn, 2015). Focusing on the functional neurological disorders literature outside of FMD, IPA has been used to understand illness experience in people with non-epileptic seizures (Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Regarding the diagnosis period, researchers noticed that this time was often characterized by 'doubt and uncertainty' and a sense of being 'left in limbo land'. They thus suggested that patients' acceptance of a 'functional' diagnosis and engagement with services could be enhanced

by helping patients to integrate the diagnosis into their own personal narratives for symptoms.

The present study used IPA to explore the experiences of adults living with FMD in a clinical sample of those presenting to a UK teaching hospital adult neurology service. The research aims were to understand the impact of FMD on individuals' lives and to gain insight into how individuals make sense of their experiences, by exploring illness experiences from symptom onset, through specialist medical assessment and diagnosis to post-diagnostic adaptation.

Methods

Design

The design and analytic approach was informed by IPA: this well-established, idiographic approach is shaped by phenomenology, the study of subjective experience, and hermeneutics (which acknowledges the 'double hermeneutic' of participant and researcher input to meaning-making; Smith, Flowers, & Larkin, 2009). IPA was selected because of the focus on the individual's unique experience and sense-making, while informing general themes with potential value for others, including service providers. NHS ethical approval was obtained from Leeds West Research Ethics Committee (Reference number: 237944). As recommended (Shaw, Bishop, Horwood, Cilot & Arden, 2019), we adhered to American Psychological Association's guidance for reporting qualitative research (JARS-Qual Guidelines; Levitt, Bamberg, Creswell, Frost, Josselson & Suarez-Orozco, 2018)

Research team

The research team comprised the lead researcher, a doctoral psychology student in clinical psychology (MD), who co-designed and carried out most aspects of the study. MD was supervised by three clinical psychology academics (CDG, with clinical and research experience in this area, CM, experienced with IPA, and GL, working in health) and a NHS Consultant Neurologist (JA), specializing in movement disorders, including FMD, and working within a positive diagnosis framework (Stone et al., 2016).

Participants and recruitment

We recruited adults over 18 years old who had been given a formal diagnosis of FMD by a consultant neurologist, were fluent in English, and had capacity to consent. The clinical service from which patients were recruited is a large NHS teaching hospital and consists of inpatient and outpatient facilities. It provides specialist assessment and treatment of patients with all neurological conditions. There was no limit on recency of diagnosis; this enabled the collection of data about the experience of route taken to, and time elapsed, before diagnosis. Eligible patients were identified by a Consultant Neurologist (JA). She explained the study to consecutive eligible patients attending her outpatient clinic or inpatient ward and, if they expressed interest, provided them with written information about the study. She also sent letters of invitation to eligible patients on her caseload lists. Contact was initiated by either the lead researcher (MD) or participants by telephone. A choice of interview venues (home, university or hospital) was offered. Patients were informed that their decision to take part would not affect their ongoing clinical

management and their participation and interview content would remain anonymous. Before the interview, participants had an opportunity to ask questions and then provided informed written consent.

In total, eighteen patients were approached; two declined, eight could not be contacted, and the final sample comprised eight participants – six recruited from outpatient clinic attendances and two from caseload lists. This number is deemed satisfactory for a study using IPA, in which there is extended analysis of the individual accounts (Smith et al., 2009). Five participants, Rita, Jude, Dan, Tina and Sundip (all pseudonyms), received their diagnosis from JA; three were diagnosed by other neurologists and then referred to JA. Sample characteristics are described in Table 1.

Data collection

The lead researcher conducted the interviews. Prior to the start of interviews, the researcher collected demographic information (including on co-morbid diagnoses) using a simple self-report questionnaire – with the participants, at the interview venue (home, clinic, university). To encourage the participants to recount specific experiences, interviews were semi-structured. Aware of the extended time many people experience symptoms before being given the FMD diagnosis, and the potential for multiple medical contacts, the interview schedule (see Appendix S1) was constructed chronologically to enable participants to tell their own story. It covered key points along the timeline from before the initial symptoms through contact with medical services – including the experience of diagnosis – and current and ongoing experiences. Interviews were conducted in a flexible format, following the participant's own account, so that unanticipated experiences could be recounted. The main questions were framed as open questions (e.g., 'Tell me about getting the diagnosis?', 'So, what is life like living with FMD?') followed by prompts to encourage examples and details, for example 'what happened next?', 'how was this for you?' Interviews were audio-recorded and transcribed verbatim. Interviews lasted between 75 and 125 minutes.

After each interview, the researcher offered participants an opportunity to discuss their experience of the interview and she provided them with an information sheet signposting additional sources of support. Participants were also offered £20 (as voucher or cash) towards travel expenses and to thank them for their time. The lead researcher was experienced in the management of emotion in challenging discussions. She kept a research diary, recording her experience of each interview, and discussed her reflections on the interviews and data analysis in supervision meetings.

Analysis

The analysis was conducted using IPA guidelines (Smith et al., 2009). The lead researcher (MD) read each participant's account several times to become familiar with the text. She then recorded initial notes, summarizing significant or interesting elements in the text, both descriptive and interpretive. The exploratory comments were then analysed to identify emerging themes and provisional theme names. These steps were then repeated with the remaining transcripts before returning to each transcript to develop individual superordinate themes, through comparison and contrast (individual analysis). She then looked for patterns across cases to produce superordinate themes for the group (group analysis). Each step was discussed with the research team.

Table 1. Participant self-reported demographic and clinical information

Participant pseudonym	Age	FMD sub-type	Previous management	Time from symptom onset to FMD diagnosis	Time since FMD diagnosis	Current mental (M) or physical (P) health problems	Current employment
Zoe	20s	Tremor and dystonia	Physiotherapy medication	2-3 years	2-3 years	P	Yes
Rita	30s	Tremor	Physiotherapy psychology	10 months	2 years	P	Yes
Jude	50s	Dystonia	Botulinum toxin	10-15 years	1 year	M/P	No
Mary	40s	Tics and tremor	Medication	10 years	1 year	P	No
Dan	30s	Dystonia	Medication	Under 4 years	Unsure	P	Yes
Tina	50s	Tremor	None	8 years	5 years	M/P	No
Sundip	60s	Tremor and dystonia	Botulinum toxin	1 year	2 weeks	M	Yes
Anne	70s	Dystonia	Botulinum toxin	16 years	Unsure	P	No

Table 2. Themes and their distribution across participants

	Zoe	Rita	Jude	Mary	Dan	Tina	Sundip	Anne
1. Something is wrong with me								
Who's in control?								
My body has a mind of its own		x	x	x	x	x	x	x
It's not getting sorted!		x			x	x		
Who am I?								
I'm not myself	x	x	x	x	x	x	x	x
Having to let go of my old life	x		x	x				
Who believes me?								
People expect too much	x	x	x					
Dismissed and silenced	x		x	x			x	x
2. At last! What now?								
Someone understands!	x	x	x	x		x	x	x
What can help me?	x	x	x	x		x	x	x
3. Living my life with it								
Not in control of myself			x	x	x	x	x	x
I want my old self back			x		x	x	x	x
I'm proud of myself	x	x		x				

Guidelines for quality assurance were considered throughout the study (Elliott, Fischer, & Rennie, 1999): in addition to the use of the reflexive journal, team members independently analysed selected brief extracts of transcript, which were then discussed together in order to facilitate the development of themes and their relationship with each other.

Results

Analysis revealed three super-ordinate themes (Table 2), offering a narrative from first symptoms to current experience.

Super-ordinate theme 1: Something is wrong with me

During the period that symptoms appeared, six sub-themes captured experiences, reactions, and meanings. Three domains were identified: loss of control and helplessness (*Who's in control?* comprising *My body has a mind of its own* and *It's not getting sorted!*); identity and role changes (*Who am I?* comprising *I'm not myself* and *Having to let go of my old life*) and changes in the quality of relationships (*Who believes me?* comprising *People expect too much* and *Dismissed and silenced*).

Who's in control?

Seven participants experienced sudden and absolute loss of control, leaving them frightened and confused (*My body has a mind of its own*). '...out shopping... and we was in middle of the road, me eyes just went like that... There was traffic at back of us, traffic in front of us... I couldn't see a thing...' (Anne). Rita said: 'I realised that my forefinger was trembling and then as I unsupported my arm, the whole hand was

tremoring... frightening... to have control of all your body parts and then all of a sudden you've got your dominant arm tremoring, that's a big, shock almost... that's what I found so scary, the fact that there was no control at all over my arm'. This affected daily activities: '...couldn't butter bread... still can't butter bread properly... my hands don't do what I want 'em to do'. (Jude).

The affected body part often became an 'it' rather than 'mine'. Mary said: '...it's [arm] not like it belongs to me. I have no control over what it does, so it is "it" at that time'. Rita explained: '...you're looking at your left arm... it's absolutely fine... and then the right arm is just going! And I'm thinking: "Right, I'm trying really hard"... to try and make it still, and it just won't!... It's almost like it's just got a mind of its own...'. For Sundip: 'I could not write... it (hand) wasn't corresponding with my mind. I had beautiful handwriting before... it wouldn't write where I was writing. It would be writing; it would be going somewhere else'.

Participants found no explanation and received conflicting advice, which left them feeling anxious, and frustrated (*It's not getting sorted!*). Rita said: 'it took quite a while for me to... find out... I wasn't sure if it were like Parkinson's or something else... you go onto all these websites and start researching... you start scaring yourself almost about the things that you read and whether that would apply to me'. (Rita). Three experienced long waits, allowing time to anticipate the worst: '...frustrated... with the hospital... it's talked about a lot... "probable diagnosis", "possible diagnoses..." "this is what we guess it is"... but not, "this is what we definitely think it is"' and 'is this gonna lead to any more serious things, loss of sight, death...'. (Dan).

Who am I?

Participants experienced anger, sadness, and grief at the loss of their identities (*I'm not myself*), as they struggled with home, work, recreational pursuits and close relationships (*Having to let go of my old life*). Zoe said: 'you're not the same person... you don't have anything left of that lifestyle other than memories... you just spend your whole day resenting your life and grieving the life you used to have before'.

Some turned anger on themselves, as contempt and self-blame (*I'm not myself*). Jude said: 'I just felt stupid, silly, and people didn't understand; people thinking I were just taking the piss. I couldn't tell them how I felt coz I couldn't understand myself; I... couldn't open a can of things, I'd get right frustrated, start crying... chuck things and get right angry with meself'. Feeling intensely ashamed, she described herself: '...I was a lazy, idle cow... even though I worked every day, went shopping, cooking, cleaning and ironing, I were still lazy; but it wasn't coz I couldn't be bothered, it was because I couldn't do it, physically'. Jude's employer moved her to a 'lesser' role, like an 'apprentice' doing 'the jobs nobody wanted to do...': 'Just thought I were ready for knacker's yard... sell-by date's gone... I felt embarrassed coz I couldn't do a proper job; it were just like, like licking stamps, like rubbish. Just felt like... shove me in [the store cupboard], pay me for sitting on my backside...'.

When Rita lost valued roles, she redefined herself as the 'problem', '...blaming myself... blaming my body... why have I got such a rubbish body?... [My husband did] all the extra duties that he wouldn't normally have to do... be kept working more and more... just to compensate for... the loss of a wage... [Before, I was] going to work and feeling as though I'm really making a difference to patients as well as bringing some money in for the house. So all those factors I think really played on my confidence...

[then] I was just this poorly person at home and I didn't want to be that, I wanted to get on with my daily life again. . . I was useless, like there was no real reason for me'.

Three questioned the purpose of their existence. Mary said: *'I went out less. . . I just didn't want to do anything that was going to embarrass me. . . you just feel helpless. . . a burden. . . What is the point of me when I'm like this. . . a waste of a life. I was no use, to anybody. I just thought I was worthless'.*

Participants struggled until they had to surrender (*Having to let go of my old life*). In the absence of diagnosis, they felt they had no choice but to continue. Mary was *'trying to push myself all the time and nothing was happening. I think that, that's what brought the dark days. . . I felt exhausted from trying to continue to be normal'.* Surrender brought relief. Jude explained: *'[I] just got on with things. . . didn't think of being poorly. Just thought of everyday things I've got to get done. . . washing, cooking and cleaning. . . I had to do it all. . . coz I were mother and wife'. 'Everything just got on top of me. . . I couldn't do my job properly. . . it just got really bad. And then they cut me down to three days a week. . . better, but I just knew that I couldn't carry on'.*

Who believes me?

Some experienced relationship changes; four gave extended accounts of difficulties across personal, social, work (*People expect too much*) and health relationships (*Dismissed and silenced*). Participants found that others doubted them (*People expect too much*). Previous experiences fuelled Mary's fears: *' . . . at times I wouldn't go out, for six months, because I wasn't at work and if somebody saw me, what would they be thinking. . . I might be having one good day in six months. But if I go out and they see me. . . "Well she looks fine," and that's the sort of people I worked with. . . "She looked fine to me but she's not been in work for however long"'*.

They described others moving from puzzlement to criticism. Zoe felt isolated: *' . . . they're just like, "Why can't they find out what's wrong?" . . . you're just explaining yourself all the time. . . it just makes you feel horrid because then friends and family. . . are like second-guessing you. . . you can just feel them thinking . . . "what on earth is she on about?" . . . "Well nothing can be wrong with you because [the doctors] said it's fine." You lose trust in everybody. . . you do just feel alone'.*

Five talked about frustrating early medical consultations (*Dismissed and silenced*); *'it was like they didn't believe you. . . "Well none of it makes sense so you can't be experiencing all these. . . We'll do some bloods and your obs and things" and like, "Oh well, they're reasonable." Just fobbed you off. . .'* (Zoe). Sundip's tremor caused difficulties at work: *'I mentioned it to my GP. . . she said, "can you type? . . . Well why don't you just type and not write." . . I said, "But no, I've to sign. . . that's not the solution." So anyway, . . . it carried on and I felt quite down about it because sometimes . . . when you're running your own home you have to write. Finally, I went back to the GP and I said, "this is getting worse." I thought, I could press upon the GP to refer me at least. . . they should investigate'.*

Three doubted their sanity. After contact with several services, Zoe felt desperate, but *'passed from pillar to post'.* She began to blame herself; *'you have nothing in, to put your anger onto, other than yourself, when you don't have a diagnosis. . . you start to second guess yourself. . . "Am I actually getting these symptoms or is it all in the head."'* Jude said: *'I thought I were going mental. . . I knew there was something wrong. . . I kept going to doctors. They kept saying nowt's wrong. . . "There is something wrong. There is. There is." Nobody'd listen'.*

Super-ordinate theme 2: At last! What now?

This theme focused on diagnosis and treatments. All participants experienced a specialist clinic and this episode had a specific quality (*Someone understands!*). Although participants were offered treatments before diagnosis, as well as from the specialist clinic, these accounts differed (*What can help me?*).

Someone understands

All entered the specialist service and saw the recruiting neurologist. Seven described relief because diagnosis meant that they had a confirmed neurological condition. The diagnosis reassured three. Rita explained: *'Relief... because obviously there was something there... rather than things being up in the air, like, could it be Parkinson's? Could it be MS? Could it be something else? Some rare... neurological thing? It was nice to know it was just that, rather than... a major thing like MS or Parkinson's, so that was a relief...'*

A warm and collaborative relationship with the specialist clinician was important; five described relief and hope when the neurologist listened, believed them, was interested and engaged with them to figure out 'the mystery'. *'It made you feel better knowing that somebody was interested in what was the matter with you. Rather than somebody who just made you feel as though they didn't care less' (Anne)*. Three felt vindicated. Jude said: *'I have got something wrong with me medically... I've got a name for it now, so I know that it's not in my mind, it's not all me... it wasn't me going mad thinking I'm going crackers'*.

Disappointment often followed, when participants recognized that their symptoms remained: *'... being told that you had something the matter... and they knew what it was, felt better. But it didn't really make any difference to my life, I still had it' (Anne)*. Two, however, now found solace attributing blame to the condition: *'I can swear and call it names and talk to it... you've got something; you've got that "it"... when you're having a bad day, it's... "Damn you, FND," ... when you can put the blame onto something else, then you can think about how to overcome that something else, how you're gonna get there coz you're not just blaming yourself all the time. I think that was probably a big turning point for me' (Zoe)*.

What can help me?

Participants described disappointing pre-diagnostic treatments. Mary, for example, stopped oral medication after ten years of unsatisfactory prescriptions. Sundip's handwriting improved after botulinum toxin injection: *"Yes! I can write!"... it wasn't in a line, but people could read it. It felt really joyful... I thought... I'm going in the right direction now... but then it would go back to it. That solution wasn't permanent'*.

The specialist clinic offered a multidisciplinary management plan including neurophysiotherapy and neuropsychology. Zoe and Rita undertook physiotherapy. The support and therapy benefitted their wellbeing as much as their physical condition; these interventions were described in a more positive way than earlier drug treatments. Zoe, for example, described changes to lifestyle and mood:

I saw them a couple of weeks' ago... "you're a completely different person"... I'm doing more swimming and trampolining and things that help with the physical aspect; but then it also helps with the psychological aspect because you're getting out, you're having fun, and exercise releases your happy hormones and stuff, don't it... I think it's all just

been learning about your own body and what works better and getting that balance. . . now I have that positivity, that get up and go to want to manage it. Whereas before I didn't, before diagnosis.

Rita described constructive sessions with a clinical psychologist. While the tremor remained, she reported that she understood the contribution of psychological factors and had developed strategies for recognizing and managing anxiety:

I felt a little bit alienated, like: . . . Why do I need to come to [psychology]? . . .but I think it has helped me, because it's just helped me learn to accept the tremor, and. . . understand a bit more about how functional neurological disorders work. . . it's all to do with. . . a signal in the brain not working. . . causing a tremor, and then I guess it's just about re-training that again. . . Before, I was just getting on with life, letting things stress me out, I always used to think about things that had happened, and I try to not do that so much anymore because I realise it's not very helpful and it doesn't help the tremor either. . . it just goes berserk, so I just try and keep as calm as possible now.

Superordinate theme 3. Living my life with it

Participants continued to experience symptoms, limiting their daily lives (*Not in control of myself*), but differed in how they lived with FMD: some were distressed and seemed self-critical (*I want my old self back*), whilst others felt more positive about their lives and themselves (*I'm proud of myself*).

Not in control of myself

Six expressed frustration at limitations: for Mary, '*it's. . . life-limiting. . . I'm forty! I should be able to brush my own teeth. . . to dress myself. . . and make myself a cup of tea. And on good days I can. . . on bad days. . . nothing*'. Anne, with functional facial dystonia, said: '*I can't do anything. . . I do a little bit when my eyes come back. . . when they don't, I just sit and listen to the telly coz I can't watch it*'. Five experienced symptoms as malevolent and unpredictable. Tina spoke of anxiety about tremor; '*. . . if I. . . pick kettle up. . . it's moving all about and it's hot water. . . I'm just frightened it might end up burning me*'. Three feared going outside: '*Never knowing what's gonna set me off or how bad it's going to be. . . is scary. . . to go out alone*' (Mary).

I want my old self back

Five were unreconciled and self-critical, demoralized, yearning for their old lives. Tina's comment was typical: '*why I'm. . . so useless? . . . get really angry with myself not being able to just do summat what's really simple*'. Anne feared others' reactions: '*when your face goes to one side, . . . you feel as ugly as sin. . . I don't like going out because I feel like a freak and . . . everybody's staring at me. . . I cover my face up with a handkerchief. . . so they can't see it*'.

I'm proud of myself

Three viewed themselves compassionately and less self-critically, reporting recovered confidence and wellbeing: '*I got myself to where I want to be and I'm proud of myself*' (Zoe). Mary said: '*I just think it's part of me now. . . [I'm] more capable*'. They had recalibrated, pursuing attainable goals; '*you just live with it and then you adapt and then*

it just becomes part of your life and you feel okay about it because you know what you can do with it and what you can't do with it' (Rita). Zoe said of 'bad days' that 'you don't like feeling poorly. . . but you don't mind them as much now. I think it's just part of the life now, but then I just enjoy my good days more. . . I appreciate them more'.

Discussion

These eight accounts offer insight into the experiences of living with FMD, through onset of symptoms, diagnosis to present functioning. All participants experienced a period of fear and some endured extended periods of feeling disbelieved before reaching a neurologist with knowledge and experience of the condition. Diagnosis offered relief and reduced self-criticism and anxiety, although for some participants this was quickly followed by disappointment that there was no cure. At interview, three had adapted constructively to living with FMD but five remained distressed and continued to grieve their losses.

These narratives help us to understand the findings of quantitative studies, which have reported affected quality of life and mood in FMD (Anderson et al., 2007; Vroegop et al., 2013), extending and elaborating themes observed in an earlier qualitative study of people with FMD participating in a trial of physiotherapy (Nielsen, Stone, et al., 2019). For example, Nielsen, Stone, et al. (2019) documented social isolation, loneliness and distress as common experiences in FMD. Additional nuanced aspects of the emotional and identity impact of FMD were observed in the present study: emotional responses like self-doubt, self-criticism, self-blame, shame and embarrassment accompanied interactions with others, health professionals and losses in roles. Participants reported that their relationships with others became compromised, especially when it appeared that family, friends and doctors did not believe their symptoms were legitimate: they felt alone and became estranged from others, as they either found it hard to trust others or avoided difficult conversations. This had psychological consequences: self-doubt and loss of confidence followed, with some participants fearing that FMD meant they were losing their mind. Similar findings have been reported in studies with patients with other functional neurological disorders (Karterud, Risor, & Haavet, 2015; Rawlings, Brown, & Reuber, 2017), explicating how stigmatized societal views of 'medically unexplained symptoms' can impact on people with such conditions.

As participants gave up activities and roles, they experienced multiple losses, not only externally – things that they stopped doing – but also with regards to their identity (i.e., how they saw and related to themselves.) Participants described a struggle to maintain old identities (e.g., mother or employee), and it was only after a period of adjustment and mourning that some were able to value themselves in new, albeit more limited, roles. Loss of role has been documented as a significant barrier to well-being in Parkinson's disease, multiple sclerosis, and non-epileptic seizures (Barker, das Nair, Lincoln, & Hunt, 2014; Karterud et al., 2015; Mozo-Dutton, Simpson, & Boot, 2012; Rawlings & Reuber, 2016).

In common with the wider literature on living with long-term health conditions (Barker et al., 2014; Rawlings & Reuber, 2016; deRidder, Greenen, Kuijter & van Middendorp, 2008; Schwartz & Sprangers, 1999; Wyatt, Laraway, & Weatherhead, 2014), there was divergence in how effectively participants were coping with symptoms. While some still mourned their losses, continued to feel distressed and ashamed, and felt anxious about going out alone, others had developed a more compassionate view of themselves as they assimilated symptoms into their identity – they found new goals and felt more

content. Such divergent paths are compatible with several theoretical models of effective adjustment to illness (Graham, Gouick, Krahé, & Gillanders, 2016; Moss-Morris, 2013), which propose that well-being is supported by finding or maintaining a sense of purpose and taking on identities that enable meaningful activity.

In addition, to support understanding of the factors contributing to well-being in FMD, the present study offered insights into the phenomenology of symptoms previously unreported from the patient's perspective. Participants made reference to a body part that felt alien to them with symptoms ('it') taking control of the affected area. Seizures are sometimes described by people with epilepsy as an external force that takes over the body (Kilinc, Campbell, Guy, Van Wersch, 2018). However, while this experience would be expected in epilepsy, given that it is defined by periodic global alterations in consciousness, the description of a body part as separate from the self is a novel finding in FMD. This elaborates the lived experiences of phenomenon previously captured in quantitative studies, where those with FMD show less awareness of visual and sensory signals coming from the affected limb (Parees et al., 2012; Lucia Ricciardi et al., 2016), and demonstrate lack of agency over movements (Voon, Brezing, Gallea, & Hallett, 2011; Voon et al., 2010).

Clinical implications

These participants found the experience of 'positive diagnosis' (Stone, 2009; Stone et al., 2016) to be helpful, citing the sense of being believed, of being actively listened to and of interest in their symptoms. This contrasted with accounts of previously feeling invalidated by doctors, family and friends. Participants valued the specialist's priorities for building a warm therapeutic alliance and confirming their belief that the symptoms are real, not feigned nor under their control. This affirming approach was continued in accounts of contact with other professions who offered support to those with FMD; this may be relevant for the uptake and progress of physiotherapy (Jacob et al., 2018; LaFaver, 2020; Nielsen et al., 2017) and psychological approaches. Given the contrasts in the accounts, there is value in researching the influence of service delivery on patients' mental health.

Regardless of the aetiology of FMD, the present study suggests that psycho-social factors contribute to well-being. There have been no methodologically robust trials of psychological interventions for FMD (Ricciardi & Edwards, 2014). Smaller intervention studies of psychotherapies targeting the psychological factors theorized to be causing symptom have returned mixed findings (Dallocchio et al., 2016; Kompoliti et al., 2014; Shapiro & Teasell, 2004). Psychological therapies also have value for improving functioning and distress in physical health conditions (Butler, Chapman, Forman, & Beck, 2006; Graham et al., 2016; Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007) and similar approaches may have value for living well with FMD. These participants described struggles to maintain key activities and loss of valued roles, attributing experiences of shame, self-blame and self-criticism to these failures. For them, the losses resulting from symptoms were their priority. This constellation invites the consideration of newer cognitive behavioural approaches such as Compassion Focused Therapy (CFT) (Gilbert, 2009) and Acceptance and Commitment Therapy (ACT) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), which aim to increase activity that is personally meaningful even in the presence of challenging experiences. There is a detailed case example of applying ACT to FMD (Graham et al., 2017), but we are unaware of any trials of CFT with functional neurological disorders.

Finally, the impact of societal misperceptions or misunderstanding about the legitimacy or causes of FMD appeared to affect participants' relationships and social functioning. Patients may benefit from improved public understanding of functional neurological disorders through public education campaigns, by supporting advocacy services and patient-led charities.

Limitations

This sample was typical in terms of presentation, albeit variable in the duration of symptoms and time to diagnosis. This does mean, however, that the present study was able to explore the whole patient journey from symptom onset to post-diagnosis symptom management and demonstrated the value given by participants to their positive experiences of medical input. Future studies might recruit samples homogeneous in relation to pathway and duration. The mix of participants who remained distressed and those who felt more positive resulted in themes concerned with current experience that overlap with pre-diagnostic experience. Further research might recruit by outcome and explore factors influencing adaptation. Perhaps atypically, all participants had interactions with a neurologist with significant interest in FMD and a sympathetic positive approach, which appeared to have shaped their accounts.

In addition, there may be differences between those who volunteered to take part and those who did not. The findings were obtained from a predominantly white British female sample; therefore, further data would demonstrate whether these findings are equally transferable to other sub-groups of those with FMD. Also, it is worth acknowledging the subjectivity implicit in the qualitative analysis. Themes emerged from a careful discussion at each stage within the research team. They reflected our focus on the experience of patients in relation to both living with their symptoms and their attendance at a specialist clinic, requiring a storytelling approach. This interest has shaped the structure of the analysis, as experience prior to the clinic was separated from subsequent experience.

Conclusions

These findings illustrate the lived experience of FMD from symptom onset to post-diagnosis. Participants described the experience of multiple losses: losing control of one's body, identity, and credibility. They then described the bittersweet consequences of diagnosis. Finally, there were divergent post-diagnosis paths – some let go of previous roles and identities and found ways to live well, while others appeared demoralized and distressed. Findings enhance our understanding of the bio-psycho-social aspects of FMD, outlining the experience of feeling separated from the affected body part. Participants valued the clinical relationship, communication of belief in the patient, and recognition of the emotional impact of the symptoms. Psychological interventions focused on self-compassion, acceptance, and identity may support patients learning to live with FMD.

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Conflict of interests

All authors declare no conflict of interests.

Author contributions

Mandip Dosanjh (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing) Jane Alty (Conceptualization; Formal analysis; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing) Carol Martin (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Supervision; Validation; Writing – original draft; Writing – review & editing) Gary Latchford (Conceptualization; Data curation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing) Christopher Graham, PhD DClinPsychol (Conceptualization; Formal analysis; Investigation; Methodology; Project administration; Supervision; Validation; Writing – original draft; Writing – review & editing).

Data availability statement

Raw data, beyond those displayed in this article, are not shared.

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Supporting Information

The following supporting information may be found in the online edition of the article:

Appendix S1. Interview schedule.