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Doctoral Thesis:

Functional movement disorders:

Exploring lived experiences and psychological interventions.

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Word Count Statement

Section	Main Text	Appendices (including tables, figures and references)	Total
Thesis Abstract	300	-	300
Literature Review	7,967	13,997	21,964
Research Paper	7,975	12,576	20,551
Critical Appraisal	3,513	765	4,278
Ethics Section	5,990	2,639	8,629
Total	25,745	29,977	55,722

Thesis Abstract

This thesis examines issues related to functional movement disorders (FMD) and consists of three papers: a literature review, a research paper and a critical appraisal of the research process.

The scoping literature review explored the characteristics of psychological interventions for FMD in research studies in the last 20 years. It found that FMD was conceptualised differently across the studies and interventions employed various techniques to target different assumed FMD mechanisms. The review identified that although psychological wellbeing, co-morbid physical symptoms and quality of life are important factors influencing and influenced by FMD, they are often not monitored in research studies. Acceptability of the interventions has also not been measured despite preliminary evidence of their low uptake and high dissatisfaction with psychological explanations of FMD. A number of recommendations have been made for future studies to improve design and evaluation of psychological interventions for this population.

The research paper explored lived experiences of people with FMD. Ten semi-structured interviews were analysed using Interpretative Phenomenological Analysis. Three superordinate themes were generated: (1) The tug of war with the secret agent within: the power struggle with symptoms; (2) Navigating risks of disclosing the diagnosis: stigma and self-preservation (3) Pursuing hope, knowledge and treatments against helplessness and passivity. The findings indicate that people with FMD may face many internal and interpersonal battles whilst trying to maintain hope, a sense of control and identity. A sense of oppression, loss of control and stigma were explained in the context of discriminatory power distribution in the society and healthcare settings. Recommendations for research and clinical practice focus on facilitating patients' empowerment and access to adequate

treatments in FMD-informed services.

The critical appraisal discusses the studies' finding in the context of interpersonal and systemic power dynamics and reflects on the research process from critical theory perspective.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from June 2018 to July 2020. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Sylwia Bazydlo

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Date: 01.08.2020

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Firstly, I would like to thank everybody who shared their experiences of living with FMD. It was humbling to hear your stories, it made me laugh and it made me cry. It is my hope that this project will help raise the awareness of FMD and the battles it involves. My thanks also go to FNDHope for the consultation and help with the recruitment.

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I am grateful to my daughter who was a constant reminder of what really mattered during these busy four years. And lastly, I will be forever thankful to Emmanuel, without whose support I cannot imagine ever finishing this project. You held me safe and guarded my sanity, and you made the best cakes!

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Psychological interventions for functional movement disorders.

A systematic scoping review

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Psychological interventions for functional movement disorders – a systematic scoping review

Abstract

Purpose: To synthesise available research in relation to the main characteristics of psychological interventions for people with functional movement disorders (FMD).

Method: A scoping review methodology was adopted. PubMed, CINAHL, PsycINFO and Scopus databases were systematically searched. Studies reporting psychological interventions for FMD published from year 2000 in peer-reviewed journals in English were included. Data was extracted in relation to therapeutic modality of the interventions, techniques employed, theoretical conceptualisation of FMD, outcome domains and measures, and methods of evaluating intervention effectiveness and acceptability.

Results: 921 articles were identified, of which 23 were eligible. Cognitive behavioural therapy was the most commonly employed intervention. The theoretical conceptualisation of FMD varied across the studies, which employed various therapeutic techniques to target different assumed underlying processes or their impact. Comorbid symptoms, psychological wellbeing and quality of life were often not monitored. Acceptability of interventions was mostly not examined. The effectiveness of interventions was reported on the basis of statistical significance, without calculating effect sizes or clinically significant changes across all domains.

Conclusion: Future research should examine specific therapeutic techniques and their impact on the hypothesised processes involved in FMD. A variety of psychosocial and physical outcomes should be measured and analysed in terms of effect sizes and clinically significant changes to capture meaningful changes in the syndromic nature of FMD. The acceptability should be routinely measured to build up evidence for socially valid and feasible interventions. Development of a competence framework for psychological interventions is needed to guide clinicians and set standards for practice.

Keywords: functional movement disorder, functional neurological disorder, psychogenic disorder, conversion disorder, psychological intervention, psychotherapy, literature review

Introduction

Functional movement disorders (FMD) involve altered movement control, such as tremor, dystonia, limb weakness, gait disturbance, spasms or fixed postures. They belong to a wider category of functional neurological disorders (FND) and frequently occur alongside other sensory or cognitive functional symptoms, neurological disorders, physical illnesses and psychological difficulties [1]. They are described as a disruption to the nervous system's functioning, rather than structural damage or an organic disease, and are often explained metaphorically as a 'brain software' issue [2].

FMD have incidence of four to five cases per 100 000 of population per year [3] and the wider FND account for around 16% of all neurology referrals in the UK [4]. The symptoms are often persistent and disabling [5] though people affected are regularly left without effective treatments [6]. The prognosis remains poor [7-9] with mortality higher [8] and general health and quality of life lower [10] than comparable organic neurological disorders.

Traditionally FMD have been explained by psychoanalytic theories as a conversion of psychological distress, conflict or trauma into physical symptoms that symbolised the threat, unmet need or unexpressed impulses [11]. Psychological therapy targeting the assumed underlying trauma or psychological 'disturbance' was thus the treatment of choice. With time, the traditional conversion model has been challenged as lacking empirical evidence and reductionistic [12,13]. In the move away from the emphasis on psychological distress as the key causal factor in FMD, the criterion of an identifiable psychological stressor has been removed from the formal diagnosis in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) [14]. However, the term 'conversion disorder' and 'psychogenic movement disorder' are still used synonymously with FMD and the role of stress is

commonly accepted as influencing FMD trajectory [15]. Nevertheless, there has been a growing recognition that, unlike in other somatoform disorders, distress and physiological arousal alone fail to explain FMD and for some people it has less relevance [16].

Increased appreciation of the complex multifactorial determinants of FMD [17] alongside advances in neuroimaging and pathophysiological studies [18-22] facilitated the re-emergence and developments of neurobiological theories [23] which shifted the focus towards broader biopsychosocial models incorporating more neurobiological and psychosocial factors in FMD. The newer models built on previous insights and many described FMD as a brain circuit disorder with altered network activity and connectivity, altered metabolic demand during tasks, and expressed in the context of predisposing, precipitating and perpetuating factors: genetic, neurological, cognitive, emotional and environmental [1,3,20,24].

The changes in conceptualisation of FMD instigated changes in recommended treatments, from mainly insight-oriented psychotherapy to multidisciplinary approaches [1,3]. The most robust evidence currently exists for specialist physical rehabilitation with psychological input [25]. Current evidence to support particular psychological interventions for FMD is growing but limited with most studies involving cognitive behavioural therapy (CBT). However, the available research is insufficient to support CBT at the evidence-base level [16]. Additionally the focus and type of CBT may vary, from generic stress-focused to specialist protocols developed for particular FMD symptoms. The most robust evidence for CBT amongst the wider category of FND is for non-epileptic seizures and yet the most recent, and the biggest, randomised controlled trial (RCT) failed to find significant change in the frequency of seizures when compared to standardised medical care. It did however show significant improvements in distress, quality of life, somatic symptoms and impression of

overall clinical improvement as rated by patients and clinicians [26]. The changes in these domains are likely to be important to patients' overall functioning and wellbeing but their correspondence with patients' initial treatment goals has not been examined. Furthermore, this particular CBT approach was based on assumption of avoidance of fear as associated with seizures and hence targeted this process via exposure and challenging seizure-related thoughts. However, it is possible that whilst this approach reduced anxiety and avoidance as some of the perpetuating factors, the targeted processes or techniques had limited influence on the factors initiating seizures. Therefore an exploration of theoretical assumptions and therapeutic targets might be of crucial importance when designing and evaluating interventions. Indeed, there is an increased emphasis on delivering interventions across different FNDs according to the specific symptoms and their various underlying processes [27].

The patients' perspectives have been under-represented in this debate but their dissatisfaction with psychological explanations for their physical symptoms has been frequently reported [28,29] suggesting a discord between clinicians' and patients' conceptualisations of FMD and goals for treatment. Carson illustrated the frustration and invalidation of patients in a metaphor of going to a garage with a flat tyre but being persuaded to buy shock absorbers first [16]. However, the acceptability of psychological interventions for FMD has not been systematically studied. Adopting biopsychosocial models of FMD which emphasize the different interactions of a variety of factors offer the opportunity to match various psychological interventions and their different therapeutic targets and techniques to the individual needs of the person. Collaborative formulation of the predisposing, precipitating and perpetuating factors relevant to each individual person could guide the choice of the target area of functioning that is most likely to generate positive changes, meaningful to the patient.

The dynamically evolving understanding of FMD, dissatisfaction with traditional psychological explanations and poor prognosis of people with FMD warrant a closer examination of contemporary psychological interventions for this population. There has been no knowledge synthesis in the research literature to describe what psychological interventions entail, which assumed underlying or maintaining processes are targeted, nor which goals/outcomes are expected and evaluated. Such an overview would help identify areas in need of revision, in line with modern insights, expert consensus and acceptability to patients. This is especially important now, in the context of renewed interest and research activity, to guide future investigations by posing the right questions. Therefore the current study was proposed to examine characteristics of psychological interventions for FMD in research studies conducted in the last 20 years using scoping review methodology.

Methods

A scoping review has been adopted as a well-suited methodology to answer broad exploratory research questions, especially in an area of new emerging evidence [30]. Systematic scoping reviews offer similar rigour to traditional systematic reviews and are concerned with mapping out and understanding complex topics from a broader perspective, contextualising and synthesising the data. They aim to identify gaps in the evidence and facilitate generation of new questions that would advance the field [31].

This systematic scoping review was guided by Arksey and O'Malley's six step framework [32,33] and guidance for conducting systematic scoping reviews produced by the Joanna Briggs Institute (JBI) [34]. Quality assessment is usually not conducted in scoping reviews as not pertinent to the research question [30,33] and was not conducted here.

Step 1: Research question

The research question was: What are the key characteristics of psychological interventions

used in research studies for FMD? This broad question includes two foci of the review that guided the search strategy, data extraction and synthesis:

(1) What therapeutic approaches and tools are used, and on what theoretical propositions about FMD?

(2) Which outcomes are targeted and measured? How is effectiveness and acceptability evaluated?

The aim is to provide an overview of the current theoretical and methodological aspects of the available research to stimulate discussion, guide further research and aid the development of psychological interventions.

Step 2: Identifying relevant studies

A systematic search of four databases (PubMed, CINAHL, PsycINFO and Scopus) was conducted on 8th March 2020. Google Scholar was also searched and the references of key papers were hand searched for additional studies. The search strategy was developed and refined in consultation with the university's subject specialist librarian. It combined the two main concepts: FMD and psychological interventions, including their various terminologies. Where available, the database thesauruses, subject headings, truncation and main terms 'explosion' were used (see Table 1).

[Table 1 around here]

Free text searches were conducted in the titles, abstracts and keywords of the articles and combined with the subject headings searches. The search strategy is presented in Table 2 and detailed searches for each database are attached in Appendix 1-B.

[Table 2 around here]

Step 3: Study selection

The search criteria included studies of any design, including case studies, which report an application of psychological intervention for FMD in people aged 18 and over. Participants had to have had at least one functional movement symptom for which they were treated, such as limb weakness, paralysis, spasms, tremor, gait disturbance, myoclonus or dystonia. Psychological intervention was defined as a specialist intervention delivered by a mental health professional and intended to improve or manage the participants' FMD. To be included in the study the interventions had to use psychological theoretical frameworks and could be in the form of psychological formulation, psychotherapy, counselling, psychoeducation, skills training or consultation. Interventions could be direct or indirect (with other professionals or family engaged in the person's treatment), standalone or part of a wider multidisciplinary treatment. The review was narrowed to papers published in English and in peer-reviewed journals since 2000. This timeframe was selected to capture contemporary evidence. Studies were excluded if the symptoms could be attributed to a known organic aetiology. Full inclusion and exclusion criteria are presented in Table 3.

[Table 3 around here]

The literature search returned 921 papers after de-duplication. The author first screened the records by reading the titles and abstracts and retrieved the full article text if the study appeared to meet the inclusion criteria. At this stage 889 records were excluded and the remaining 34 were further assessed for eligibility by reading the full texts. The study

supervisor was consulted to resolve any emerging ambiguity regarding the inclusion of a study. As a result of this process eleven studies were excluded [16,35-44] and 23[1] studies were included in the final analysis [45-67] (see Figure 1).

[Figure 1 around here]

Step 4: Charting the data

This step involved an iterative process of extracting and charting data from the papers and supplementary materials provided by the authors [32]. The categories of data extracted are presented in Table 4. Characteristics of the studies' sample, methodology and intervention's structure and modality were taken directly from the authors' descriptions in relevant sections. Passages of text relating to the conceptualisation of FMD symptoms and the interventions' techniques and targets were searched for across the entire article. Direct quotes were used in the data charting table unless this was not practical due to the amount of relevant text – in such cases a summary was constructed by the researcher.

[Table 4 around here]

1 One of the included studies with n=9 involved one participant who was 17 years old and therefore strictly did not meet the aged 18 or over inclusion criterion. The decision was reached to include this study as it was likely this breach of the inclusion criteria would have minimal to no impact on the review findings. 45. Hinson VK, Weinstein S, Bernard B, et al. Single-blind clinical trial of psychotherapy for treatment of psychogenic movement disorders [Article]. Parkinsonism and Related Disorders. 2006;12(3):177-180.

Step 5: Collating, summarising and reporting the results

An overview of the collated data guided the analytical process and decisions about aspects or subsets of studies to be summarised, compared and synthesised based on particular characteristics of interest [68]. The quantitative analysis in this review was limited to calculating basic descriptive statistics. Textual data was categorised whenever possible. Changes in FMD terminology and number of published studies over time were summarised and presented in visual graphs. Characteristics of the studies' design, conceptualisation of symptoms, psychological interventions and their evaluation methods were presented using a narrative synthesis.

Step 6: Consultation

This stage was an iterative process of consulting with the study supervisor to discuss the charted and synthesised data from methodological perspectives. An additional clinical and theoretical perspective was sought from a consultant clinical neuropsychologist and a clinical psychologist. Two experts by experience were also consulted on a draft of results to inform the discussion of the findings.

Results

A total of 23 articles published since 2000 were included in this review (see Table 1 for an overview). The studies combined involved 517 participants and were undertaken in five countries: USA (n=9), UK (n=5), The Netherlands (n=2), Canada (n=2), joint studies between Canada and USA (n=2) and UK and Italy (n=1).

[Table 5 around here]

Figure 2 shows the recent growth in publications, with more than half (61%) in the

last four years. The studies used different terms to describe FMD. In the first decade terms used were ‘conversion’, ‘somatisation’, ‘factitious’, and ‘psychogenic’ whereas from 2016 onwards, the terms ‘functional’ or ‘conversion’ were used exclusively (see Figure 3).

Seventeen studies reported interventions for mixed movement symptoms, two for dystonia, two for paralysis, one for myoclonus, and one for tremor. See Table 5 for the characteristics of the studies.

[Figure 2 around here]

[Figure 3 around here]

Design of studies

Over half (61%, n=14) of the 23 included studies used retrospective designs, mainly case reports (n=9). Nine studies used prospective designs, including four RCTs: two on the use of hypnosis [66,67], one on psychodynamic psychotherapy (PDP) [61], and one utilising CBT [47]. Seven studies involved a comparison group and out of these, only two had active psychological interventions as a comparator [65,67]. Fewer than half of the studies (n=11) conducted follow-up assessments. Out of these, five followed up their participants six months or more after the treatment [54,58,62,66,67]. Sample sizes were generally small, ranging from 1 to 45 participants, with the exception of one retrospective study of n=174 [46]. The mean sample size was 22, median 14 and mode 1.

Type and settings of interventions

Interventions were conducted in out-patient (n=15) and in-patient (n=8) services. Fifteen studies reported standalone psychological interventions with the remaining eight delivered as part of multidisciplinary treatments.

The most utilised form of intervention was individual therapy (n=20). The use of psychoeducation groups was reported in two studies [63,67]. Two studies offered co-treatment sessions with other professionals – physiotherapists, occupational therapists and neurologists – as a way of integrating multidisciplinary treatment or to facilitate adherence to the main rehabilitation model [49,51]. Three studies reported indirect interventions - consultation by a psychologist to other therapists and staff in multidisciplinary in-patient settings [51,58,65]. In two of them consultation was offered in combination with direct work and in one study it was the only psychological input [65].

Duration of interventions varied from one to 50 sessions. In in-patient settings, the duration of psychological interventions was mostly tied to the duration of the admission, which also varied, from five days to 18 weeks (see Table 6).

[Table 5 around here].

[Table 6 around here]

Therapeutic targets, tools and symptom conceptualisation

The findings are presented according to the papers' stated therapeutic modality. However, multidisciplinary treatments (MDT) can offer a broader approach to symptoms and target multiple FMD processes or their impact. Psychological interventions offered as part of such treatment might be separate or intertwined with other techniques, making it difficult to extract its distinctive elements. Therefore, the studies were divided into two groups: psychological interventions as standalone treatments and as part of MDT. Description of each study's symptom conceptualisation and therapeutic tools is presented in Table 6.

When describing conceptualisation of symptoms, only material that was explicitly present in the current papers was included, to avoid potential pitfalls of misinterpretation or making incorrect inferences. Similarly, some interventions modified previously published treatment manuals for other FNDs but it was decided to only include the description of techniques explicitly stated in the current papers as the extent of the adaptations could not be assumed.

Standalone psychological interventions

Cognitive behavioural therapies. There were seven CBT, two ACT and one DBT study in this category.

One CBT study [47] did not describe symptom conceptualisation or therapeutic techniques. The remaining six studies [46,50,52,55,59,64] shared many common techniques, such as identifying links between symptoms and cognitions, emotions, behavioural responses and the environment, symptom re-attribution or reducing behavioural avoidance and three studies [52,59,64] modified previously published manuals of CBT for NES [69-72]. However, the therapeutic priorities, emphasis on particular techniques or development of additional ones varied, often depending on the theoretical assumptions about main underlying or contributing

mechanism in FMD. Some CBT papers [50,55,59] reported targeting movement control directly through motor strategies, such as tapping with a non-tremulous body region to interfere with symptom expression [59]. The focus on practising the correct, yet feared movement was at the centre of Gros et al.'s study [55], where CBT for obsessive compulsive disorder was used on the understanding that FMD symptoms are compulsions that developed to manage health-related anxiety triggered by past injuries or disability. A unique, strategic symptom displacement technique was developed by Krupnik et al [50] and involved practising alternative movements (e.g. tying a knot on a rope) in the presence of symptom triggers to redirect attention and correct the brain's erroneous prediction of the symptomatic movement emergence (spasm). It was based on the Bayesian model of predictive coding in FND [73] and proposed symptoms to be a result of an altered brain activity in which abnormal movements are predicted and generated in error and in response to excessive somatically directed attention. Krupnik et al. also employed cognitive strategies to influence the brain's predictions via education about the symptoms' nature and to demonstrate the mind's influence on symptoms, e.g. during distraction.

Other CBT studies reported mainly cognitive strategies to alter cognitive or emotional processes and responses. For example, O'Connell et al.'s paper [46] quotes errors in attention and symptom attribution as contributing to symptoms development as well as their temporal relationship with stress and anxiety. The intervention was described as aiming to challenge the identified 'cognitive distortions' and build insight and acceptance of a 'psychological understanding' of symptoms through psychoeducation. Greater emphasis on the role of affect in FMD seemed present in Espay et al's study where increased activation of brain regions associated with subliminal emotional processing is proposed to be linked with symptom expression [52]. The authors proposed that identification and management of the implicit,

emotionally laden automatic thoughts emerging during symptom exacerbation may help reduce the hyperactivation of the affected brain regions and reduce symptoms.

A similar perception of FMD as a way of coping with unexpressed and avoided affect was described in a case study of a psychoeducational intervention combining ACT and Morita therapy concepts [63]. The aim was to increase awareness and acceptance of internal experiences, and reduce experiential avoidance. Mindfulness, psychoeducation about controllability of actions - but not internal states - and identifying primary values, were used to connect with emotional experience and facilitate a shift towards a productive, valued behavioural actions. An individual ACT therapy as the sole therapeutic approach was used in Graham's case study [57]. Whilst the therapeutic goals of increasing openness to and awareness of own internal experience and strengthening engagement with one's values was similar to the previous study, Graham considered FMD aetiology as complex and multifaceted and the exploration or challenging patient's illness beliefs was not required. Attentional processes were considered as potentially implicated in symptom maintenance and thus directly attending to them was suggested as unhelpful. Instead, altering symptom-focused attention indirectly was hypothesised as useful to reduce symptoms' interference with functioning and wellbeing.

The only study of DBT [48] described FMD as a function of emotional dysregulation and therefore targeted mainly emotional processes through skills training in emotional awareness and regulation.

Hypnosis, PDP and body-focused therapy. Five studies, employing hypnosis [66], PDP [45,56,61] and body-focused therapy [53], conceptualised the movement symptoms as a symbolic representation of a difficult affect, a psychological conflict or an unmet need. PDP and hypnosis promoted insight into the unconscious phenomena through exploration of early

life events, underlying conflicts or unexpressed feelings as well as supporting the development of new coping strategies to deal with threatening memories or feelings. Additionally, the hypnosis study used symptom-oriented hypnotic techniques, attempting to alter cue conditioning for the specific motor symptoms and reinforcing reduction of symptoms with praise [66]. The body-focused intervention [53] employed mainly movement and sensory exercises to build a sense of strength and safety in the body. This aimed to work through the traumatic past experiences by providing an alternative somatic experience without explicit verbal exploration.

Psychological interventions as part of multidisciplinary treatments

Cognitive behavioural interventions. Five CBT-informed studies were included in this category. One of them [58] combined CBT with ACT and reported symptoms as manifestations of anxiety, stress and depression. Other studies reported more nuanced and multifactorial conceptualisation whilst acknowledging cognitive/psychological factors as important in the way symptoms are expressed [62]. Stress and psychopathology was seen as often insufficient to explain symptoms [54] or as maintaining rather than causing them [49]. The CBT interventions involved identification and management of triggers and associated unhelpful thoughts, emotional and behavioural responses, in some cases aiming to build a 'more psychological understanding' of symptoms [60] or changing illness beliefs and re-attribution of symptoms, although not necessarily to psychological trauma or adverse events [62]. Yam's study rooted in CBT and ACT [58] described a two-pronged psychological intervention: individual therapy, addressing anxiety and distress through relaxation, mindfulness, exploration of thoughts and emotions, psychoeducation and identifying values to guide committed action; and consultation to other therapists to guide behavioural strategies based on reinforcement of correct movement and planned ignoring of non-functional

movements. Lidstone et al [49] assembled an integrated intervention whereby the physical, neurological and psychological interventions were interwoven and delivered by three professionals together: a neurologist, a neuropsychiatrist and a physiotherapist. This corresponded with their conceptualisation of symptoms as a maladaptive integration of different brain functions in FMD (see Table 6 for detail) [49]. The psychological elements involved desensitisation and uncoupling of sensory triggers from motor symptoms, addressing the fear of symptoms through attentional redirection exercises, and integrated body-focused work to address any psychological difficulties, e.g. anxiety, lack of confidence or sense of agency.

Behavioural interventions. Both studies utilising behavioural interventions [51,65] described FMD in terms of a maladaptively conditioned behavioural strategy in response to stress. They used indirect interventions to support physical therapies and rewarded functional movement. They also used planned ignoring or withdrawal of positive reinforcement for no progress or 'non-functional' behaviours (safety strategies, e.g. use of wheelchair, walking aids). One of the studies also provided individual therapy to improve stress management [51]. In the other study the authors introduced aversive elements, such as stating that a lack of progress or an attempt at a ‘premature discharge’ would be a proof of psychiatric aetiology and would require a long psychiatric treatment. The therapists explicitly endorsed lying and deception as necessary to actively discourage ‘dysfunctional behaviours’ [65].

Hypnosis. Moene et al.’s study [67] described symptoms as an expression of a psychological need or conflict. Hypnosis was delivered in addition to group psychotherapy and skills training, and utilised insight-oriented techniques facilitating exploration of past events and associated unexpressed emotions as well as symptom-oriented techniques, aiming to alter the cue-conditioning of triggers and symptomatic movements.

Evaluation of interventions

In this review FMD outcomes were categorised into six domains: (1) functional movement symptoms (FMS) (2) psychological wellbeing (3) co-morbid symptoms (4) life impact (quality of life, functioning and participation) (5) resource use (health and social) and (6) acceptability. The first five domains were selected according to previous recommendations in the literature [74]. The sixth – acceptability – was chosen as an important although often neglected aspect of evaluation of clinical treatments [75] offering insight into how well an intervention will be received by the recipients and the extent to which it might meet their needs [76]. The guidance for evidence-based practice issued by the American Psychological Association recommends that evaluation of interventions should involve acceptability alongside evaluation of efficacy [77]. In FMD this is particularly important given the frequent disagreement between patients and treatment providers regarding the diagnosis [78], perceived acceptability of treatments [79] and dissatisfaction with psychological explanations [29]. Outcome domains, measures and methods of evaluating effectiveness in the included studies are summarised in table 7.

[Table 7 around here]

FMS

Although all but one article [53] reported reductions in FMS at the end of the interventions, over half of the studies (n=13), including all case studies and four group studies, did not use any standardised measures to monitor symptoms. These studies created Likert-type scales to

assess changes reported in clinical records or used verbal reports [46,48,50,51,53,55-58,62-65]. The remaining 11 studies utilised the following standardised measures: Psychogenic Movement Disorder Rating Scale (PMDRS) (n=5) [45,47,52,59,61], Clinical Global Impression Scale (CGI) (n=3) [49,54,61], Video Rating Scale for Motor Conversion Symptoms (VRMS) (n=2) [66,67] and Modified Rankin Scale (MRS) (n=1) [60]. Only two of those measures were designed to evaluate FMS – PMDRS [80] and VRMS [81] – though their validity and reliability were only investigated in single studies by their authors. All case studies used verbal self-report and clinician observation. In the group studies only two included patient-rated questionnaires [54,62].

In the 14 group studies, interventions were evaluated mainly using statistical significance of mean changes in groups' scores between admission and end of treatment (n=10) and between treatment groups, where this was part of the design. Only one study calculated and reported treatment effect sizes [67]. Ten studies provided information on the proportion of participants who experienced improvement (see table 7). Only three group studies [45-47] reported the number of participants with worsening of symptoms and one case study reported an emergence of new functional symptoms after therapy ended [50].

Co-morbid physical symptoms

Presence of co-morbid symptoms was reported in 16 studies [46,48-51,53-56,58,60,62,63,65-67] with pain and fatigue being the most common. However, these were mostly not monitored despite their recognised association with worse outcomes in FMD [82,83]. Only five studies measured changes in co-morbid somatic symptoms [50,53,64].

Psychological wellbeing (PW)

18 studies reported co-morbidity of psychological difficulties or psychiatric diagnoses prior

to the interventions, with the most common being depression, anxiety or PTSD.

Nine studies did not monitor outcomes for psychological wellbeing [51,52,54,56,58,60,62,64,65]. Six of these were multidisciplinary inpatient treatments [51,54,58,60,62,65]. Eight group [45-47,49,59,61,66,67] and four case studies [48,50,53,57] used validated standardised measures to monitor symptoms of anxiety, depression, traumatic stress symptoms or used generic measures covering a range of psychosocial difficulties.

Even though the authors of group studies often reported prevalence of co-morbid psychiatric diagnoses, it was unclear what proportion of participants had clinically significant psychological difficulties at the start of the interventions. Only mean scores for the whole groups were reported and analysed. All group studies used statistical significance to evaluate improvement in PW. There was no report of the proportion of participants who had clinically significant changes in PW. Only one study reported proportion of cases with worsening PW [47]. Only two case studies conducted 'reliable change' and 'clinically significant change' analyses to assess the significance of improvements [48,57].

Life impact (LI)

Various aspects of the life impact of symptoms were measured in eight group [45,47,49,54,60,62,66,67] and six case studies [50,51,53,57,58,64]. The authors used observation, occupational therapy records and self-reported description in two case studies [51,58]. The remaining studies employed standardised and validated measures to monitor quality of life and participation. Some of the studies reported global functioning and symptom interference whilst others focused on specific domains, like activities of daily living or achievement of pre-set goals. Employment status was reported in three case studies [50,58,64] and one group study [62].

The eight group studies measuring LI used statistical significance of the change in group means without calculating effect sizes. Only one study reported the proportion of people whose LI was rated as ‘improved’ [60]. In the six case studies measuring LI, two reported only changes in employment status [50,64], one monitored achievement of goals set in therapy regarding daily activities [51], one reported changes in scores without further analysis [53], one reported changes in category/severity of limitations [58] and one used the analysis of reliable change and clinical significance of change [57].

Resource use

The use of health and social resources was generally not measured. One study reported healthcare utilisation [54] and another one receipt of financial benefits after treatment [62]. Both studies analysed statistical significance of the change in group mean.

Acceptability

Acceptability was not explicitly measured by most of the studies. Only two studies surveyed their participants about overall satisfaction with the treatment and the therapists [54,62]. Data on discontinuation and drop-out of treatments was provided by eight out of 14 group studies. Discontinuation rates ranged from 0% to 33% with the median at 30%. Comparing data was difficult due to different designs, recruitment protocols and reporting strategies. For example, one study of PDP included participants who had completed only one session and did not report these as discontinuing treatment [56]. Both studies that clearly reported uptake rate of the intervention after the initial assessment registered it at 50% [45,46]. Rates of accepting a referral for psychological intervention in naturalistic studies were unknown.

Discussion

This scoping review has described how psychological interventions for FMD have been used

and evaluated in research studies over the last 20 years. Twenty-three studies met the inclusion criteria and were examined.

FMD terminology

This review identified a notable shift away from the term 'psychogenic' towards the term 'functional' since 2016. This is in line with the overall trend in the modern FMD literature which shows the term 'functional' is more acceptable to patients [84], is favoured by neurologists, and reflects the multifactorial, biopsychosocial models of FMD [17,24]. However, the term 'conversion' was also relatively common despite its similarities with the 'psychogenic' term. The use of 'conversion' term and theory is still extensive especially in psychiatric and mental health literature [85-88], and is used synonymously with the 'functional' label in the psychiatric diagnostic manual *DSM-5*. This suggests that the traditional debate between different disciplines about the extent to which 'psychological' factors account for the symptoms is still ongoing [88,89]. Reflective of that is the newest version of the *International Classification of Diseases 11th Edition* (*ICD-11*) where FMD feature in neurological categories as 'functional' and in psychiatric categories under 'dissociative' disorders.

Characteristics of the interventions – theoretical considerations

Amongst the 23 included studies, there was a dominance of interventions rooted in the cognitive behavioural tradition (n=17), particularly CBT (n=12). The remaining six studies were made up of PDP (n=3) [45,56,61], hypnosis (n=2) [66,67] and body oriented psychotherapy [53].

Many studies, across all therapeutic modalities, perceived FMS as associated with deficits in overall emotional functioning, such as emotional awareness and regulation or more

specifically with the processing of stressors or adverse life events and hence targeted these processes in their interventions. However, modern complex multifactorial models of FMD posit that many individuals with FMD do not have any identified or relevant premorbid distress, adversity or psychopathology [87,90,91]. Additionally, some authors who used such affect-focussed conceptualisations, noted ‘compliance as a major concern’ [92, p.437] which might suggest problems with the acceptability of such an approach. This is consistent with complaints from the patients themselves [29]. However, a recent review [93] of experimental studies and neuroimaging supports the role of the emotion-motion link in generating and perpetuating FMD through enhanced functional connectivity of the motor-limbic circuits in the brain during preconscious (‘bottom-up’) emotional processing. Limbic hyperactivation, autonomic hyperarousal, altered interoception (sensory detection) of bodily emotional responses and disrupted ‘top-down’ regulation are thought to influence neural circuits involved in awareness and control of lower-level processes such as motor function [93]. The conclusions from neuroimaging studies are uncertain though, mainly due to the use of reverse inference [94] and lack of adjustment for distress and mood, which are likely to obscure the specific effect of FMD [93]. Nevertheless, the current expert consensus acknowledges the importance of emotional processes in FMD expression [1,24,93] but there has been little direct examination of whether or which of the emotional processes need to be targeted in therapy to exert influence on different domains of FMD outcomes. Many studies in this review employed various techniques and therapeutic approaches to target one or a selection of these processes, and all but one claimed some reduction or removal of movement symptoms. However, some studies reported a reduction in FMS without reducing psychological distress (and thus possibly limbic and autonomic arousal) [47,66,67]. This might challenge the utility or necessity of the distress-focused techniques, especially for those people who cannot identify emotional triggers. Further research should examine the relevance

and impact of the specific techniques on FMD outcomes and the motor-limbic brain connectivity.

Some studies placed more emphasis on altered cognitive processes as implicated in generation or maintenance of FMD in line with the neurocognitive models of attentional and agency dysregulation in FMS and supported by electrophysiological studies [24,73,95]. Those studies mainly employed CBT-informed interventions and were mostly concerned with the processes of attending to and appraising of bodily sensations, including FMS, and were less concerned with the person's past or present circumstances unless it directly impacted on their coping with or beliefs about the symptoms. However, despite many similarities in therapeutic approach, the actual targets and techniques varied. When the focus was on pre-cognitive, bottom-up neurological processes, the strategies involved altering behaviours and bodily sensations to influence attention and correct the brain's predictions and evaluations. The top-down strategies aimed to influence the person's illness beliefs and attention through reasoning and education. One case study employed both though indicated that there was no change after the initial top-down approach [50]. Another CBT study quoted common 'resistance' to the promoted explanations about symptoms [46]. This suggests that targeting symptom beliefs might act as barriers to engagement for some patients. However, education is widely regarded as crucial and therapeutic by many authors in the field [96,97] although this was examined in the context of neurological, rather than 'psychological' explanations of FMD. It is unclear which aspects of (psycho)education could be useful and for whom this might help or hinder improvements in symptoms and engagement in therapy. An ACT case study [57], which did not require changing the person's beliefs to achieve change in functioning and quality of life, provides a promising alternative when shared understanding of FMS between patients and practitioners is difficult to establish and which might otherwise exclude a patient from treatment. More research is also needed to explore acceptability and

effectiveness of approaches that do not require challenging patients' beliefs.

Authors of studies that were part of multidisciplinary treatments often quoted broader, more nuanced conceptualisations of FMD, though the techniques employed in their CBT did not differ from the standalone treatments, apart from Lidstone et al.'s study [49]. The authors designed a bespoke integrated multidisciplinary intervention in which CBT was intertwined with neurology and physiotherapy input, affording the authors the unique opportunity to respond to emerging physical and psychological needs session by session, based on individual formulations.

Psychological intervention were also integrated with other disciplines' input in the two behavioural interventions delivered in in-patient rehabilitation settings [51,65]. They involved active guidance and support for the physical therapists and other staff to ensure adherence to the behavioural model. However, one of those studies [65] used the label 'factitious' interchangeably with 'conversion' to describe FMD which implies an association with feigning and voluntary control over symptoms. Such conceptualisation by the authors, who were also clinicians delivering the intervention, might have affected their choice of an ethically dubious intervention, which involved deceit, coercion and aversive, potentially distressing elements as an incentive to discontinue FMD [65]. Additionally, although *DSM-5* and the current literature [98] distinguish functional disorder from factitious disorder, some authors state there is no reliable way of making a differential diagnosis [99]. Other authors endorse the term 'face-saving interventions' to describe treatments for FMD [100] which suggests that the interventions assume some overlap between feigning and functional symptoms. Indeed, the second behavioural study in this review, conducted in 2019, described the intervention as 'a graceful way out' of symptoms [51, p.662]. The conceptualisations of FMD as a learnt behaviour reinforced by secondary gains might be particularly susceptible to

implicit or explicit associations with feigning or manipulation. This is likely to invite negative moral judgements [101] and influence the clinicians' attitude and patients' experience of care [29].

In a qualitative study reporting the experiences of people with FMD, perceptions of being judged by healthcare professionals as feigning were common [29]. However, although some behavioural conceptualisations of FMD might lead to unfounded conclusions and questionable attitudes, behavioural techniques may still be useful and effective in treatment. Indeed, many behavioural techniques or principles were used across other studies in this review without similar ethical issues. Examples of such techniques include using de-coupling of altered movement from its identified cues in hypnosis [66,67] and CBT [50] or desensitisation of feared movements in CBT [64]. The use of positive reinforcement is also used in physiotherapy to re-train normal movement function [102]. Future research should investigate employment of behavioural interventions alongside holistic theoretical frameworks to avoid reductionistic approaches. If a sole behavioural intervention is investigated, acceptability of the procedures should be closely monitored.

This review has highlighted that conceptualisations of FMD in psychological interventions vary between and within different therapy modalities. Whilst many find some support in research examining processes implicated in FMD, their relevance to therapeutic outcomes is unclear. It is also possible that some therapeutic techniques can be acceptable and effective even when particular 'psychological explanations' are rejected by patients. Lastly, the decision of whether a 'psychological explanation' is necessary might become obsolete if practitioners and researchers adopted the language of 'neuro-bio-psycho-social explanations' instead.

Measures and evaluation of interventions

This review indicated the predominant use of snapshot clinician-rated or independently-rated measures for FMD. This presents challenges due to the changeability in symptoms and the discrepancy between subjective and objective experience of FMD symptoms [103]. Adopting more patient-reported measures as potentially more meaningful, has previously been proposed [74]. The lack of medium- or long-term follow-up in most of the included studies presents another challenge, given the often waxing and waning nature of FMD and possibility of new symptoms emerging [3,17,104]. Indeed, one of the case studies reported new functional symptoms five months after resolution of the original symptoms [50]. Additionally, co-morbid symptoms were largely not monitored in the included studies, even though poor long-term prognosis and poor quality of life have been associated with the many co-morbidities in FMD, especially fatigue and pain [25,83,105]. Recent recommendations for treatments by leading professionals and researchers in the field promote interventions tailored to patients' specific movement symptoms and their co-morbidities. This is due to their bidirectional interaction in influencing outcomes and a potential for common underlying mechanisms [17].

Similarly, psychological co-morbidities have been reported as being high in FMD. However, nearly half of the studies did not monitor psychological wellbeing, even when psychopathology was seen as driving FMD [58]. Amongst the studies conducted in in-patient settings, 75% did not monitor PW. This is surprising for various reasons: hospitalisation in itself can be a distressing experience and these participants were likely to have more severe FMD with more impact on PW. In addition many in-patient centres are located far from patients' homes and families depriving them of social support [104], and the potential role of stress on the trajectory of FMD was acknowledged in most studies. In the only study that reported rates of worsening PW, 30% of the participants were affected [47], which suggests a

need for clear reporting and monitoring of the potential detrimental effects of the interventions. The number and outcomes of those who had clinically significant PW symptoms at the start of the intervention were also not reported. In the group studies only statistical significance of changes in the group means were investigated which might lead to important insights being missed if participants varied significantly in their PW at the start. Some authors reported the PW group mean symptomatology as relatively low to begin with, therefore it would not be expected to reduce significantly [66,67]. However another author argued that initial low scores reflect the individual's lack of insight and are likely to worsen during the course of the treatment [50]. More data of the trajectory of PW outcomes during and after psychological treatments for FMD could help understand these processes better and inform treatment delivery.

Quality of life is often reported to remain low despite improvement in movement symptoms [47,54] and yet LI was measured in only half of the group studies. There was a lack of data on the proportion of people whose LI improved and to what extent. It is unclear whether the lack of sufficient improvements in QoL is due to insufficient improvement in movement symptoms or whether direct work on LI is needed to facilitate adaptive adjustments or transitioning from treatment. The measures of LI were varied and incomparable as different aspects were monitored: general quality of life, employment status or performance on specific tasks. Assessing it in a consistent manner could help highlight and address emerging issues as many people continue to experience at least some symptoms after rehabilitation or therapy [54].

The evaluation of the interventions in group studies was mostly undertaken through analyses of statistical significance without calculating effect sizes. Relying on p values and null hypothesis testing has been increasingly criticised in psychological research as

potentially misleading and clinically unhelpful when not informed by theoretical framework and clinical judgement of what constitutes a clinically significant change [106]. Analysis of estimation is promoted instead as more informative, clinically meaningful and less biased [106], especially in the case of small studies which might not detect significant changes due to lack of sufficient statistical power. Calculating the effect sizes would provide important insights into the size of the impact of an intervention which would inform more informed choices when designing and delivering psychological interventions.

Acceptability

The numbers of patients who refuse psychological interventions at the point of referral are unknown. However, the two studies that reported rates of uptake after the initial assessment at only 50% provide preliminary support to clinical observations, reporting them to be low [56]. This review offers a hypothesis, to be further examined, that although the dropout rates seem comparable with those reported in studies of psychological interventions for mental health presentations [107-110], long-term conditions [111] and neurological conditions [46], the rejection of the intervention might be occurring prospectively at the point of referral or assessment. This has been previously noted for people with FMD and other functional symptoms [112,113]. Frequent disagreement with the diagnosis [78] is also likely to impact the uptake of treatment, especially if FMD is explained as entirely attributable to psychological factors [49]. There is sufficient initial evidence of barriers to acceptability of psychological interventions to warrant closer investigation. Acceptability and social validity of an intervention is thought crucial to its effectiveness and feasibility [114,115] and thus systematic research and measurement could help identify implementation barriers [116]. Prospective (anticipated), concurrent (during the intervention) and retrospective assessments of acceptability should be employed [117]. This could be achieved by questioning the

participants about whether the treatment goals (e.g. targeting assumed underlying emotional processing dysfunction, improving quality of life whilst living with FMD), procedures (techniques) and outcomes (the size of change in an important aspect of life) are acceptable, relevant and meaningful to the participants [114]. This information should then be used to design, improve and evaluate further interventions [116].

Development of a stakeholders' consensus competence framework for psychological interventions in FMD would help guide clinicians in the changing landscape of emerging insights into functional disorders and their implications for psychological practice. In addition, changing the question from increasing patients' acceptance of 'psychological explanations' to improving the acceptability of the interventions to patients might help shift the focus towards collaborative care and enhanced engagement.

Limitations, strengths and implications for practice

This scoping review included only studies written in English from a few western countries. The qualitative data was limited and relied on the authors' selective reporting of particular therapeutic techniques and understanding of FMD. Some psychological interventions constituted part of multidisciplinary treatments and it was impossible to establish whether they used the same or different formulations of symptoms. Similarly, in reports of retrospective studies it is difficult to state whether the descriptions reflected the actual interventions or general ideas about the therapeutic models. Not including grey literature introduces publication bias and is likely to have excluded some of the approaches practised in clinical settings. Additionally, the literature search, data extraction and analysis were conducted by one researcher only. This introduces risk of inadvertent omissions of relevant studies or data within them. Where sections of text were summarised/interpreted this also increased the risk of bias and independent checks by other researchers would have enhanced

reliability of the findings. However, this review is the first study to summarise the research in this area in a systematic way, covering conceptual underpinnings as well as methodological and clinical aspects of evaluation of psychological interventions for FMD.

Although as a scoping study it has limited ability to make clinical recommendations, it points to important issues of acceptability of psychological interventions and a wide range of available and changing conceptualisations of FMD. A revision of the emphasis on any single 'psychological explanation' of FMD is needed, and knowledge of wider biopsychosocial frameworks should be promoted to reflect the diversity and lack of certainty in this field. There is a role for psychological practitioners to promote multidisciplinary working where possible. Where psychological interventions are offered as standalone treatments, their breadth and variety affords the opportunity to match them with particular needs of the patient. It should be guided by a collaborative formulation whereby the understanding of symptoms, therapeutic techniques and priorities take into account the person's unique circumstances and preferences as well as being based on recent developments in the field.

Conclusions

This scoping review has found that FMD is conceptualised differently across different psychological interventions which then employ different therapeutic techniques to achieve different goals. Whilst standalone psychological interventions are not able to target the multiple bio-psychosocial factors involved in FMD, they offer a variety of therapeutic tools that could be matched with the patients' individual needs, circumstances, preferences and goals. However, more research is needed to examine specific therapeutic techniques, and to develop interventions embedded in contemporary frameworks. The acceptability of psychological interventions has not been systematically examined though the preliminary

data suggests low uptake. Research studies are needed to explore acceptability of particular techniques, treatment goals and theoretical assumptions to build up evidence for socially valid and feasible interventions. A variety of psychosocial and physical domains need to be measured to capture relevant outcomes affected by the syndromic nature of FMD. Analysis of effect sizes and clinically significant change is required to conduct meaningful evaluation and comparison between different interventions.

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Table 1. Subject headings used in database searches, where available

Concept	MESH Terms/subject headings/thesaurus searches
Psychological intervention	Psychotherapy, counselling.
FMD	Conversion disorder, hysteria, movement disorder, functional disease, motor dysfunction.

Table 2. Free text search strategy used in database searches

Combined with 'OR':		Combined with 'OR':		Combined with 'OR':
Intervention Therapy Psychotherapy Treatment Hypnosis Hypnotherapy Counselling	AND	Functional Non organic Psychogenic Somatoform Conversion Hysteria	AND	Movement Motor Weakness Paralysis Tremor Spasm Dystonia Myoclonus Parkinsonism Gait

Table 3. Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
(1) Published in peer reviewed journals in English from 2000 onwards. (2) Reported application and evaluation of a psychological intervention in the treatment of people aged 18 and over; including multidisciplinary or combined approaches with an active psychology input, e.g. psychoeducation, psychotherapy or consultation. (3) Participants given diagnosis of FMD, including different diagnostic terms such as FND, FNSD, conversion symptoms/disorder, psychogenic symptoms/disorder, or hysteria. (4) FMD was the main concern and a target of treatment. (5) Symptoms consisted of altered main movement function, such as: spasms, tremor, paralysis, limb weakness, dystonia, or gait disturbance.	(6) Opinion, theoretical paper or clinical guidelines. (7) Treatments without an active psychological intervention or where the intervention was not described or evaluated, only mentioned. (8) Psychological intervention not part of the study, e.g. a referral made to an external source. (9) Symptoms reported to be a 'functional overlay' in an organic disorder. (10) A comorbid condition was the primary target for treatment.

Table 4. Data extraction categories

Main categories	Sub-categories				
Study	Year of publication Country				
Sample	Number of participants Diagnosis FMD symptoms Comorbidity				
Methodology	Design Comparison group Follow-up				
Intervention	Setting: • Inpatient or outpatient • Service: psychiatry, neurology, rehabilitation, community MH • Standalone or multidisciplinary	Type, duration and frequency of intervention: • Psychotherapy • Consultation • Psychoeducation • Individual or group • Direct or indirect	Theoretical conceptual isation of FMD	Therapeutic modality and therapeutic techniques used	Target of the intervention: • Physical symptoms • Underlying processes • Maintaining factors • Consequences of symptoms
Outcomes	Domain measured: • Movement symptoms • Comorbid symptoms • Psychological wellbeing • Life impact • Resource utilisation • Acceptability		Outcome reporting: • Outcome measures • How effectiveness reported: statistical significance, clinical significance or other		

Table 5. Overview of the included studies

Author, year	Sample size; Country	Design	Diagnosis and symptoms, duration, comorbidities
Baslet, G. et al. 2011 [63]	1 USA	A case report	**Conversion disorder**: left sided paralysis, bilateral tremor. Comorbidity: PNES, dissociative amnesia, depression, anxiety, headaches, fibromyalgia. Duration: 8 weeks.
Dalocchio, C. et al. 2016 [59]	21 Italy/UK	A pilot, single-blinded randomised study	**Functional movement disorder (conversion disorder**), mostly tremor (75%). Comorbidity: not reported. Duration: mean 1.5 years.
Espay, A.J. et al. 2019 [52]	15 USA/ Canada	A prospective cohort study	**Functional tremor**; Comorbidity - depression (5/15, 33%); PTSD (4/15, 26%); excluded from the study if had any other comorbid FND. Duration: 2.3 ± 1.6 (range, 1–4) years.
Graham, C.D. et al. 2017 [57]	1 UK	A case study	**Functional propriospinal myoclonus** – limb weakness and pelvic spasms Comorbidity: low mood, sleep dysfunction; no other health complaints. Duration: 12 months.

Gros, D.F. et al. 2018 [55]	1 USA	A case report	**Psychogenic movement disorder PMD**: neck and hand tremor; freezing movements - cataplexy-type state. Comorbidity: speech disruption, neck pain, OCD, personality disorder, major depressive disorder. Duration: not reported.
Hardin, A.S. et al. 2019 [51]	1 USA/ Canada	A case report	**FNSD-based cataplexia** and **paralysis** symptoms. Comorbidity: mast cell activation disease, gastroparesis with possible irritable bowel syndrome, autonomic nervous system dysfunction, sleep apnoea and attention deficits. Duration: not reported.
Hinson, V.K. et al. 2006 [45]	9 USA	A single-blind clinical trial	**Psychogenic movement disorder (conversion disorder)**: tremor, myoclonus, dystonia, bradykinesia (slowness of movement), tics, gait disorders. Comorbidities: major depressive disorder (n=5, 55%), PTSD (n=2, 22%), personality disorder (n=2, 22%), anxiety disorder (n=1, 11%) and bipolar disorder (n=1, 11%). Duration: ranged from less than 8 months (n=8, 88.9%) to 78 months (n=1, 11.1%).
Jacob, A.E. et al. 2018 [54]	32 USA	A retrospective follow-up study	**Functional movement disorder**: abnormal gait (31.2%), hyperkinetic movements - tremor, chorea or myoclonus (31.2%), dystonia (31.2%), weakness 6.3%. Comorbidity: depression (81.3%) and anxiety (62.5%), PTSD 35.5%; 84.4% - comorbid physical health conditions. Duration: mean 7.4 (+-10.8) years
Kompoliti, K. et al. 2014 [61]	15 USA	A randomised clinical trial	**Psychogenic movement disorder**: conversion disorder (n=8), somatoform disorder (n=5), and somatization disorder (n=2). symptoms: (n=6, 40%) tremor, (n=5, 33.3%) myoclonus, (n=1, 6.6%) dystonia, (n=7, 46.6%) gait impairment. Comorbidity: depression (n=9, 60%), depression with anxiety (n=3, 20%), PTSD (n=5, 33.3%). Duration: 63.2 ± 73 months.
Krupnik, V. et al. 2019 [50]	1 USA	A case study	**Motor conversion disorder:** 'freezing' - inability to move; tics. Comorbidity: PTSD, chronic neck pain, convulsions. Duration: unclear.
LaFrance, W.C. et al. 2009 [64]	1 USA	A case report	**Psychogenic movement disorder:** dystonia. Duration: 5 years.
Lidstone, S.C. et al. 2019 [49]	11 Canada	A prospective cohort study	**Functional movement disorder**: gait disorder and episodic movement symptoms. Comorbidity: 100% pain and fatigue; pre-morbid anxiety and depression (36%) Duration: mean 6.2 ± 7.0 years
McCormack, R. et al. 2014 [60]	33 UK	A retrospective comparative study	**Severe chronic motor conversion disorder**: loss of motor function (n=29, 87.9%), abnormal motor function (e.g., tremor, dystonia, ataxia) (n=4, 12.1%). Comorbidity: non-epileptic dissociative features (n=18, 55%); A non-dissociative psychiatric co-morbidity (n=20, 60.6%): somatoform pain disorder (n=7, 21.2%); somatisation disorder (n=6, 18.1%); Neurological co-morbidity (n=6, 18.2%): epilepsy (n=2; 6%) a neurological disorder (n=6, 18.1%), neurogenic bladder (n=2; 6%), MS (n=1, 3%). Duration: median 48 months; mean not reported.
Moene, F.C. et al. 2002 [67]	45 The Netherlands	A randomised controlled clinical trial	**Conversion disorder, motor type, or somatization disorder with motor conversion symptoms**: paralysis or paresis (n=38, 86.4%), gait disorder (n=25, 56.8%), coordination problems (n=19, 43.2%), tremors (n=7, 15.9%), spasms (n=8, 18.2%), myoclonus (n=7, 15.9%). Comorbidity: other functional symptoms or pain (n=37, 84.1%);

			psychiatric Axis I diagnosis in 33.3%. Duration: mean 3.9 years with a range of 2 months to 22 years (SD 4.5 months).
Moene, F.C. et al. 2003 [66]	44 The Netherlands	A randomised controlled clinical trial	**Conversion disorder, motor type, or somatization disorder with motor conversion symptoms**: paralysis or paresis (n=22, 50%), gait disorder (n=3, 6.8%), coordination problems (n=16, 36.3%), tremors (n=10, 22.7%), spasms (n=7, 15.9%), myoclonus (n=6, 13.6%). Comorbidity: other functional symptoms, pain; psychiatric Axis I diagnosis in 29.7%. Duration: mean 3.7 years with a range of 2 months to 16.7 years (SD=4.7 months).
O'Connell, N. et al. 2020 [46]	174 UK	A retrospective comparative study	**Conversion disorder** or **functional motor or movement symptoms** without formal diagnosis: weakness, tremor, shakes, jerking, dystonia. Comorbidity: - other functional disorders (headaches, fibromyalgia, CFS, IBS) - 38.8%. - a current physical health condition in 79.2%. Duration: mean 9.9 ±9.6 years.
Papadopoulus, N.L.R. et al. 2018 [53]	1 UK	A retrospective case study	**Conversion disorder**: Paralysis of the arm. Comorbidity: somatoform pain disorder in the leg and back; insomnia and depression. Duration: 2 years.
Rancourt, D. et al. 2019 [48]	1 USA	A case report	**Conversion disorder (FNSD) with motor dysfunction**: bilateral paralysis of legs. Comorbidity: PTSD and depression; chronic pain, migraines. Duration: 2 months.
Saifee, T.A. et al. 2012 [62]	26 UK	A retrospective follow-up study	**Functional motor symptoms (FMS)**: dystonia, jerks, tremor, weakness, paralysis. Comorbidity: fatigue, headaches, pain, sleep disturbance, dizziness, gastrointestinal problems, seizures, anxiety, low mood. Duration: most patients (63%) had symptoms for more than 3 years.
Shapiro, A.P. et al. 2004 [65]	39 Canada	A repeated case series, cross-over design	**Non-organic (conversion/factitious) motor disorders**: paralysis or paresis, astasia basia (unsteady gait with lack of coordination) and/or ataxic-like symptoms, leg shaking, tremors. Comorbidities: pain (33% in the acute and 70% in the chronic group), bladder/bowel dysfunction (0% in the acute and 27% in chronic group), other functional symptoms (11% in the acute and 60% in the chronic group). Duration: acute (2 months or less) or chronic (more than 6 months).
Sharma, C.D. et al. 2017 [56]	30 USA	A retrospective study	**Functional movement disorder**: shaking/jerky movements (50%) and tremor (43%). Comorbidity: 13/30 (46%) depression or anxiety, 1 (3%) bipolar disorder, 3 (10%) fibromyalgia or/and IBS. Duration: mean 3.2 years (range 2 months to 17 years).
Vizcarra, J.A. et al. 2019 [47]	13 USA	A pilot randomised clinical trial	**Functional dystonia** Comorbidity**:** - functional tremor (n=4, 30%), depression (n=5, 38.4%), anxiety (n=4, 30.4%), panic disorder with or without agoraphobia (n=3, 23.07%), obsessive-compulsive disorder (n=2, 5.36%). Duration: mean: 4.4 ± 3.4 years in Placebo + Cognitive Behavioural Therapy (CBT) and 2.1 ± 3.5 years in BoNT + CBT.
Yam, A. et al. 2016 [58]	1 USA	A case study	**Functional neurological symptom (conversion) disorder (FNSD):** mixed symptoms, including motor dysfunction: gait disturbance - left-leg drag, difficulties with balance and fine motor dexterity. Comorbidity: anxiety and depression; other FND symptoms: speech disturbance and impaired cognition; pain, headaches, insomnia. Duration: 5 months.

Table 6. Characteristics of the psychological interventions delivered as standalone or multidisciplinary treatments

Author, year	Intervention type, setting and duration	Conceptualisation of symptoms	Therapeutic tools and targets
Standalone psychological intervention			
Baslet, G. et al. 2011 [63]	Inpatient psychiatric ward. 3 psychoeducational ACT based and Morita therapy group sessions and 2 individual sessions.	Avoidance tendencies and difficulties in verbal expression of affect contribute to the development of symptoms and are a way of coping with difficult affect.	In group sessions: - Defining primary values and actions that would be consistent with their life goals; - Mindfulness meditation; - Psychoeducation facilitating a shift in perceiving - 'reperceiving'; - Facilitating acceptance instead of avoidance and alexithymia as a strategy to cope with aversive internal experiences; - Psychoeducation about uncontrollability of thoughts, feelings, and body sensations, and controllability of actions. In individual sessions: - Projective cross-sectional house drawings of family of origin and current family; - Journaling as a way of shifting focus to a productive activity and connecting to emotional experience.
Dalocchio, C. et al. 2016 [59]	Outpatient CBT: 60 or 90 min sessions/week for 12 weeks.	Not described.	CBT protocol adapted from Goldstein et al's manual in CBT study for NES [69]: - Identifying **somatic misinterpretations**, negative thoughts, and **illness beliefs** maintaining FMD and low mood or anxiety; - Establishing alternative hypotheses for the bodily sensations; - **Distraction** techniques were developed; - **Motor strategies** were implemented (for instance tapping at a certain frequency with a non-tremulous body region) to be used to reduce/interrupt the specific FMD; - Planning and review of homework, which included completing records about FMD**, avoiding behaviours, problem solving**.
Espay, A.J. et al. 2019 [52]	Outpatient clinic. CBT using cognitive elements from the model	Symptoms associated with alterations in activity in several brain regions, including the anterior cingulate/paracingulate cortex - thought to be activated in emotional processing and theory of mind; symptom	CBT protocol adapted from LaFrance et al's manual in CBT study for NES [72]

	for PNES - weekly for 12 weeks.	associated with increased activity of the brain regions during (subliminal) emotion processing.	- **Examining and managing automatic thoughts** and cognitive **distortions** emerging during symptom exacerbation: Socratic questioning, thought monitoring, thought restructuring; - Education on relapse prevention – managing re-emergence of symptoms.
Graham, C.D. et al. 2017 [57]	Clinical neuropsychology outpatient service. Acceptance and Commitment Therapy (ACT) - 6 sessions.	Symptoms pathogenesis complex and ambiguous; Altered attentional processes often implicated and thus treatments altering symptom-focused attention indirectly might be useful for reducing symptoms interference.	ACT techniques aimed at increasing psychological flexibility and orienting the person towards meaningful activity (rather than targeting FMD symptoms): - Relational framing (- Defusion - Mindfulness; Perspective taking; - Exploring values to underpin committed action; - Altering symptom-focussed attention indirectly by focusing on meaningful goals
Gros, D.F. et al. 2018 [55]	Outpatient veteran medical centre. CBT for OCD: exposure and response prevention – 1hr/week for 4 weeks.	Symptoms result from psychiatric, rather than organic, neurologic disturbance. FMD symptoms as compulsions (e.g slowed movements) developed to reduce anxious thoughts resulting from past injuries and disability.	CBT for OCD: exposure and response prevention (ERP) [118] - Repeatedly **exposing the patient to feared movements** - while preventing the use of unhelpful coping strategies (slowing movements, self-talk, hesitancy).
Hinson, V.K. et al. 2006 [45]	Outpatient movement disorder clinic. 12 weeks of 1 h/week individual brief Psychodynamic Psychotherapy (PDP).	Not described.	Psychotherapy aimed at treating identified psychiatric diagnoses: - Exploration of historical and early life experiences, parenting dynamics, enduring personality traits; - Identifying links between these and current life experiences and problematic emotions and behaviours to reshape the intrapsychic structure of the patient.
Kompoliti, K. et al. 2014 [61]	Outpatient Movement Disorder Clinic. Short term psychodynamic psychotherapy (PDP)- hourly sessions every week for 12 weeks.	Symptoms result from an underlying psychiatric illness or are representing unconscious conflicts, unidentified emotions and can be linked to historical and early life experiences.	- Exploring historical and early life experiences, parenting dynamics, enduring personality traits, as well as the links between these and current life experiences, problematic emotions and behaviours; - Developing insight into unconscious phenomena or addressing alexithymia with the goal of making unconscious phenomena conscious and working through underlying conflicts.

Krupnik, V. et al. 2019 [50]	Outpatient treatment. An integrative CBT-informed approach based on Bayesian model of predictive coding.	Symptoms are a result of **dysfunctional predictive coding** - hyper-precise prior beliefs (priors). Priors can be conscious or unconscious from perceptive to cognitive. The prior beliefs about causes of sensory information acquire an abnormally high value and may cause its failure to be appropriately updated and corrected by prediction errors. Instead, the brain will then 'fulfil' the belief by generating a corresponding abnormal sensation or movement, or lack thereof in case of a negative symptom. These abnormal sensations/movements are perceived as involuntary and eliminate the prediction error. Thought to stem from excessive somatically directed attention. An injury or a random sensation may capture attention and then be reinforced into a belief/prior. Symptoms can be traced back to a 'somatic' triggering event and do not need to have a 'symbolic' meaning.	Strategic modification of priors via: 1. Strategic symptom displacement (targeting prior beliefs at the level of symptoms - from the bottom-up, on a pre-cognitive level. Practicing an alternative motor behaviour in situations of anticipated triggers and generating a strong enough prediction error to affect and correct the target priors. 2. A top-down cognitive processing - Cognitive-educational component through insight about the nature of symptom and its links with triggers, and cognitive-experiential component testing the mind's impact on the motor symptoms, strengthening the prediction error.
LaFrance, W.C. et al. 2009 [64]	Outpatient individual 12 weekly sessions of CBT.	Not described.	Modified from a CBT-informed manual for nonepileptic seizures (NES) [70,71]: - Monitoring and **taking control of movements**; - Training in **healthy communication**; - Understanding medications; - **Functional behavioural analysis** and examining **triggers**; - Addressing **mood-cognition-environment** connections, automatic thoughts (ingrained core thoughts about oneself), and **somatic misinterpretations.**
Moene, F.C. et al. 2003 [66]	Psychiatric outpatient clinic. Hypnosis - manualised - 10 weekly sessions and preceded by a preparatory educational session.	Symptom as an expression of a psychological need or conflict.	Hypnotic techniques manualised for different movement symptoms: 1. Symptom oriented: - Direct and indirect suggestions designed to alter cue-conditionings relevant to the specific motor symptoms; - Emphasizing and praising every occurrence of small (spontaneous) movements. 2. Expression and insight oriented: - Age regression to explore the perceived cause of the symptom or the distressing experiences that apparently initiated the symptom;

			- Expression of the “pent-up" or dissociated emotions encouraged (when the history suggested that a distinct psychological stressor was related to the onset or exacerbation of the symptom); - Learning self-hypnosis to practice symptom-oriented techniques 1/day for 30 minutes.
O’Connell, N. et al. 2020 [46]	Outpatient neuropsychiatry clinic. CBT individual therapy, weekly, 2-15 weeks.	Symptoms explained by an information-processing account that involves: **attentional processes**, **attribution errors**, and **behavioural avoidance**. It acknowledges the temporal relationships between **symptoms and stress**, mood, anxiety, **or dissociation**.	- Psychoeducation; - **Challenging 'cognitive distortions'** that affect motivation, attempting to ‘**build insight** so that patients may **learn to accept a psychological understanding of symptoms’**; - Mood and thought diaries; - Relaxation and graded exposure to **reduce behavioural avoidances**; - **Symptom re-attribution**.
Papadopoulus, N.L.R. et al. 2018 [53]	Outpatient mental health service. Body oriented psychological therapy - 50 weekly sessions over 1.5 years.	The symptom as a somatic expression of the body's symbolic response to precipitating traumatic life events: being numbed, paralysed and impotent. Stuckness in a habitual fear based, inappropriate survival response.	- Physical movement and exploring bodily sensations in the context of simple warm-up exercises; - Deep abdominal breathing and releasing of tension in the voice box and throat; - Props (balls, beanbags) utilized to experience the body in a positive way; - Grounding exercises and movement patterns that support a sense of strength, (physical) boundary setting and self-defence.
Rancourt, D. et al. 2019 [48]	Primary care mental health clinic for veterans. DBT informed psychotherapy – 25 sessions over 8 months.	Symptoms as a function of emotion dysregulation; a maladaptive coping strategy that occurs in response to a stressor in an attempt to get an emotional need met.	- Teaching distress tolerance and emotion regulation skills: self-soothing, radical acceptance, emotional awareness training, taking opposite action; - Problem-solving skills; - Interpersonal effectiveness skills; - Identifying values; - Increasing social support.
Sharma, C.D. et al. 2017 [56]	Outpatient movement disorder clinic. Psychodynamic Psychotherapy (PDP) - Mean number of sessions 4.9 (range 1 to 21).	Symptoms fuelled by unconscious conflicts and unresolved past trauma. The physical symptom is a way of avoiding the painful awareness of the trauma or/and conflict.	- Exploring early life experiences in the family home of origin to identify possible relationship between past experiences and current problems; - Developing new thought patterns and coping strategies that would reduce symptoms.

Vizcarra, J.A. et al. 2019 [47]	Outpatient movement disorder clinic. CBT weekly sessions – 12 or less if FMD remitted.	Not described.	Not described.
Psychological intervention as a part of multidisciplinary treatments			
Hardin, A.S. et al. 2019 [51]	Inpatient rehabilitation (IR) unit – 22 days. A multidisciplinary approach guided by operant behavioural model. Individual sessions, cotreatment sessions and consultation to other staff to maximize adherence to the model.	Treatment as providing 'a graceful way out' of symptoms which are seen as non-functional behaviours.	Co-treatment and consultation: - Reinforcing functional behaviours while ignoring non-functional behaviours; - Decisive language used to promote the expectation of functionality and expectation of return to full premorbid functioning; - Building self-efficacy for physical capabilities. Individual intervention: - Psychological skill building; - Stress management training; - Couples counselling; - Education on CBT; - Interpersonal effectiveness training; - DBT based coping skills training; - Engendering a biopsychosocial perspective on wellness; - Minimizing excessive focus on physical symptoms.
Jacob, A.E. et al. 2018 [54]	Inpatient multidisciplinary rehabilitation program. CBT 1hr/day for 5 days of the inpatient stay.	. Symptoms are the result of abnormal motor control thought to be caused by psychological factors, However, presence of stress and psychopathology often absent and insufficient to explain symptoms.	Using treatment manual for FND [119]: - Identifying factors that may trigger symptoms; - Recognizing and improving unhelpful thought and behavioural patterns; - Mental imagery training.
Lidstone, S.C. et al. 2019 [49]	Outpatient movement disorders clinic. Biweekly 6 session integrated therapy (45min)	Symptoms as a maladaptive integration of "psychological" and "physical" brain functions, such as motor–limbic communication, sensorimotor integration and agency, symptom-related beliefs and expectations, self-directed attention, conditioning, autonomic and neuroendocrine changes and others.	- Desensitization and uncoupling of sensory triggers from motor symptoms; - Targeting fear of symptoms; - Attentional redirection exercises;

	simultaneously delivered by three professionals CBT - informed.	Psychiatric comorbidities and psychosocial stressors considered as perpetuating rather than causal factors.	- Integrated body-focused work (e.g. implementing dance and previously well practised motor programmes) to address some psychological difficulties, e.g. anxiety, lack of confidence or agency.
McCormack, R. et al. 2014 [60]	Inpatient neuropsychiatry unit. Multidisciplinary specialist treatment including offer of CBT (84.9% accepted), time-limited but tailored to the individual. The median length of stay was 101 days (IQR 84–130).	Symptoms' link with possible environmental and psychological aspects are explored in terms of their predisposition, precipitating and maintaining role. Links between past experiences and development of symptoms are considered but not essential for progress in therapy.	- Challenging cognitive distortions that might affect a patient's motivation, determination or ability to engage; - Build insight into a more psychological understanding of symptoms; - Shifting the locus of control from external to internal by fostering insight and assertiveness; - If important - discovering links between past or present experience and physical symptoms (not essential); - Mood and thought diaries (to link moods and thoughts with environmental exposures); - Relaxation techniques; - Graded exposure (if avoidance is employed as a coping strategy); - Neuropsychological testing if needed.
Moene, F.C. et al. 2002 [67]	Inpatient psychiatric hospital - multidisciplinary treatment team (a nurse, a group therapist, a creative therapy therapist, a sports therapist and a physiotherapist). Group psychotherapy and psychoeducation, skills training. Experimental group - additional hypnosis (8 weekly sessions of 1 h, preceded by a preparatory educational session).	Symptom as an expression of a psychological need or conflict.	Group psychotherapy and skills training: - Cognitive and behavioural techniques to increase problem-solving skills; - Social skills training; - Facilitating recognition of the relationship between the symptoms and existing problem areas. Hypnotic techniques manualised for different movement symptoms using operant and cue conditioning: 1. Symptom oriented: - Direct and indirect suggestions designed to alter cue-conditionings relevant to the specific motor symptoms; - Emphasizing and praising every occurrence of small (spontaneous) movements. 2. Expression and insight oriented: - Age regression to explore the perceived cause of the symptom or the distressing experiences that apparently initiated the symptom; - Expression of the "pent-up" or dissociated emotions encouraged (when the history suggested that a distinct psychological stressor was related to the onset or exacerbation of the symptom); - Learning self-hypnosis to practice symptom-oriented techniques 1/day for 30 minutes.

Saifee, T.A. et al. 2012 [62]	Neuropsychiatry ward - 4 weeks admission. Inpatient multidisciplinary programme. CBT.	Movements are volitionally generated yet abnormally perceived; cognitive/psychological factors are important in the way symptoms are produced. Symptoms are reversible via rehabilitation.	- Developing coping strategies - Changing illness beliefs, - The treatment does not, unless individually relevant, seek to reattribute symptoms to underlying psychological or emotional trauma.
Shapiro, A.P. et al. 2004 [65]	Inpatient rehabilitation ward on a neurology unit. Standard and strategic behavioural intervention guiding physiotherapy and other staff. Individual counselling offered.	Symptoms represent maladaptive behavioural responses to stress that are maintained by positive support from others and successful avoidance (via disability) of stressful life situations.	<u>Standard behavioural treatment</u> - Indirect: staff to praise successful performance and to encourage patients to try again if they failed to achieve a desired goal in therapy. <u>Strategic-behavioural treatment</u>: 'masking' instructions to patients and their families about the recovery: - That full recovery constituted proof of physical aetiology and failure to recover evidenced psychiatric aetiology; - That if symptoms were physical, the progress would be rapid and recovery complete. If conversion disorder, they would not fully recover because of an 'unconscious need to remain disabled'; - That if they sought pre-mature discharge from treatment that would be proof of psychiatric cause; - The use of 'deep rest' when patients failed to meet therapy goals – withdrawal of activities, visits and rewards- removed from the protocol as after first 3 patients; - If no improvements - minor inconsequential changes were introduced to physiotherapy; - Use of family conferencing to convey the notions of recovery - to 'overcome resistance' and create pressure and expectation from the family.

Yam, A. et al. 2016 [58]	Inpatient rehabilitation setting: coordinated interdisciplinary approach - 18 weeks. Individual rehabilitation psychology sessions 3/week, rooted in CBT and ACT; ongoing consultation and support for staff from other disciplines.	Symptoms as manifestations of anxiety, stress and depression.	1. Individual therapy: a) Explanation of symptoms, including reference to "stress" as a probable cause; b) Relaxation training, including controlled breathing and autogenic muscle relaxation; c) Promotion of mindfulness and cognitive defusion/de-literalization via written thought monitoring and labelling of emotions and thought logs; d) Writing therapy; e) Examination of core values as guides for committed action; f) Establishment of a fear hierarchy to guide exposure-based treatment for social anxiety. 2. Consultation to other therapists: a) Educating staff and instructing other therapists in incorporating behavioural strategies (differential reinforcement and planned ignoring, expectation of positive outcomes); b) Support and encouragement for staff.

Table 7. Outcome measures and methods of evaluating the interventions by study design

Study design and N	Outcome measures by outcome domain	How change/effectiveness was evaluated/reported
GROUP STUDIES		
Dalocchio et al. 2016 [59] N=21 A pilot, single-blinded randomised study. CBT versus standard care.	**FMS** PMDRS rated by a blinded rater. **CS** PHQ-15 **PW** HAM-D, BAI, PHQ-9	Statistical significance of mean group change in scores, within and between groups. Statistical significance of mean group change in scores, within and between groups. Statistical significance of mean group change in scores, within and between groups.
Espay et al. 2019 [52] N=15 A prospective cohort study. CBT	**FMS** PMDRS tremor score rated by a blinded clinician. 4T MRI -functional and anatomic brain images.	Statistical significance of mean group change in scores. Proportion of patients with 'complete' and 'near-complete' (>75% reduction in score) resolution of tremor. Changes in levels of activation of anterior cingulate/paracingulate brain area during emotion processing.
Hinson et al. 2006 [45] N=9 A single-blind clinical trial of PDP.	**FMS** PMDRS rated by blinded raters. **PW** HAM-D, BAI MMPI-2 **LI** GAF	Statistical significance of mean group change in scores. Proportion of participants whose scores reduced >50% or worsened. Statistical significance of mean group change in scores. Number of patients whose profiles 'suggested decreased psychopathology'. Statistical significance of mean group change in scores.
Jacob et al. 2018 [54] N=32 A retrospective follow-up study. Multidisciplinary treatment with CBT.	**FMS** CGI- self report. PMDRS A self-report 7-point Likert scale of symptom severity. Clinical record of ambulatory status. **LI** HRQoL, SDS **RU** Self-reported physician visits and emergency department visits.	Proportion of participants who rated themselves as 'much' or 'very improved at discharge and at follow-up. Statistical significance of mean group change in scores. Percentage of improvement in mean group scores. Statistical significance of mean group change in scores. A change in number of people mobilising independently, using a cane, a walker or a wheelchair. Statistical significance of mean group change in scores. Statistical significance of mean group change in scores.
Kompoliti et al. 2014 [61] N=15	**FMS** PMDRS rated by blinded raters, CGI	Statistical significance of mean group change in scores, within and between groups.

Study design and N	Outcome measures by outcome domain	How change/effectiveness was evaluated/reported
RCT, cross-over design. PDP vs standard care.	**PW** HAM-D, BAI MMPI-2	Statistical significance of mean group change in scores, within and between groups. Statistical significance of mean group change of severity rating within and between groups. Numbers of 'improved', 'unchanged' or 'worse' cases.
Lidstone et al. 2019 [49] N=11 A prospective, cohort study. Integrated multidisciplinary with CBT	**FMS** CGI **PW** BDI, STAI **LI** Neuro Qol	Proportion of people who were rated by clinicians as 'very much improved' or 'much improved. Statistical significance of mean group change in scores. Statistical significance of change in mean of a subgroup of those whose FMS improved. Statistical significance of mean group change in scores.
McCormack et al. 2014 [60] N=33 A retrospective study. Multidisciplinary with CBT.	**FMS** MRS score assigned by authors at admission and discharge by reviewing clinical records. Mobility ranked on ordinal scales agreed by the authors by reviewing clinical records. Use of mobility aids. **LI** ADL ranked on ordinal scales agreed by the authors by reviewing clinical records.	Proportion of people who were assessed by authors as 'improved' in MRS score. Statistical significance of the change in mean group score. Proportion of people who were assessed by authors as 'improved' in mobility score. Statistical significance of the change in mobility. Change in the proportion of people mobilising unaided or with a stick/crutches and those who are wheelchair dependent. Statistical significance of the change in proportion of people using mobility aids. Proportion of people who were assessed by authors as 'improved' in ADL score. Statistical significance of the change in proportion of people being independent with ADL.
Moene et al. 2003 [66] N=44 A randomised controlled clinical trial. Hypnosis versus waiting list group.	**FMS** VRMC rated by blinded raters using video recordings or frequency of symptoms. **PW** SCL-90 **LI** ICIDH	Statistical significance of the change in group mean score within and between the groups. Proportion of patients rated by independent raters as 'improved'. Statistical significance of the change in group mean score within and between the groups. Statistical significance of the change in group mean score within and between the groups.
Moene et al. 2002 [67] N=45 A randomised controlled clinical trial.	**FMS** VRMC rated by blinded raters using video recordings or frequency of symptoms recorded by patients and clinicians.	Statistical significance of the change in group mean score within and between the groups. Effect size of the mean change in scores. Proportion of patients who were 'substantially' to 'very much' improved.

Study design and N	Outcome measures by outcome domain	How change/effectiveness was evaluated/reported
Multidisciplinary treatment versus multidisciplinary treatment with hypnosis.	**PW** SCL-90 **LI** ICIDH	Statistical significance of the change in group mean score within and between the groups. Statistical significance of the change in group mean score within and between the groups.
O'Connell et al. 2020 [46] N=174 Retrospective comparative study. CBT for FMD vs CBT for organic neurological problems.	**FMS** A 3-point scale created to represent improvement: allocation based on reviewing notes and discharge letters. **PW** CORE-OM, HoNOS-ABI, PHQ-9	Proportion of people allocated to each category: 'improved', 'remained the same', or 'got worse'. Statistical significance of the change in group mean score. Changes in descriptive category of the group mean, e.g. 'clinically moderate' to 'clinically low'.
Saifee et al. 2012 [62] N=26 A retrospective follow-up study. Multidisciplinary with CBT.	**FMS** Retrospective self-report Likert scale evaluating perceived change from admission to discharge. **LI** WSAS Employment status. **RU** Self-report of receipt of health-related financial benefits.	Proportion of people who considered their symptoms 'improved to some extent', 'not changed' or 'worsened a lot'. Statistical significance of the change in proportion of participants in each category at admission, discharge and follow-up. Statistical significance of the change in group mean score. Statistical significance of the change between admission and follow-up. Statistical significance of the change between admission and follow-up. Statistical significance of the correlation between improvement and receipt of benefits.
Shapiro et al. 2004 [65] N=39 A case series, cross-over design. Multidisciplinary with standard vs strategic behavioural intervention.	**FMS** Symptoms rated by authors - delivering the interventions - by reviewing charts from physiotherapy sessions: 'Complete/near complete recovery', 'Significant improvement' or 'Minimal/no improvement'.	Proportion of patients in each category.
Sharma et al. 2017 [56] N=30 A retrospective study. PDP	**FMS** Outcomes rated by authors on review of clinical notes and categorised as: 'good', 'near complete resolution' of symptoms, 'modest to mild' or 'poor'.	Proportion of patients in each outcome category: 'good', 'near complete resolution' of symptoms, 'modest to mild' or 'poor'.

Study design and N	Outcome measures by outcome domain	How change/effectiveness was evaluated/reported
Vizcarra et al. 2019 [47] N=13 A pilot RCT. CBT with OnabotulinumtoxinA vs CBT and placebo.	**FMS** PMDRS **PW** HAM-A, HAM-D **LI** ADL, iADL	Statistical significance of the change in group mean score within and between groups. Statistical significance of the change in group mean score within and between groups. Statistical significance of the change in group mean score within and between groups.
SINGLE CASE STUDIES		
Baslet et al. 2011 [63] N=1 A case report - ACT, Morita therapy.	**FMS** Observation and self-report. **PW** Observation and self-report.	Presence/absence of tremor and weakness. Verbal description of changes in mood.
Graham et al. 2017 [57] N=1 A case study of ACT.	**FMS (not measured but change reported)** Self-report. **PW** –AAQ-II, CORE-10 **LI** - WSAS	Verbal description of the extent of change: 'almost entirely stopped by the end of treatment'. Reliable Change Index (RCI) and Clinically Significant Change (CSC) analysis conducted to ascertain the extent of change and indication of clinical recovery.
Gros et al. 2018 [55] N=1 A case report. CBT	**FMS** Observation and self-report. **PW** Observation and self-report.	Absence/presence of symptoms at discharge. Presence/remission of obsessions and compulsions; descriptive verbal report: 'doing great'.
Hardin et al. 2019 [51] N=1 A case report. Multidisciplinary operant behavioural approach.	**FMS** Frequency and intensity of 'cataplectic' episodes based on clinical records. Physical distance walked without assistance, amount of steps climbed and use of mobility aids. Berg Balance Score from and Johns Hopkins Fall Risk. **LI** Observation and self-report regarding changes in functioning – dressing, personal care.	The difference evaluated subjectively by the clinician. Change described in physical measurements. Significance of change not formally analysed. Use/disuse of mobility aids. A change in the category of risk of falls (from "high" to "no risk"). Change assessed by the achievement of pre-set goals.
Krupnik et al. 2019 [50] N=1 A case study.	**FMS** Self-report and observation. Rated by clinicians as 'severe', 'moderate', 'mild' or 'absent'.	Change in frequency, severity of symptoms reported, not formally evaluated.

Study design and N	Outcome measures by outcome domain	How change/effectiveness was evaluated/reported
CBT-informed therapy based on the Bayesian model.	**CS** Self-report and observation. **PW** - PCL-5, PHQ-9, GAD-7 **LI** (not measured but change reported) Employment status.	Presence/absence of symptoms. Change in severity as per descriptive categories of each measure, e.g. from 'moderate' to 'mild'. The extent of change not evaluated further. Change in employment status.
LaFrance et al. 2009 [64] N=1 A case report. CBT	**FMS** Observation and self-report. **CS** Observation and self-report. **LI** (not measured but change reported) Employment status.	Absence/presence of symptoms. Absence/presence of symptoms. Change in employment status.
Papadopoulus et al. 2018 [53] N=1 A retrospective case study. BOP	**FMS** Observation and self-report. **CS** PHQ-15 **PW** - CORE-OM **LI** Life functioning subscales of CORE-OM.	Absence/presence of symptoms. Change in raw scores. Change in descriptive categories of scores, e.g. from 'severe' to 'moderate'. Change in raw scores.
Rancourt et al. 2019 [48] N=1 A case report of DBT	**FMS** Observation and self-report. **PW** PCL-C, PHQ-9	Presence/absence of symptom. Use of mobility aids/independent walking. 'Reliable change' and 'clinically significant change' criteria proposed in literature for each of the scales.
Yam et al. 2016 [58] N=1 A case study. Multidisciplinary treatment with ACT and CBT therapy.	**FMS** Observation and self-report. **CS** NSI-22 **LI** MPAI-4, BREF Employment status. Self report – activities of daily living.	Verbal description of the presence/absence of symptoms. Verbal description of 'overall improvement' in neurobehavioural functioning. Change in the category of scores, e.g. from 'moderate' to 'mild' limitation in adjustment and participation. Change in employment status. Verbal description of changes in independence in activities of daily living.

CS - Comorbid symptoms; PW – psychological wellbeing; LI – Life impact, RU – resource use; AAQ-II - Acceptance and Action Questionnaire II [120]; ADL - Katz index of independence in activities of daily living [121]; iADL - Lawton instrumental ADL [122]; BAI – Beck Anxiety Inventory [123]; BDI – Beck Depression Inventory [124]; BREF (WHOQOL-BREF) - World Health Organization Quality of Life – BREF [125]; CGI - clinical global impression scale change [126]; CGI-SR - Self-report version of the Clinical Global

Impression Scale [126]; CORE-OM - Clinical Outcomes in Routine Evaluation-Outcome Measure [127]; CORE-10 - Clinical Outcomes in Routine Evaluation 10-item scale [128]; GAD-7 – Generalised Anxiety Disorder Scale [129]; GAF - Global Assessment of Function; HAM-A – Hamilton Anxiety Rating Scale [130]; HAM-D – Hamilton Depression Rating Scale [131]; HONOS-ABI - Health of the Nation Outcome Scales for Acquired Brain Injury [132]; ICIDH – the International Classification of Impairments, Disabilities and Handicaps [133]; MMPI-2 - Minnesota Multiphasic Personality Inventory-2 [134]; MPAI-4 - Mayo-Portland Adaptability Inventory [135]; MRS - Modified Rankin Scale [136]; Neuro QoL - the National Institutes of Health Neuro Quality of Life [137]; NSI-22 - Neurobehavioural Symptom Inventory [138]; PCL-C - PTSD Checklist–Civilian Version [139]; PCL-5 - The Posttraumatic Stress Disorder Checklist for DSM-5 [140]; PHQ-9 – Patient Health Questionnaire-9 [141]; PHQ-15 - Patient Health Questionnaire-15 [142]; PMDRS - Psychogenic Movement Disorder Rating Scale [25]; SCL-90 - The Symptom Checklist-90 [143]; SDS - Sheehan Disability Scales [144]; STAI - State/Trait Anxiety Inventory [145]; VRMC – The Video Rating Scale for Motor Conversion Symptoms [26]; WSAS - The Work and Social Adjustment Scale [146].

Figure 1. PRISMA flowchart, from Moher et al. [147]

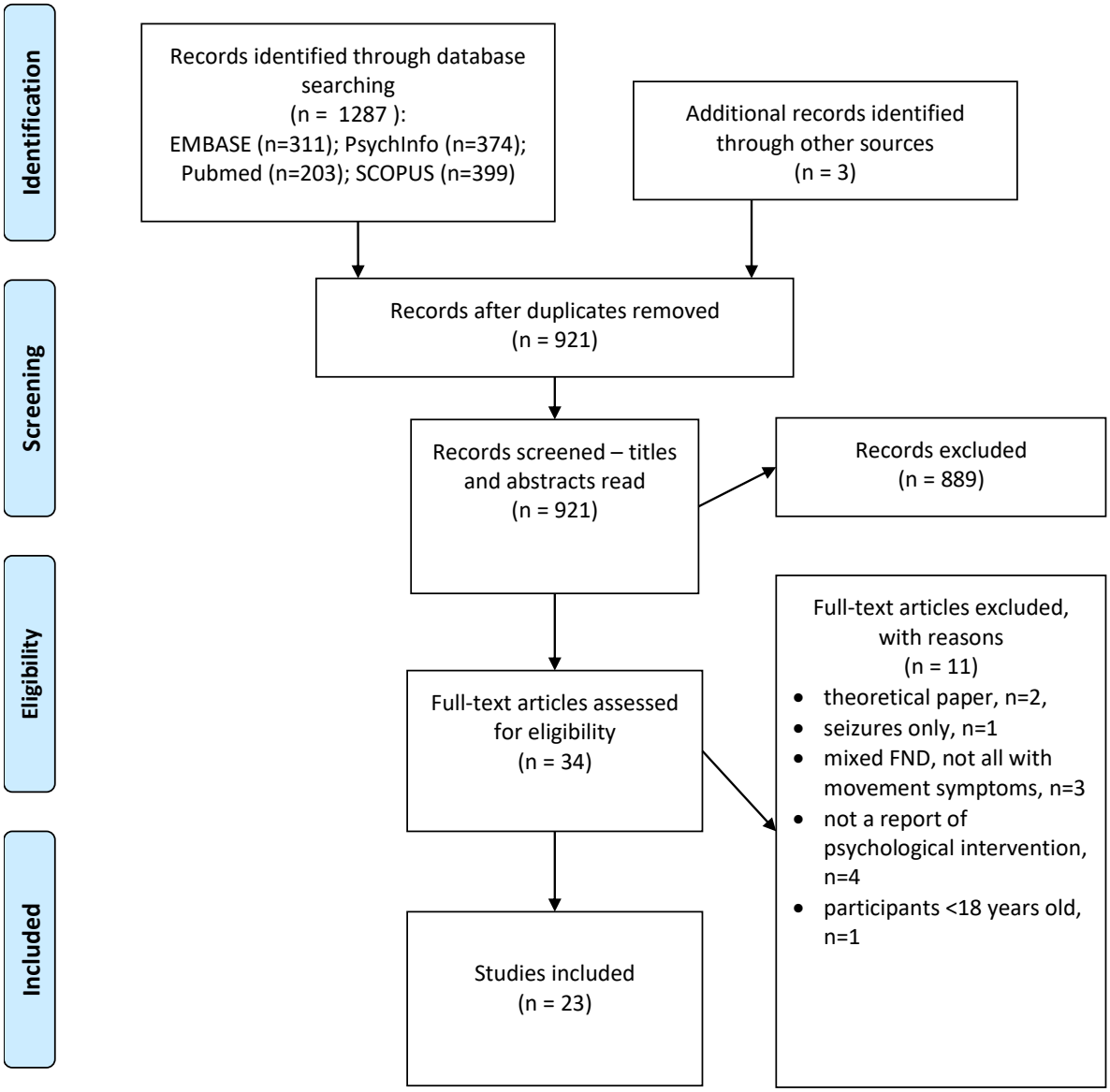


Figure 2. Study publications by year[2]

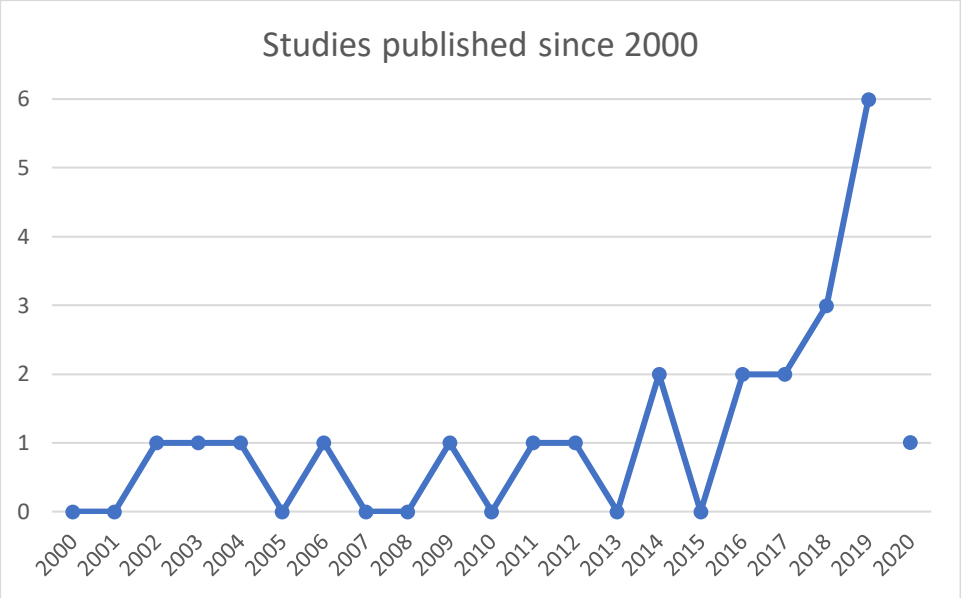
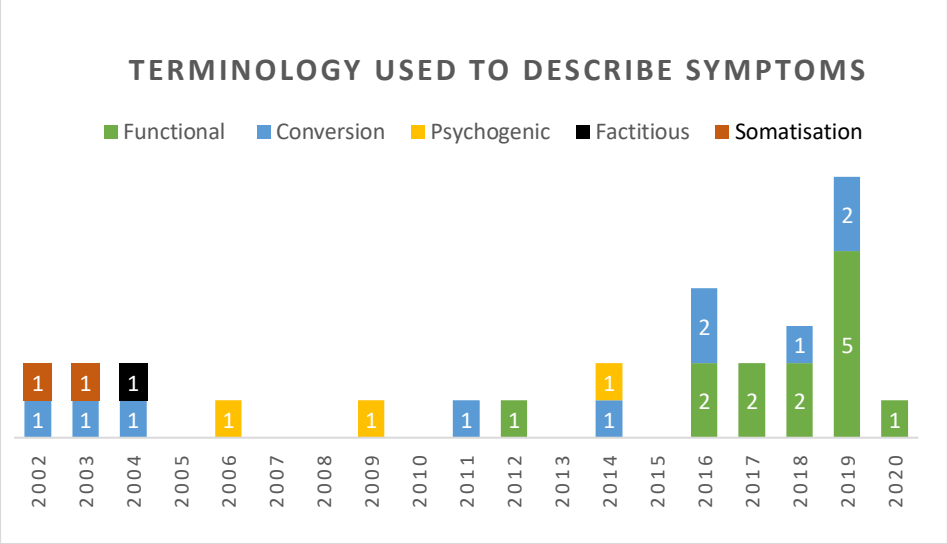


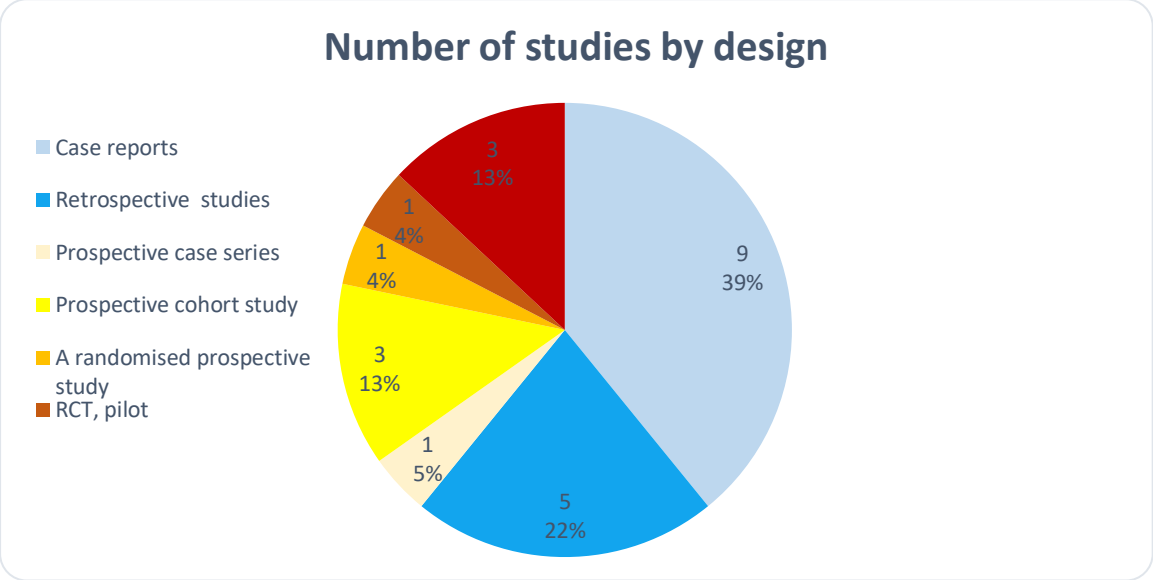
Figure 3. Number of studies using specific diagnostic labels since 2000[3]



[2] The database search was conducted on 8th March 2020 so the count for 2020 is low as it only includes the first two months.

[3] Some studies used a combination of two diagnostic names, e.g. Conversion Disorder/Functional Movement Disorder. In such cases, both names are included in the count.

Figure 4. Studies by design



APPENDIX 1-A

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Structure
Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).
In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.
Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.
The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

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Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.
Please use any spelling consistently throughout your manuscript.
Please use double quotation marks, except where "a quotation is 'within' a quotation".
Please note that long quotations should be indented without quotation marks.
For tables and figures, the usual statistical conventions should be used.
Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

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2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on Implications for Rehabilitation. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:
   Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.
  Example 2: Multiple Sclerosis
- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.

6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
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11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

13. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about **mathematical symbols and equations**.
14. **Units.** Please use **SI units** (non-italicized).

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APPENDIX 1-B

Detailed Database Search Strategy

PUBMED SEARCH STRATEGY

Query	Items found
Search ((((((((("functional neurologic* disorder"[Title/Abstract] OR "functional disorder*"[Title/Abstract] OR "Functional symptom*"[Title/Abstract] OR hysteria[Title/Abstract] OR hysterical[Title/Abstract] OR ""conversion disorder*"[Title/Abstract] OR ""conversion symptom*"[Title/Abstract] OR somatoform[Title/Abstract] OR psychogenic[Title/Abstract]))))) OR conversion disorder[MeSH Terms]) OR ((movement disorder[MeSH Terms]) AND (((functional[Title] OR non-organic[Title] OR ""non organic"[Title] OR psychogenic[Title])) AND movement disorders[MeSH Terms]))) OR ((mFND[Title/Abstract] OR "functional motor disorder*"[Title/Abstract] OR "functional movement disorder*"[Title/Abstract] OR "functional motor symptom*"[Title/Abstract] OR "functional movement symptom*"[Title/Abstract] OR "psychogenic movement disorder*"[Title/Abstract] OR "psychogenic movement symptom*"[Title/Abstract] OR "psychogenic motor disorder*"[Title/Abstract] OR "psychogenic motor symptom*"[Title/Abstract])))) AND ((motor[Title/Abstract] OR movement[Title/Abstract] OR ""limb weakness"[Title/Abstract] OR ""arm weakness"[Title/Abstract] OR ""leg weakness"[Title/Abstract] OR ""muscle weakness"[Title/Abstract] OR paralysis[Title/Abstract] OR tremor[Title/Abstract] OR spasm*[Title/Abstract] OR myoclonus[Title/Abstract] OR dystonia[Title/Abstract] OR gait[Title/Abstract])))) AND (((((((Psychotherapy[Title/Abstract] OR therapy[Title/Abstract] OR hypnosis[Title/Abstract] OR hypnotherapy[Title/Abstract] OR intervention[Title/Abstract] OR treatment[Title/Abstract])))))) OR ((psychotherapy[MeSH Terms]) OR counseling[MeSH Terms])) Filters: Case Reports; Clinical Study; Clinical Trial; Comparative Study; Controlled Clinical Trial; Evaluation Study; Multicenter Study; Observational Study; Randomized Controlled Trial; English	**261**

PSYCHINFO SEARCH STRATEGY

Search	Search Options	Results
S13	S10 AND S11 Filters applied: • 18years and over • Methodology: treatment outcome, clinical trial, prospective study, follow-up study, retrospective study, longitudinal study, clinical case study, quantitative study, empirical study • English language	**423**
S12	S10 AND S11	1,252
S11	S1 OR S4	1,049,402

S10	S9 AND S7	3,814
S9	S3 OR S5 OR S6 OR S8	18,821
S8	(TI functional OR non-organic OR “non organic” OR psychogenic) AND (S2)	3,868
S7	AB motor OR movement OR “limb weakness” OR “arm weakness” OR “leg weakness” OR “muscle weakness” OR paralysis OR tremor OR spasm* OR myoclonus OR dystonia OR gait	236,246
S6	AB "functional neurologic* disorder" OR "functional disorder*" OR "Functional symptom*" OR hysteria OR hysterical OR “conversion disorder*” OR “conversion symptom*” OR somatoform OR psychogenic	14,844
S5	AB mFND OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "psychogenic motor symptom*"	215
S4	AB Psychotherapy or therapy or hypnosis or hypnotherapy or intervention or treatment	978,866
S3	DE "Conversion Disorder" OR DE "Hysterical Paralysis"	1,691
S2	DE "Movement Disorders" OR DE "Alien Limb Syndrome" OR DE "Apraxia" OR DE "Ataxia" OR DE "Athetosis" OR DE "Catalepsy" OR DE "Cataplexy" OR DE "Chorea" OR DE "Dyskinesia" OR DE "Dyspraxia" OR DE "Myasthenia Gravis" OR DE "Paralysis" OR DE "Spasms" OR DE "Tics" OR DE "Torticollis" OR DE "Tremor"	22,718
S1	(DE "Psychotherapeutic Counseling" OR DE "Family Therapy" OR DE "Psychotherapeutic Techniques" OR DE "Active Listening" OR DE "Animal Assisted Therapy" OR DE "Autogenic Training" OR DE "Brief Relational Therapy" OR DE "Centering" OR DE "Cotherapy" OR DE "Dream Analysis" OR DE "Empty Chair Technique" OR DE "Ericksonian Psychotherapy" OR DE "Free Association" OR DE "Guided Imagery" OR DE "Life Review" OR DE "Mirroring" OR DE "Morita Therapy" OR DE "Motivational Interviewing" OR DE "Mutual Storytel ...	211,544

EMBASE SEARCH STRATEGY

#	**Query**	**Results**
20	limit 19 to (human and english language and article and journal and (adult <18 to 64 years> or aged <65+ years>))	**372**
19	15 and 18	1673
18	5 or 16 or 17	6858414
17	(Psychotherapy or therapy or hypnosis or hypnotherapy or intervention or treatment).ab.	6755795

16	(psychotherapy* or psychological therapy* or psychological intervention* or psychological treatment* or psychosocial intervention*).kw.	12864
15	13 and 14	3719
14	(motor or movement or limb weakness or arm weakness or leg weakness or muscle weakness or paralysis or tremor or spasm* or myoclonus or dystonia or gait).ab.	761209
13	2 or 3 or 4 or 6 or 8 or 9 or 12	24441
12	10 and 11	1021
11	1 or 7	27737
10	(functional or non-organic or non organic or psychogenic or conversion or hysteri*).ti.	304953
9	(functional neurological disorder or functional disorder* or Functional symptom* or hysteria or hysterical or conversion disorder* or conversion symptom* or somatoform or psychogenic).ab.	22675
8	(mFND or "functional motor disorder*" or "functional movement disorder*" or "functional motor symptom*" or "functional movement symptom*" or "psychogenic movement disorder*" or "psychogenic movement symptom*" or "psychogenic motor disorder*" or "psychogenic motor symptom*").ab.	607
7	movement disorder*.kw.	3595
6	(Functional movement disorder* or functional neurological disorder* or functional motor disorder* or conversion disorder* or hysteria or hysterical).kw.	1199
5	psychotherapy/ or exp assertive training/ or exp autogenic training/ or exp aversion therapy/ or exp balint group/ or exp behavior contracting/ or exp behavior modification/ or exp behavior therapy/ or exp catharsis/ or exp client centered therapy/ or exp cognitive behavioral therapy/ or exp cognitive rehabilitation/ or exp cognitive therapy/ or exp couple therapy/ or exp emotion-focused therapy/ or exp "eye movement desensitization and reprocessing"/ or exp family therapy/ or exp gestalt therapy/ or exp group therapy/ or exp guided imagery/ or exp hypnosis/ or exp logotherapy/ or exp marital therapy/ or exp mentalization-based treatment/ or exp milieu therapy/ or exp mindfulness/ or exp narrative therapy/ or exp psychodrama/ or exp psychodynamic psychotherapy/ or exp rational emotive behavior therapy/ or exp reality therapy/ or exp relaxation training/ or exp role playing/ or exp sex therapy/ or exp short term psychotherapy/ or exp sociotherapy/ or exp therapeutic community/ or exp validation therapy/	234592
4	exp functional disease/th [Therapy]	368
3	exp hysteria/th [Therapy]	329
2	exp conversion disorder/th [Therapy]	284
1	exp motor dysfunction/th [Therapy]	24442

SCOPUS SEARCH STRATEGY

Search Terms	**Results**
(((TITLE-ABS-KEY ("conversion disorder*")) OR ((TITLE-ABS-KEY ("movement disorder*")) AND (TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*))) OR (TITLE-ABS-KEY (mfnd OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "functional neurological disorder" OR hysteria OR hysterical))) AND (TITLE-ABS-KEY (motor OR movement OR "limb weakness" OR "arm weakness" OR "leg weakness" OR "muscle weakness" OR paralysis OR tremor OR spasm* OR myoclonus OR dystonia OR gait))) AND (TITLE-ABS-KEY (psychotherapy* OR "psychological therapy" OR "psychological intervention*" OR "psychological treatment" OR hypnosis OR hypnotherapy OR therapy)) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (SRCTYPE , "j"))	460
(((TITLE-ABS-KEY ("conversion disorder*")) OR ((TITLE-ABS-KEY ("movement disorder*")) AND (TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*))) OR (TITLE-ABS-KEY (mfnd OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "functional neurological disorder" OR hysteria OR hysterical))) AND (TITLE-ABS-KEY (motor OR movement OR "limb weakness" OR "arm weakness" OR "leg weakness" OR "muscle weakness" OR paralysis OR tremor OR spasm* OR myoclonus OR dystonia OR gait))) AND (TITLE-ABS-KEY (psychotherapy* OR "psychological therapy" OR "psychological intervention*" OR "psychological treatment" OR hypnosis OR hypnotherapy OR therapy))	838

((TITLE-ABS-KEY ("conversion disorder*")) OR ((TITLE-ABS-KEY ("movement disorder*")) AND (TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*))) OR (TITLE-ABS-KEY (mfnd OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "functional neurological disorder" OR hysteria OR hysterical))) AND (TITLE-ABS-KEY (motor OR movement OR "limb weakness" OR "arm weakness" OR "leg weakness" OR "muscle weakness" OR paralysis OR tremor OR spasm* OR myoclonus OR dystonia OR gait))	3,041
TITLE-ABS-KEY (motor OR movement OR "limb weakness" OR "arm weakness" OR "leg weakness" OR "muscle weakness" OR paralysis OR tremor OR spasm* OR myoclonus OR dystonia OR gait)	2,206,216
(TITLE-ABS-KEY ("conversion disorder*")) OR ((TITLE-ABS-KEY ("movement disorder*")) AND (TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*))) OR (TITLE-ABS-KEY (mfnd OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "functional neurological disorder" OR hysteria OR hysterical))	15,055
TITLE-ABS-KEY (mfnd OR "functional motor disorder*" OR "functional movement disorder*" OR "functional motor symptom*" OR "functional movement symptom*" OR "psychogenic movement disorder*" OR "psychogenic movement symptom*" OR "psychogenic motor disorder*" OR "functional neurological disorder" OR hysteria OR hysterical)	11,935
(TITLE-ABS-KEY ("movement disorder*")) AND (TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*))	1,171
TITLE (functional OR non-organic OR "non organic" OR psychogenic OR conversion OR hysteri*)	514,021
TITLE-ABS-KEY ("movement disorder*")	41,822
TITLE-ABS-KEY ("conversion disorder*")	3,651
TITLE-ABS-KEY (psychotherapy* OR "psychological therapy" OR "psychological intervention*" OR "psychological treatment" OR hypnosis OR hypnotherapy OR therapy)	4,517,334

APPENDIX 1-C

Studies excluded after reading full text – with reasons

Study	Title	Reason for exclusion
Andrade et al., 2009	"Systematic enhancement of functioning as a therapeutic technique in conversion disorder." Indian Journal of Psychiatry **51**(2): 134-136.	Use of physiotherapy, not psychological intervention.
Aquilina & Fondacaro,, 2016	"Outlining the psychopathology behind a case of conversion syndrome: Is a holistic approach beneficial?" Psych J **5**(1): 31-35.	No report of psychological therapy, for which the patient was referred out elsewhere.
Ayaz et al., 2015	"Conversion disorder; an unusual etiology of unilateral foot drop." Acta Neurol Taiwan **24**(2): 47-51.	Not a report of psychological intervention
Counsell & Johnson, 2013	"Road traffic accidents: more than just whiplash?" BMJ Case Rep **2013**.	Not a report of psychological intervention
Graham et al., 2018	"A case series of Acceptance and Commitment Therapy (ACT) for reducing symptom interference in functional neurological disorders." Clinical Psychology and Psychotherapy **25**(3): 489-496.	The study participants' with FND, not all had FMD; not possible to extract data for FMD only.
Hubschmid, et al. 2015	"Efficacy of brief interdisciplinary psychotherapeutic intervention for motor conversion disorder and nonepileptic attacks." General Hospital Psychiatry **37**(5): 448-455.	Participants with FMD or non-epileptic attacks, not possible to extract data for FMD only.
Kanarek et al., 2013	"Inpatient rehabilitation approach for a young woman with conversion hemiparesis and sensory deficits." PM and R **5**(1): 66-69.	Participant aged 16 year old.
Kizilkurt et al., 2018	"An approach to conversion disorder with comorbid major depression using pharmacotherapy and psychodrama techniques: A case report." Dusunen Adam **31**(4): 413-420.	Seizures only, not FMD.
O'Neal & Baslet, 2018	"Treatment for patients with a functional neurological disorder (conversion disorder): An integrated approach." American Journal of Psychiatry **175**(4): 307-314.	Theoretical paper.
Sharpe et al., 2011	"Guided self-help for functional (psychogenic) symptoms: a randomized controlled efficacy trial." Neurology **77**(6): 564-572.	Mixed FND, not able to extract data about FMD only.
Stephen et al., 2017	"A case of functional dystonia with associated functional neurological symptoms: Diagnostic and therapeutic challenges." Harv Rev Psychiatry **25**(5): 241-251.	Theoretical paper

Section Two: Research Paper

Living with functional movement disorders

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Word Count: 7975 (excluding references, tables, figures, and appendices)

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Prepared for submission to *Disability and Rehabilitation* (see appendix 2-A for Author Guidelines)

Living with functional movement disorders

Abstract

Purpose: Functional movement disorders (FMD) have poor prognosis, high physical and psychological co-morbidity and low quality of life. Their pathogenesis remains unclear and clinicians often find it difficult to treat. This qualitative study aimed to explore the experiences of living with FMD to improve understanding of its impact and patients' needs.

Method: Interpretative Phenomenological Analysis (IPA) was used to analyse semi-structured interviews. Ten participants from the UK were recruited and interviewed.

Results: Three superordinate themes were generated: (1) The tug of war with the secret agent within: the power struggle with symptoms; (2) Navigating risks of disclosing the diagnosis: stigma and self-preservation (3) Pursuing hope, knowledge and treatments against helplessness and passivity.

Conclusion: For participants in this study living with FMD involved internal and interpersonal battles to maintain hope, control and identity. Perceived ignorance and passivity in healthcare professionals was seen as promoting hopelessness and an unnecessary burden adding to the already depleting internal resources. A sense of oppression, loss of control and stigma have been described in the context of discriminatory power distribution in the society and healthcare settings. Antonovsky's model of salutogenesis could offer a useful framework for facilitating empowerment of patients and clinicians in healthcare services.

Keywords: functional movement disorder, functional neurological disorder, IPA, qualitative study, psychogenic disorder, conversion disorder

Introduction

Functional movement disorders (FMD) involve disrupted movement functions which are incongruent with patterns of pathophysiological (organic) disease [1]. People with FMD might experience one or a variety of symptoms, such as unsteady gait, tremor, spasms, muscle weakness, paralysis or dystonia. The symptoms might be episodic or continuous. Their severity or frequency might fluctuate, with an inconsistent or escalating pattern. The disorder's trajectory often involves the occurrence of new symptoms with time although it can sometimes remit spontaneously [2].

FMD are part of a wider diagnostic category of functional neurological disorders (FND) which account for 16% of outpatient neurology referrals in the UK [3] and with an incidence of four to five new cases per 100 000 of population per year for FMD [4]. The prognosis is poor [5-7] with a symptom remission rate comparable to organic neurological disorders, and with higher mortality rates [6]. People affected by FMD are reported to experience poorer physical and mental health and greater impact of their symptoms on functioning, quality of life and financial status than in people with similar symptoms that are due to an organic neurological disease [8]. Despite this FMD patients are traditionally left without effective treatments [9] even though symptoms are persistent and disabling, and active and targeted therapy is recommended [6,10].

Originally a diagnosis of exclusion based on lack of organic pathology, the diagnosis of FMD is now made on the basis of positive signs, such as tremor entrainment or Hoover's sign [10,11] to improve diagnostic credibility and reliability [12,13]. The symptoms' variability and inconsistency are also believed to be positive clinical features supporting the diagnosis [1,11]. Co-morbidity with other physical, functional and non-functional symptoms is common in FMD, often making it more difficult to treat the movement symptoms, e.g.

when fatigue and pain are severe [14] and triggering or being triggered by the movement symptom [15].

FMD and its parent category FND are included in the *Diagnostic and Statistical Manual of Mental Disorders 5th edition* (*DSM-5*) [16]. This reflects the traditional views of FND as a psychiatric condition caused by a 'conversion' of emotional distress or trauma into a physical symptom [17,18] and thus also called a conversion disorder (CD). Various other labels have also been used including hysteria, somatoform and psychogenic disorder and even feigning or factitious disorder [19-21]. However, the understanding of FND has evolved and the lack of an obvious stressor or psychological trauma in many people with FMD has led to changes in the DSM-5 diagnostic criteria which no longer require an identification of a psychological stressor. In addition, in the newest version of the *International Classification of Diseases 11th Revision* (*ICD-11*) [22] the separate symptoms of FMD (e.g. functional tremor) have been placed in neurological as well as psychiatric categories.

Renewed interest in FMD, developments in neuroimaging and pathophysiological studies [23-27] and increased recognition that not all cases of FMD can be explained by psychological trauma or adversity led to developments of newer models of FMD that revised or expanded the conversion models. The contemporary models incorporate neurobiological processes, such as sensorimotor integration and agency [26,28], autonomic and neuroendocrine function [29] or motor-limbic communication [30,31] as well as the role of emotional, cognitive and behavioural processes, such as symptom-related beliefs and body-focused attention [32,33], maladaptive conditioning [34] and emotional processing [24]. This shift towards a broader multifactorial conceptualization of FMD emphasizes the unique interaction of biological, environmental and psychological factors in FMD generation and expression for each individual [35-38].

However, the inconsistency in terminology still exists, often depending on the professional discipline of those who use it [41]. To respect the preferences of people with FMD [40] and to reflect its biopsychosocial determinants the term ‘functional’ over ‘psychogenic’ or ‘conversion’ was chosen for this study.

In the last 20 years a variety of treatments for FMD have been explored including physiotherapy, multidisciplinary rehabilitation, psychotherapy, transcranial magnetic simulation, botulinum toxin, therapeutic sedation, hypnosis, electromyographic biofeedback [4] and recently virtual-reality-delivered mirror visual feedback [42]. The most robust evidence currently exists for intensive FMD-specific physical rehabilitation with some psychological input [43]. However, specialist treatment centres are scarce and a lack of clear care pathways and clinical guidelines present challenges to accessing treatments [44,45]. The evidence for the effectiveness of interventions is growing but limited and many researchers and clinicians emphasise the importance of tailoring the interventions to the individual needs of the patients, their goals, and potential barriers [41,46,47].

Partnership and collaboration have become especially significant in the light of patients’ dissatisfaction with care [48], oversimplified explanations for FMD [45] and low uptake of psychological therapies that assume underlying psychological issues [49]. Patients have often been labelled ‘resistant’ to psychological accounts of symptoms and lack of progress in therapy was attributed to lack of insight [50,51]. Patients have been marginalised in the medical system for decades [52] and their perspectives overlooked in research studies. As the revision of current terminology and understanding of FMD is ongoing, it is crucial that patients are heard and involved in shaping the understanding of FMD and its treatments [48]. An exploration of the experiences of people with FMD through qualitative studies is needed to facilitate representation of their perspectives to inform treatment planning and service developments.

However, there is scarcity of qualitative research in this area with most studies conducted with people with non-epileptic seizures (NES) [53-57]. NES, like FMD, are a subset of the wider FND category but have a different symptoms phenomenology. A systematic qualitative synthesis conducted in 2016 [58] highlighted the interpersonal burden of having NES and conflicts between patients and healthcare practitioners regarding the symptom's nature. A report on experiences of living with FND, including FMD, emphasised its debilitating impact on patients and their families, and a lack of affordable healthcare provision in Australia [44]. Only one qualitative study was conducted in the UK and used thematic analysis to investigate experiences of people with FMD [45]. This study was undertaken as part of a randomised controlled trial of physiotherapy. The participants were recruited from the physiotherapy waiting list in a specialist tertiary care centre after an initial consultation with a leading neurologist in the field. Most people with FMD do not have access to specialist services or even physiotherapy and thus their experiences of having FMD and its treatment might be very different to those from the sample used in the study.

The current study was proposed to explore experiences of people living with FMD across the UK, regardless of their treatment access or engagement with national health services. Interpretative phenomenological analysis (IPA) was chosen to provide an in-depth exploration of participants' idiographic experiences embedded in their individual circumstances and interpreted from within that framework. It is hoped that this method may facilitate the previously neglected and dismissed narratives of people with FMD.

Method

Design

A qualitative methodology was adopted to examine the experiences of living with FMD. IPA was chosen as an approach particularly suited to under-examined topics [59] and which

privileges the narratives and meaning making [60] of the participants. IPA has a dual focus combining phenomenology – the study of what is being experienced – with hermeneutics, the theory of interpreting it [61]. It can facilitate rich understanding through the analytical process of exploring unique experiences embedded in the individuals' context whilst acknowledging an interpretative stance when doing so [61].

Ethical approval for the study was granted by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (see Ethics section: Appendix 4-D). An additional approval was gained from FND Hope, a charity organisation involved in the study recruitment. Three experts by experience who were members of FND Hope were consulted regarding the recruitment and design to ensure that relevant ethical and practical issues were adequately addressed, and to enhance the study's contextual sensitivity, and the results of the study to validate the findings and enrich the discussion and inform practical implications. The structure of the interview guide was informed by the recommendations by Smith et al. [61]

Recruitment

The first ten participants who met the inclusion criteria and consented to the study were accepted and the recruitment was then closed. Potential participants were required to confirm (but not to evidence) that they had been diagnosed with functional movement symptoms. The formal diagnosis could include labels such as functional movement/motor disorder (FMD), functional neurological disorder (FND), functional neurological symptoms disorder (FNSD), psychogenic movement disorder (PMD), somatoform disorder, conversion disorder or others using the main symptom as the diagnostic label, such as functional dystonia. At least one movement symptom as part of the functional disorder was required: paralysis or weakness in an arm or leg, muscle spasms, dystonia, myoclonus, tremor or gait disturbance. People who

had co-morbid conditions were not excluded provided that they did not have another neurological disorder that could account for their symptoms.

Eligible participants needed to be 18 years old or over and living in the UK to ensure a homogenous group in terms of received healthcare and exposure to common cultural influences that might have shaped their understanding of their condition. The diagnosis had to have been received at least twelve months prior to the interview to ensure sufficient time had elapsed to reflect on living with the condition and the impact of the diagnosis.

Participants were recruited through FND Hope who advertised the study on their website, social media and patient engagement platforms: Twitter, Facebook and Health Unlocked. The posts included a link to the study information on the Lancaster University DClinPsy student research page.

Nineteen people expressed their interest in the study and contacted the researcher via email or phone. Five people did not meet the eligibility criteria: one lived outside the UK and four had had the diagnosis for less than twelve months. Four people did not follow up after the initial response and ten decided to proceed with the study and were interviewed. Participants' symptoms and time since diagnosis are presented in Table 1. All participants were given pseudonyms to protect their anonymity.

[table 1 around here]

The sample consisted of eight women and two men, aged between 24 and 66 years old. Time since diagnosis varied between one and six years, with majority of participants having the diagnosis for one to three years. Three people were working full time, one was

retired, one was a student and one was caring for a disabled child. The remaining four were unemployed as a result of FMD. Four of the participants' occupation was in healthcare, two in social care, two in teaching, one in performing arts and one in law. Symptoms experienced were tremors, spasms, twitches, limb weakness and numbness, paralysis of legs and of the whole body, gait disturbance, leg drag and drop attacks. All participants also experienced pain or fatigue or both, and many had other functional neurological symptoms, such as speech problems, cognitive difficulties or seizures.

Data collection

Ten semi-structured video interviews were conducted over Skype (due to geographical distance) ranging in length from 54 to 98 minutes. Participants were encouraged to talk about the issues that were most salient to them, and the interview schedule (Ethics section: Appendix 4-A) was used as a flexible guide to facilitate the discussions.

Data analysis

The interviews were transcribed verbatim by the researcher and an idiographic approach adopted to analysis. Each transcript was analysed separately and fully before moving on to others. Notes were taken during transcription to capture initial impressions and capture the researcher's potential pre-conceptions and automatic associations. These were then further examined to identify the researcher's bias in line with IPA's principles [61]. Further analysis involved taking thorough analytical notes including the descriptive, conceptual and linguistic nature of participants' line-by-line utterings (for a sample of a coded transcript – see Appendix 2-B). The notes were then organised into code clusters and initial themes (Appendix 2-C). The main themes and subthemes were then generated for each participant (Appendix 2-D). This process was followed for each transcript. The generated themes for all participants were clustered together to seek patterns, similarities and differences. The

superordinate and subordinate themes resulting from this stage of analysis were noted and underwent further scrutiny to check for internal validity and reliability. As the transcripts provided rich and extensive material, the most salient themes were chosen for the purpose of this project and to highlight clinically relevant issues. The table of final themes, subthemes and corresponding quotes is attached in Appendix 2-E.

Validity and reflexivity

A number of steps were undertaken to ensure the validity of the study, informed by a framework of principles for qualitative research developed by Yardley [62]. Triangulation of interpretative perspectives [62] was used when analysing data. One transcript was coded separately by the researcher and one supervisor and then compared. The codes were then checked by a second supervisor. The emerging themes were modified in discussions with both supervisors to increase consistency and reliability of the analysis. Further validation was strengthened by a final re-reading of the transcripts with the emergent themes in mind to check whether the themes were supported or challenged by the data. As a result, amendments were made to the themes to include examples of significant divergence and convergence within and across themes.

Transparency and a reflexive stance were maintained throughout the process of planning, collecting and analysing data. Every attempt at understanding a phenomenon is inevitably influenced by the researcher's own beliefs, expectations and experiences [63]. In qualitative research this is not considered an error [62] but an inherent part of learning about the interaction between the explored phenomena and those who engage with it. A reflexive approach helps to capture some of those interactions and consider their meaning. The use of a reflective diary helped the researcher consider her own bias and its potential impact on the study. Noticing and bracketing of explicit and implicit judgements might highlight not only

personal but also cultural, societal or a professional bias resulting from accepted discourses. Dialogue between the various interpretations and alternative perspectives helps to enrich the analysis through triangulation of interpretations and their embeddedness in specific contexts.

The main researcher is a woman in her late thirties with a professional background in psychotherapy and a special interest in the interrelatedness of physical and psychological aspects of health. She worked with people with persistent physical symptoms during her clinical placement in physical health psychology. The researcher became aware of her desire to challenge the use of theoretical concepts when they seem to override the lived experiences of individuals affected by functional conditions and their expressed treatment needs. It is the researcher's belief that full 'bracketing' of one's own assumptions is not achievable or necessary as every interpretation is embedded in a specific context that introduces bias. The researcher aimed therefore to contextualise the assumptions and interpretations, especially those in the dominant narratives available in psychological research and theory.

Results

Three superordinate themes were generated from the data: (1) The tug of war with the secret agent within: the power struggle with symptoms; (2) Navigating risks of disclosing the diagnosis: stigma and self-preservation; (3) Pursuing hope, knowledge and treatments against helplessness and passivity.

Theme 1: The tug of war with the secret agent within. The power struggle with symptoms.

This theme relates to participants' efforts to control symptoms and their own body, which was perceived as a host to or a hostage of a forceful entity to be wrestled with for control and identity.

The symptoms, seen as unpredictable and uncontrollable, fuelled a sense of fear, frustration, bafflement, and urge to regain control. Gemma felt trapped and protested at the loss of control when experiencing paralysis: "*I couldn't talk, I couldn't move my mouth, I was just making noises, sort of screaming and wailing because I was angry and scared".*

Participants described the FMD as a powerful force orchestrating the symptoms according to its own agenda and having a mind of its own – capricious, uncontrollable, and resistant. *"My head will rock back and will stay there for however long it feels like staying for" (Frances).* Sometimes symptoms were envisaged as an expression of the body acting as a 'safety valve' in response to overload from specific triggers, e.g. exertion, emotional or physical strain or sensory stimulation: "*If I push through pain, which I quite often have to do… It's almost as if my body goes: actually, this is enough, you need to just stop"* (Gemma). However, the speculated protection was also viewed as excessive, leaving Gemma feeling oppressed, rather than relieved by the symptoms: "*It's not an escape, it's a terrifying trap!*".

The perceived lack of satisfactory biological explanation for symptoms made some participants question their sanity or led to self-blame for lack of influence over their own body. Distraction techniques were employed to prevent or postpone symptoms and regain some sense of control and agency. However, some participants viewed this strategy as only effective in the short term and often prolonging the struggle. Lynn frequently attempted to ignore symptoms out of fear of becoming overpowered by them: "*I think my main fear was that if I acknowledged what was happening… that it would suddenly overwhelm me"* (Lynn). Paradoxically, this exacerbated symptoms and was leaving her feeling defeated and retaliated against: "*The more I tried to ignore it, the more it would slap me around my face"* (Lynn). Frances felt that letting the symptoms run their course was the only way of extinguishing them. For those who found their symptoms unresponsive to any influence, fighting felt futile.

Symptoms were seen as an inescapable force dictating the rules and the only way to respond was to accept them and not waste the little valuable energy that was left.

Some participants understood symptoms as an error of their malfunctioning nervous system that could be corrected. They engaged in persistent efforts to overpower symptoms with training of motor functions, taking pride in setting and achieving goals, which provided a sense of triumph: "*I'm trying to teach my body: look, shut up, I'm gonna do this. It's… [a] psychological way of winning over"* (Peter). However, Peter found the body to be a fierce opponent resisting the conscious mind's influence. "*It is very difficult to impose a conscious decision on top of those… you try it and the mismanagement signals make your feet stop or not walk, walk a little bit then stop and fall over*". Successfully overcoming symptoms was described as involving unrelenting persistence, counterintuitive actions and mind tricks. Leyla described undergoing mirror therapy as one of the mind-tricking techniques to overcome the faulty neurological processing: *"You've got to look in the mirror and imagine that you're seeing the other leg and for the first few attempts I kept thinking: it's a mirror, I know it's a mirror!... but over time it's easier"* (Leyla).

The battle with symptoms was fought not only for the control over one's own body but also to retain a sense of self. FMD was experienced as claiming and violating the individuals' identity. Participants had to make conscious attempts to retain or re-build the sense of who they are despite feeling permanently changed.

Harriett spoke about developing a dual identity to maintain her previous sense of self: "*I'm two different people, the one that is covering up that I have a condition versus the one that actually now needs to recover from that condition"* (Harriett). The perception of self as independent, competent and able whilst witnessing oneself with FMD as dependent, restricted and disabled was a big challenge and felt irreconcilable: "*It's really hard 'cause it's*

like being in somebody else's body… you're left with this kind of not-you trying to be you… I think that was harder than learning to walk" (Lisa).

Peter explicitly rejected the notion of disability: *"No, no, no, no, I'm somebody who has limits on my ability, that's what I've got, I'm not disabled, big difference [laughs]"*. All participants wanted to preserve an identity that was built on positive experiences rather than defined by the deficits: *"You have to look at the positive things... I just started up drawing, I never knew I could draw, you know, stuff like this. Finding a hobby that I can do, rather than one I can't*" (Mark). This, however, often required a continuous effort and re-defining of own identity.

Theme 2: Navigating risks of disclosing the diagnosis: stigma and self-preservation.

This theme relates to the participants' experience of the FMD diagnosis carrying unwelcome consequences as a result of misconceptions and stigmatising attitudes from other people, including healthcare professionals. The participants had to navigate carefully the perceived risks and employed various strategies to mitigate them by concealing symptoms, using alternative diagnostic labels or withdrawing from contacts. Educating others was also attempted and seen as aspirational but practiced when the resources to mitigate the potential risks were available or outweighed the risk.

Participants experienced their symptoms as bizarre, unpredictable and attracting unwanted curiosity, suspicion or exasperation from others. Some participants felt insecure about being unable to identify a clear cause or give an explanation that would be understandable to others: "*Even though I knew that what was happening to me was real, I still worried that because I couldn't explain why it happened and what it was, that people wouldn't believe me"* (Leyla). Explaining the diagnosis to others was daunting and burdensome. A lack of traditional tests to evidence the condition, its conceptual complexity, a

lack of consensus amongst healthcare professionals and a lack of awareness of FMD in general left the participants feeling deprived of the usual concepts and ways of communicating a health condition.

Many participants experienced stigmatising attitudes to be the result of the assumptions of a psychological cause of FMD or associated characterological deficits**.** They experienced the diagnostic label as a prompt for others to scrutinise their behaviour or sanity and to undermine their credibility as a person or a professional. Mark felt that those assumptions, once acquired, were impenetrable and the attempts to challenge them were futile: *"Some people have a fixed idea that it's a psychological condition and that's what hurts the most because they won't listen. They think you're just lazy or not bothered, that you've just given up. I don't have the energy to try and put them right because you could be going on days, weeks, months and years… it's an endless task."* (Mark). He chose to communicate his symptoms as 'myoclonus' avoiding the FMD label and hurtful judgements. Harriett feared that the diagnosis, if known to others, would undermine her competence as a professiona: "*[colleagues] don't know about what the condition is… I didn't tell them. I didn't want to appear weak… I liked being good at what I did and I didn't want anyone to think that I couldn't perform my job".* She told people she had a 'natural tremor' and took annual leave on days when she was too unwell to come to work. Emma found that by telling people she had a brain injury made it easier for them to understand: "*Some people can't comprehend it, it's hard to put into perspective for them, so by going: 'I've got a brain injury'… I found that the easiest way".*

Most participants underwent a process of figuring out how and whether to disclose their diagnosis to others. Those conversations were difficult even with some family members, who struggled to grasp or empathise with the physical or the emotional aspects of the

condition. Some participants sought professional support to prepare them for conversations with their partners and families.

Many participants found themselves particularly vulnerable when seeking medical help and disclosing their diagnosis. They felt silenced, shamed and often struggled to challenge communication conveying disbelief or blame: "*I had a GP say to me: '[it's]a unicorn condition' which I found quite offensive… I was taken aback and didn't say anything but I wish that I had"* (Hannah). The usual coping strategies used, such as concealing or re-labelling symptoms, withdrawing from contacts or educating others were particularly difficult in healthcare settings as they violated the unspoken rules of engagement and were challenged by the experienced differences in power between the professional and the patient. The combination of perceived prejudice and power of health professionals made participants feel unsafe in healthcare settings. They perceived their physical complaints being overattributed to FND and their diagnosis creating a barrier to receiving standard care for other ailments. "*Now it's on my medical record, I am really concerned that if I do have a stroke – because I can still get strokes or anything else – they're gonna just assume it's FND and write me off"* (Hannah). Perceived stigmatisation created mistrust and many participants decided to conceal their diagnosis, when possible and practical. Lynn felt she did not have the capacity to educate others or deal with potential prejudice when feeling vulnerable and in need of immediate medical care. Peter, who by his profession was used to speaking up and challenging others, willingly educated his doctors about FMD and often experienced it as rewarding, contributing to a positive change. He, however, also found it a tiring task, mentally and emotionally.

A unique perspective was presented by those who were both patients and healthcare professionals. They feared disclosing their symptoms in their workplace knowing their colleagues' misunderstanding of functional symptoms and fearing a negative judgement.

Lynn described her shock when the consultant explained her diagnosis in detail: "*I was like: oh my God. How have I come this far as a professional and not been told about what this really was?… I myself stigmatised against functional patients because I didn't know any better… My colleagues had taught me: 'it's functional, they're just making it up, there's nothing we can do to help them, but you just have to go along with it'"*. Those participants feared the shift in the position from a 'professional' to a 'functional patient', sensing it would endanger their credibility and ability to make themselves heard. Emma used her professional healthcare background to challenge her interviewer during a psychology assessment, striving to establish an equal, professional to professional relationship and feel protected from the 'functional patient' narrative.

The participants experienced an internal conflict between the desire to address the stigma and the strain of doing so. They negotiated their position between disclosure and withholding of the diagnosis, weighing up the physical, social and emotional burdens against their available internal and external resources. Fighting stigma through self-disclosure was often seen as virtuous or liberating but could lead to further depletion and exhaustion, already inherent to the condition. Avoiding disclosure of FMD maintained energy needed for recovery but often involved guilt or a sense of disconnection and exclusion from others.

Theme 3: Pursuing hope, knowledge and treatments against helplessness and passivity.

This theme relates to the participants' relentless striving to maintain and pursue hope. This powerful but fragile process was experienced as constantly threatened by an equally powerful force of hopelessness and helplessness when dealing with uncertainty, dismissal by healthcare professionals and fears of the deterioration or permanence of symptoms.

Most participants emphasised the importance of holding on to hope to maintain wellbeing and to find the right treatments. Leyla, Lisa, Lynn and Peter have all accessed

helpful treatments but only after a long and arduous journey that demanded stubborn determination and hope against self-doubts, despair and resignation. Most participants engaged in some form of coaching self-talk to prevent feelings of helplessness: *"Part of me is scared that it won't get any better but I've just got to keep hoping for the best and preparing for the worst"* (Leyla).

The pursuit of hope through seeking knowledge and treatments was often endangered by perceived passivity, helplessness or ignorance of healthcare professionals, seen as jeopardising the recovery. This was seen as additional, though avoidable, burden when they were already grappling with fear: **"***I couldn't sit in a wheelchair without falling out because my tremors were so bad and they said, 'maybe you should just go home, sometimes these things happen'"* (Lisa). Even when under ongoing neurological care, Frances experienced her appointments as wasteful and disheartening as they lacked an active plan and felt purposeless: "*You go and see the neurologist, but they can't do anything for you – 'we'll see you at the next appointment' – which makes you think, why go to the next appointment because what's the point?... it feels like a waste of time".*

Participants often experienced healthcare professionals as passive and leaving the participants to learn about and manage the symptoms on their own. However, when researching FMD independently, they often found the information confusing, abstract or impractical. Emma, despite being a healthcare professional herself and an avid reader of research, found it challenging to make sense of her symptoms: *"There is so much literature out there that takes you off on different tangents and you're trying to look at 'OK, what box do I fit in?" It is very confusing to say the least".* Participants looked to professionals for guidance and practical support with the symptoms, not just theoretical explanation: "*I understood in principle what was going on… but I found it very difficult to apply it to me, just*

by reading it or just by having someone tell me… rather than work through it with me…" (Lynn).

With a lack of clear guidance many participants employed random, chaotic or unhelpful strategies, ending up feeling helpless, lost or discouraged: *"It's like trudging through mud in a maze"* (Hannah). Some participants felt disheartened and hopeless after undergoing ineffective treatments. They felt given up on and abandoned, reinforcing the sense of FMD being a lost cause or 'unworthy' of investment. At the same time healthcare professionals were seen as crucial to the recovery, holding the expertise the participants felt themselves lacking. They continued to seek support and guidance, maneuvering between hope of finding a helpful and interested professional, the despair of being untreatable and fear of being dismissed and shamed.

The instances of meeting professionals with knowledge of FMD and a proactive approach to treatment was often experienced as a turning point for the recovery, an antidote and a stark contrast to previously seen passivity and inertia, a renewal of hope that change is possible. Lisa, after feeling helpless and given up on by doctors, met a movement disorder specialist and things changed dramatically: "H*e just went, 'it's FMD… your brain's malfunctioning and the good thing is that we can get it functioning better again, we just need to do rehab…' and that's what I did. As soon as I started rehab, I got a lot better".* Leyla felt stunned by the neurologist who worked out an active care plan with her, reinstating her hope and a sense of direction: *"She was really amazing, it was almost like the starting gun for the start of a race… Instead of constantly being fobbed off by everybody else… she listened and said, 'OK, let's see what we can do*' ".

After numerous rejections or lack of adequate care some participants found support outside the NHS: "*The only professional support I get from a neurologist and from neurophysio I pay for… very good, extremely" (Peter).* Like Peter, Lynn and Lisa spoke

about hope being the key to accessing effective treatments. These required unrelenting perseverance, private funding or social influence to find the right support against the systemic barriers: "*I have a very persistent wife, she made a meeting with all the head people from the department and she just wen,: 'we've got to figure it out because this is ridiculous' and that's when they found me a movement specialist"* (Lisa)'.

There were also many participants who could not afford private treatments or did not have the same social or personal resources. Mark experienced benefits from physiotherapy, but he could not sustain it as the input in the NHS was limited. He has experienced gradual worsening of his symptoms since.

Advancing knowledge was seen by all as the main driver of change that could improve the understanding and treatment of FMD. Most participants spoke about taking part in this study to make their own contribution. They saw research as a beacon of hope and an active stance against uncertainty and resignation. Some were actively involved in their own initiatives and research projects, raising awareness and educating the public and health professionals. It provided a sense of hope and influence in an environment that otherwise felt stagnated, indifferent and resistant to change.

Discussion

The purpose of this study was to explore experiences of living with FMD. Through the process of IPA, three main themes were generated (1) The tug of war with the secret agent within: the power struggle with symptoms; (2) Navigating risks of disclosing the diagnosis: stigma and self-preservation (3) Pursuing hope, knowledge and treatments against helplessness and passivity.

The first theme represented an internal battle – with the malfunctioning body and a powerful alien force within it that threatened the body's integrity and selfhood. Reported

experiences of loss of control, feelings of oppression, confusion, powerlessness and entrapment by the symptoms reflect the findings of previous studies on living with FND [44,56,57,64]. Loss of control over the body had been previously described as triggering a series of losses in life choices, activities and opportunities [44] which in turn led to a loss of valued self-representations [65] and a crisis of identity, often reported as inherent to chronic conditions generally [66]. Some authors have proposed that identity changes in chronic illness are forced by the split between the disabled body and the 'old' self [67]. A study of men with FND identified a fight between two identities – with and without symptoms – generating a sense of disconnection or estrangement from the dysfunctioning body and having to fight to 'not lose oneself' [64], which was also reflected in the present study. Similar experiences of lost selfhood, betrayal and alienation from the body are reported in other neurological and movement disorders. For example, people with Parkinson's reported their self taken over by 'an evil twin' [68] and women with multiple sclerosis depicted their bodies as 'unrecognisable' and a hindrance [69].

Negotiating and bargaining for control was present in the accounts of all participants in this study. However, the coping strategies employed varied depending on the extent of control they experienced and how they conceptualised FMS: as an unfathomable force with its own agenda, an oppressor and abuser, an authoritarian protector, an error of the nervous system or a representation of their inadequacy or weakness. Many of the participants in this study endorsed a mixture of different conceptualisations, fluctuating between them in a dynamic process of meaning making. According to the self-regulation model (SRM) of health and illness people construct common-sense illness representations to help them make sense of their experiences which then shapes their coping responses [70]. Illness beliefs were shown in Stone's study to predict reduction in functional symptoms more than the number of symptoms, disability or distress [7]. In the SRM model, perceived illness controllability is

postulated as one of five key dimensions of illness beliefs and has been found to affect coping strategies [71], health outcomes, psychological wellbeing, social functioning [72] quality of life and engagement with health services [73] across various physical conditions. Leventhal et al. divided illness controllability further into treatment control and personal control [70]. Failure to explore illness perceptions early in participants' care, lack of shared understanding and collaborative care plan might have led to participants' increased anxiety and reduced treatment control [74].

Personal control and the broader concept of perceived control has been extensively researched for its importance in general health and wellbeing [75-77]. Maier and Seligman in their reviewed theory of helplessness posited that the active personal experience of control over adverse stimulus inhibits a default neurological response of passivity. This time-limited effect prevents feelings of helplessness and is generalised to other situations even when faced with uncontrollable circumstances [78]. Related concepts of self-efficacy, sense of agency and a sense of mastery have also been shown to facilitate a reduced sense of powerlessness [79] and improved health-related quality of life [80] in chronic conditions.

However, attempts to exert direct conscious influence over symptoms were found by some participants in this study to be frustrating or counterproductive, which is supported by findings in other qualitative studies [44,64]. Indeed, common physiotherapy interventions for FMS involve training the affected motor function whilst diverting attention away from it [81] based on theoretical models explaining FMS as a failure in explicit movement control with automatic processes being preserved [82]. In this case, paradoxically, regaining control might be achieved through relinquishing efforts to control. Some psychological interventions, especially acceptance and commitment therapy (ACT) propose shifting the attention from the control over FMS towards achieving valued goals and in this way regaining a general sense of control over one's life direction and meaning [83]. Aujoulat et al. [84] argued that the

process of exerting control as well as relinquishing control are not mutually exclusive and that empowerment can be achieved by integrating both.

The internal struggle for control was made even more wearisome by others' assumptions and expectations of such control. This leads onto the theme of the interpersonal struggle with stigmatising views and oppressive attitudes experienced from other people. Movement symptoms are often visible and expose the individual to others' attention and curiosity. However, initial unfavourable judgements can instantly change to empathy when an organic diagnosis, such as Parkinson's, is disclosed [85]. Conversely, the labels 'functional' or 'psychogenic' were found in this and other studies [44,45,58] to evoke withdrawal of empathy, negative judgement, scepticism or confusion in social interactions and in healthcare settings. Goffman [86] defined stigma as a mark of undesired difference, causing rejection by society as a deviation from the established 'norm'. The threat of rejection drives stigmatised individuals to employ coping strategies aimed at minimising the harm of exclusion or securing acceptance by concealing their unwelcome difference to pass as the society's 'normals'. In this study the participants navigated between self-disclosure and its withdrawal depending on the significance of potential losses (e.g. losing valued professional credibility, dignity, loss of relationships), an individual's resources to mitigate the risks (e.g. strong supportive social network, socioeconomic status), perceived chances of a positive outcome and perceived costs of a negative outcome (e.g. mental and emotional exhaustion, shame, guilt).

Some studies on liberation movements have highlighted the health impact of secrecy in the context of stigma, describing it as 'private hell', leading to preoccupation with the stigma and reduced wellbeing [87]. It has been suggested that self-disclosure can facilitate empowerment and improve self-esteem. In this study some participants reported guilt or disconnection from others as a result of concealing their diagnosis but did so to protect

themselves from anticipated more burdensome consequences, such as shame, negative judgements and blame. Corrigan [88] recognised the tensions inherent in disclosure in stigmatised groups and advocated ‘strategic disclosure’, driven by the individual’s circumstances and cost–benefit analysis. Many participants in this study engaged in a strategic disclosure of their symptoms and used alternative socially acceptable and recognised labels, such as myoclonus, brain injury or essential tremor. Those alternative labels were chosen due to the perceived lack of adequate narratives that could be safely shared with and understood by others. The challenges experienced by the participants might also reflect the lack of consensus in the literature, as the terminology and theoretical explanations of FMD are being revised and disputed [39,43,89].

Despite a rapid growth of research uncovering the complexity of biological, physical and psychosocial factors implicated in FMD there are still new studies being published which describe functional symptoms as a psychiatric illness [90] or state the presence of ‘severe deficits in personality functioning' in people with FND [91,p.546]. This, as well as a sole reliance on psychological explanations in clinical practice, is likely to fuel potential misconceptions and attract stigma associated with mental illness or psychological difficulties [48,86,92], making it hard for the participants to share the diagnosis with others or to see value in psychological approaches to treatment.

Dissatisfaction with psychological explanations has been identified as one of the dominant experiences in patients awaiting physiotherapy for FMD in a qualitative study by Nielsen et al. [45] and the present study partially confirms this. However, Nielsen et al. suggested that individuals’ rejection of psychological explanations might be driven by an attempt to distance themselves from the stigmatised population of people with mental health problems. Most participants in this study either had or were planning to have psychological therapy and many openly admitted to some psychological difficulties, past or present. All

participants actively engaged in examining the role of psychological factors in their symptoms but most found them insufficient to account fully for the symptoms. Some participants wished for the psychological cause to be true as they felt more equipped to deal with it. One participant chose to state depression and anxiety as a reason for absence at work rather than reveal the FMD diagnosis. This might suggest that for some people the dissatisfaction with psychological explanations might go beyond avoiding the stigma of psychological difficulties, and that the label of FMD itself might carry an additional, distinct layer of stigma and prejudice.

A study by Rawlings et al. reported that patients with functional seizures perceived psychological explanations as lacking personal relevance and being inconsistent with their experience of symptoms [58]. An explanation should be applicable to the unique circumstances of the individual for it to be acceptable, and this has been increasingly emphasised when communicating the diagnosis of FMD to patients [13]. However, participants in this study reported feeling unsafe, stigmatised and disbelieved in healthcare settings. This might bring into question the potential for acceptable and shared meaning making to inform a treatment plan. In a UK survey in 2011 44% of consultant neurologists believed there was an overlap between conversion disorder and feigning symptoms [93]. Such views, alongside perceptions of personality pathology as an underlying factor in FND [91], are likely to translate into patients' experiences of being invalidated and shamed, which was found in this and other studies [44,45]. The negative impact of repeated invalidation on wellbeing is well established [94,95] and some studies suggest that the invalidation by clinicians of patients' experience also influences wellbeing and experience of pain, as shown in a study of a different functional disorder, fibromyalgia [96]. A multidisciplinary expert review of stigma associated with FND highlighted its impact on poor service provision, poor treatments and poor prognosis for patients [48]. Link and Phelan [97] argue that

stigmatisation occurs on multiple levels simultaneously: intrapersonal, interpersonal and structural (e.g. discriminatory and/or exclusionary policies and systems) and thus should be addressed on all levels.

Some participants in this study accessed effective treatments at the cost of enduring numerous rejections and experiences of shame and resentment. This required a vast array of personal resources, resilience, energy and tenacity to avoid being thrown into despair and self-blame whilst already feeling vulnerable and depleted. They also did so thanks to private financial and social resources. This highlights significant health inequalities in accessing treatments, potentially reducing chances for recovery in the disadvantaged groups.

Implications for practice

The participants' experiences of battling through FMD point to important issues of power and control in relation to their bodies, identity, place in the society and in accessing healthcare. Specialist interventions as well as wider systemic changes are needed to facilitate provision of adequate, stigma-informed care for this population, focusing on issues of empowerment and engagement for both the patients and the clinicians.

A model of salutogenesis [98,99] has been found useful for informing health education for chronic illnesses [100] and could offer a framework for guiding service design and care provision for FMD. The model's core concept – a sense of coherence (SOC) – is a construct expressing the degree to which a person has a pervasive feeling that the internal and external stimuli and stressors in their environment are (a) comprehensible – can be understood, are ordered and explicable, (b) manageable – there are resources to cope with them and (c) meaningful – the demands and challenges are worthy of investment. SOC was found to have strong associations with good health outcomes and adaptive coping [101]. It is proposed that interventions and services are designed and delivered with the view to facilitate

SOC. The experiences of individuals with FMD in this study could be understood as a result of threat to SOC's three elements. Interventions could be shaped around those needs for regaining the sense of (i) comprehensibility – through supporting individuals and their families to develop shared, empowering and understandable narratives of FMD that are communicable to others and so identifying internalised stigma and negotiation of new valued identities, (ii) manageability – through developing resources to strengthen a sense of control with symptom-focused and coping-focused strategies, and involvement in shaping the treatment, (iii) meaningfulness – through setting up workable plans towards valued, meaningful goals.

Clinical psychologists are uniquely positioned not only to implement those recommendations in direct clinical practice, but to drive systemic changes and develop stigma-sensitive and accessible services through education, influencing and leadership as part of their everyday jobs. The power threat meaning framework (PTMF), developed by psychologists, highlights how a set of diagnostic ideas imposed by the powerful groups in the society can reinforce oppression of those given the diagnosis, trapping them in an inescapable disempowered position. Clinical psychologists have a role in highlighting and challenging the power-laden unhelpful narratives about FMD and facilitating culture of non-defensive inclusive practice.

Limitations and strengths

This study is a unique study in its exploration of experiences of FMD using IPA methodology. This method facilitated insight into individuals' lived experiences from a context-sensitive perspective of the current organisation of healthcare provision and societal dynamics. The study sample consists of people across the UK, reaching people in different locations and stages of treatment and recovery with different resources and different levels of

disability. Conducting interviews using teleconferencing facilitated access for those who would otherwise be excluded from the study. Healthcare practitioners made up 40% of the study sample, providing a unique insight from both patient and professional's perspectives, exposing the power dynamics and stigma in healthcare from an insider's perspective. Future research investigating the perspectives of professionals who provide FMD services and have the diagnosis might be particularly insightful and potentially helping to shift the stigma of this diagnosis. The relatively high representation of healthcare professionals in this study can be considered a strength and a limitation of the study, potentially amplifying the recruitment bias. The participants recruited through social media were self-selecting, with access to IT technology and following FND Hope's updates. It is possible that they were more informed and educated about their condition than those without engagement with information-based sites and online peer support. It is also possible that participants represented those who demonstrated greater persistence and determination or had greater personal and social resources to participate in research despite the many challenges that FMD presents, including fear of judgement. The interviewer's identity as a psychologist may have influenced who volunteered to take part and the content of the interview. The recruitment strategy may have excluded those who did not agree with their diagnosis of FMD. Future research could benefit from engaging those populations as well as those who accepted the diagnosis but did not access any support or services.

Conclusions

Participants in this study described continuous internal and interpersonal battles as part of living with FMD. Perceived ignorance and passivity in healthcare professionals was seen as promoting hopelessness, actively preventing recovery and being an unnecessary burden. This added to the already depleted internal resources, fear and helplessness. A number of barriers

to positive engagement with healthcare services and provision of effective interventions have been identified. A sense of oppression, loss of control and stigma in the participants have been described in the context of discriminatory power distribution in the society and healthcare settings. Antonovsky's model of salutogenesis could offer a useful framework to guide the design and delivery of services to facilitate empowerment of patients and clinicians alike.

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Table 1. Participant characteristics

PARTICIPANT[1]	**Age**	**TIME SINCE DIAGNOSIS**	**MAIN MOVEMENT SYMPTOMS**
Mark	53	6 years	tremors, spasms, limb weakness
Hannah	34	2 years	weakness in legs, drop attacks, muscles twitches, gait disturbance
Gemma	43	3 years	episodic paralysis, leg drag
Emma	50	2 years	arm weakness, leg drag
Harriett	32	14 months	tremor, leg weakness
Frances	45	13 months	gait disturbance, dystonia, body jerks, muscle weakness, episodic paralysis
Peter	66	2 years	gait disturbance, myoclonus
Leyla	35	18 months	spasms, gait disturbance, limb weakness
Lynn	24	18 months	one sided weakness, twitches, gait disturbance
Lisa	34	2 years	tremor, gait disturbance, legs weakness,

[1] Names of participants have been changed to protect anonymity

APPENDIX 2-A

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   Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
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- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

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APPENDIX 2-B Example of the coded interview for one participant - withheld from the final online version of the thesis to protect the participant's anonymity

APPENDIX 2-C Example of code clustering and emergent themes for one participant - withheld from the final online version of the thesis to protect the participant's anonymity

APPENDIX 2-D Final themes and sub-themes generated for one participant - withheld from the final online version of the thesis to protect the participant's anonymity

APPENDIX 2-E Table of final themes, subthemes and corresponding quotes - withheld from the final online version of the thesis to protect the participants' anonymity

Section Three: Critical Appraisal

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Word Count: 3513 (excluding references, tables, figures, and appendices)

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This critical appraisal summarises the main research findings and considers them further in the context of interpersonal and systemic power dynamics, and in relation to the findings from the literature review. Strengths and limitations of the main study are further discussed, followed by personal reflections on the engagement with the study from a critical theory perspective, and the role of clinical psychology in advancing research and practice.

The qualitative research study

The qualitative study described experiences of people living with functional movement disorders (FMD) as engaged in internal and interpersonal battles to regain control, dignity and hope. This was represented by three superordinate themes: (1) The tug of war with the secret agent within: the power struggle with symptoms; (2) Navigating risks of disclosing the diagnosis: stigma and self-preservation; (3) Pursuing hope, knowledge and treatments against helplessness and passivity. Perceived ignorance and passivity in healthcare professionals was seen as promoting hopelessness and actively preventing recovery. This was seen as an unnecessary burden adding to the already depleted internal resources, reinforcing fear and helplessness. Furthermore, access to treatment often required unrelenting determination and social and financial resources, which meant additional barriers for those who were socially and economically disadvantaged.

A sense of oppression, loss of control, personal and social identity were described by the participants as inherent to this diagnosis and could be understood in the context of stigma and discriminatory power distribution in society and healthcare settings. The experience of being dismissed, overpowered or misunderstood was common and made the participants feel unsafe and vulnerable when seeking medical care or social support. However, it seemed that they were not always seen as vulnerable or requiring help. It has been emphasised in the

literature that acknowledging vulnerabilities of particular groups highlights the responsibility and moral obligation to protect them, crucial to eliciting caring attitudes [1].

Even though the participants had a clear diagnosis, they reported many clinicians perceiving their FMD as medically unexplained and viewed them as having no medical cause to be treated. A review of literature offers useful insights into the interpersonal dynamics between health professionals and patients whose symptoms are not seen as attributable to known organic pathology, often called ‘medically unexplained symptoms’ (MUS). Such patients, pursuing treatments, explanations and care, are reported to elicit feelings of frustration, helplessness and inadequacy in healthcare professionals who feel coerced into providing more care whilst believing that medical care is not required [2-4]. Patients’ pursuits of help are not seen as an admirable perseverance but as undermining the doctors’ authority and trigger defensiveness, resentment and power struggles [5]. As a result, doctors have been reported to be ‘more firm’ and to take a more paternalistic stance, leading to a break in collaboration, drop out and discharges [6]. The perception of one’s role and possession of specialist knowledge might be crucial to professionals’ attitudes. In O’Connell’s study [7], health professionals saw their role in managing functional stroke symptoms as mostly providing re-assurance and psychological support, and acting as gatekeepers to prevent unnecessary investigations and procedures. It could be argued that seeing oneself as a ‘gate-keeper’ rather than a facilitator of an active treatment is likely to shape the direction of the consultation towards reassuring and dissuading from seeking treatment, which is experienced as dismissal by the patients, who are still left with the same troublesome symptoms after such consultations.

In the current study participants reflected that some professionals seemed caring and empathic to their suffering but at the same time lacked knowledge about FMD and its treatment. As a result, the clinicians were perceived as making harmful clinical decisions that

overrode the participants' requests and dismissed their concerns. Lack of knowledge about FMD and broader functional neurological disorders (FND) amongst healthcare professionals has been identified in previous studies [8-10]. In contrast, some participants encountered professionals who expressed empathy towards their struggles as well as understanding of FMD, and offered a clear treatment plan that was mutually agreed, workable and made sense to the patient. The perception of vulnerability or expression of empathy may not be sufficient to facilitate adequate care. Paradoxically, in the context of imbalance of power and lack of agreement between professionals and patients, it can encourage paternalism [6]. Power, agency and vulnerability have been proposed as interconnected and fluid and should not be separated [11]. The participants in the current study grappled with vulnerability, helplessness, and self-doubts whilst also demonstrating determination, influence, tenacity, and creativity. Defining a group of people by their vulnerability might foster assumptions of weakness or fragility, and facilitate paternalistic, patronising practice and disempowering attitudes [12,13]. In healthcare settings it could further deprive people with FMD the chance to assert their needs and access treatment. Recognising the agency, power and the right to exert influence alongside vulnerability may help prevent paternalism and promote truly collaborative care [6].

The salutogenesis model [14,15] has been found useful for informing health education for chronic illnesses [16] and could offer a framework for guiding service design for FMD. It could also be used to address potential feelings of inadequacy, frustration or helplessness in healthcare professionals. The model describes factors that help people maintain health and wellbeing in adverse circumstances. Its core concept - a sense of coherence (SOC) expresses the degree to which a person has a general feeling that the internal and external stimuli in their environment are (a) comprehensible – are ordered and explicable, (b) manageable - there are resources available to cope with the demands they present and (c) meaningful - the

demands and challenges are worthy of engagement and investment. Providing education for healthcare professionals about FMD and its modern frameworks could increase the sense of comprehensibility. The sense of manageability could be strengthened through clear care pathways, interdisciplinary working or access to specialist supervision to address intrapersonal, interpersonal and systemic barriers to positive engagement with patients. Sense of meaningfulness, the motivational and emotional component of SOC, is strengthened when individuals believe they can influence decisions and outcomes. If the professionals see their input as stimulating collaborative partnerships with patients, they are likely to experience less anxiety, reducing defensive practice and power struggle with patients.

Literature review

The literature review explored psychological interventions for functional movement symptoms (FMS) usually constituting the diagnosis of FMD. The psychological therapies were, for a long time, a treatment of choice for this population on the assumption that the physical symptoms were an expression of psychological distress, past trauma or internal conflict [17]. Therefore, FMD were seen as a mental health issue, not a medical one. However, the evidence base for psychological interventions is still insufficient and understanding of FMD has significantly changed in the last 20 years [18-21].

The scoping review highlighted that different psychological interventions use different conceptualisations of FMD and target different assumed underlying mechanisms. Additionally, a variety of outcomes are measured, suggesting that different researchers consider different outcome domains as important in FMD. Evaluation of the interventions usually did not incorporate any measures of acceptability of the interventions, which is disappointing in the context of reported dissatisfaction with psychological explanations for FMD and low uptake of the referrals to psychology. The available explanations for this in the

literature quote patients' lack of insight [22] resistance [23] or investment in secondary gains, coming from the sick role [24]. It is striking that these narratives have been repeated for decades and little evidence exists to support them. Patients are often not offered alternative treatments if they do not accept the provided explanations. In one study, patients who did not accept the rationale for having cognitive behavioural therapy (CBT) were not accepted into the multidisciplinary treatment programme [25]. Similarly, one of the participants in the current qualitative study spoke of conditional access to physiotherapy only upon completion of psychotherapy. Such conditions are unsupported by evidence and it is physiotherapy, not psychotherapy, that has accumulated most evidence for its effectiveness in FMD [21,26,27]

These findings support the main study's results regarding presence of judgemental narratives and the exclusion of people with FMD from shaping the understanding or treatments of FMD. The implications of this will be explored further in the personal reflections section.

Strengths, limitations and future projects

It is acknowledged that participants in the research study might not be representative of the whole of FMD population. To access the advert about this study, the participants had to be engaged with social media and subscribe to updates from an international FND charity organisation. Having potentially experienced the stigmatising attitudes and misunderstandings of healthcare professionals, the thought of participating in research conducted by a psychologist may understandably have been aversive to some, and likely the research would have appealed only to those people who felt prepared and resourced enough to deal with such self exposure. It is possible that others, who felt more vulnerable, hopeless or had no access to supportive communities, would not take the risk of speaking up about their experiences and hence their experiences might not be reflected in this study. However,

this in itself poses an important issue. Participants in the research study described considerable emotional, physical, social and material investments needed to persevere to access treatments despite rejection, humiliation or passivity from healthcare professionals. If a group of fairly informed, determined, resourced people, most of whom occupied professional roles, are experiencing fear, helplessness, self-doubt and lack of power and control in healthcare services, then people who do not have social, financial or personal resources are likely to struggle even more. The Health Stigma and Discrimination Framework [11] emphasises that stigma in healthcare intersects with other axes of disempowerment and marginalization making some people more disadvantaged by health-related stigma. Due to this, it is reasonable to suspect that people with FMD from disadvantaged or marginalised groups are at particular risk of suffering from stigma, health inequalities and poor outcomes.

This study used online recruitment and video interviews. This facilitated access to the study across UK and for those whose physical disability would make it difficult to attend in person. It was the first study exploring experiences of FMD nationally and with participants recruited regardless of their engagement with the health service or stage in treatment. This allowed a wide breadth of experiences and perspectives. Employing interpretative phenomenological analysis facilitated in-depth exploration of the individuals' meaning making, embedded in the wider societal context.

People who fully recovered from FMD might have not considered themselves as eligible for the study and might no longer be engaged with symptom-related websites. Although case studies describing full recovery exist, narratives of people who recovered are missing from the literature and could contribute important insights about the process and factors enabling recovery from the participants' point of view.

Qualitative methodology should be employed by future researchers to further examine different aspects of the experiences of people with FMD whose perspectives have been

neglected. A number of issues were highlighted in the scoping literature review that could benefit from qualitative enquiry. For example, studies examining reasons and experiences of rejecting referrals to psychological therapies or experiences of undergoing psychological therapies - of different therapeutic modalities (e.g. CBT, psychodynamic psychotherapy, hypnosis, acceptance and commitment therapy). Additionally, regular evaluation by the patients' of the acceptability of these interventions, their particular techniques, therapeutic goals and achieved outcomes – would help understand patients' needs and improve social validity of treatments. Research and practice-based projects involving education and collaborative, multidisciplinary re-formulation of FMD could help revitalise the field and inspire dialogue about new ways of delivering psychological therapies, that would incorporate novel biopsychosocial models and patients' perspectives.

Personal reflections

Interpretative phenomenological analysis [28] posits that the researcher introduces their own interpretation to the collected data and those interpretations and assumptions need to be identified and 'bracketed off' so as not to be imposed on the experience of the participants of the study. By keeping a research journal and a reflective stance during the project I was able to identify many of the emerging interpretations, impressions and emotions. I became aware how my life experiences have influenced the choice of the topic, the type of the analysis and the interpretative stance.

As a child I had numerous illnesses which influenced my relationship with pain, illness and others affected by it. In my adult life, I had an episode of medically unexplained symptoms and have a family member who frequently experiences a variety of symptoms during times of intense stress or worry. These experiences contributed to the development of beliefs about the complexity and diversity of ways in which the body and mind interact as

well as the appreciation of pain and physical illness' impact on emotional wellbeing, identity and self-worth. Striving to avoid theoretical oversimplifications, to respect and learn from the insights of those with lived experiences and to critically appraise dominant narratives - have undoubtedly influenced my engagement with the study.

During the project I observed in myself a growing sense of obligation and a debt to the participants, for their courage and for entrusting me with their stories and their hope. I found myself feeling the weight of responsibility for carrying their messages so that they could be heard. I did not want to disappoint, to let them down by giving up and joining the passive and indifferent crowds they encountered before. I recognised this as potentially a common phenomenon that happens in therapy called, in the psychoanalytical tradition, a projective identification [29]. Through this lens I could see myself identifying with the projected hope, responsibility and longing for a positive change, for the voices to be heard and understood - with the 'good' nurturing figure that was needed and that I wanted to be. However, I also noticed the discomfort of being in this position, of being indebted and feeling pressure to use what I've been given to good effect. It felt tiring as I did not know whether I could fulfil the expectations, the task seemed big and I felt too small for it. Part of me wanted to get out of this obligation. Perhaps by explaining it as a collusion with the unconscious transference processes I could distance myself from it and describe it as the participants' 'stuff', not mine, to carry. I could just 'name' it, 'bracket it off' and stand aside.

Another way of interpreting the emotional and motivational impact of listening to the participants' stories would be that their passion and determination were contagious and their suffering and struggle humbling and evoked a natural instinct to help. Another, a political motivation, would be to call out prejudice and oppression in the society. It is possible that coming from a non-privileged group myself made me identify with those who are treated with a patronising tone and approached with dominance and superiority. Such interpretation

introduced a risk that perhaps this was my battle and I projected it onto the participants. In such case this narrative might need to be put aside, to not blur the participants' experience. There were many motives and many possible interpretations of them. The question of which one was more accurate or less biased and therefore should guide my approach, was gradually replaced with the question of who benefits from which interpretation and who is disadvantaged by it. It is my belief that full 'bracketing' of own assumptions and bias is not achievable nor necessary and I attempted to contextualise different perspectives instead in line with critical theorists' propositions that 'a theory is always for someone and for some purpose' [30].

Critical approaches to epistemology have been useful in providing a wider systemic lens. They see all knowledge and interpretations as embedded in the social and political context produced in tensions between power relations [30]. Dominant narratives carry bias of underrepresenting the underprivileged narratives and interpreting reality from the positions of privileged groups. From this framework, my role as the researcher would be to examine the power relations underlying the participants' experiences and to challenge the social order that creates identified inequality or injustice.

This study confirmed that people with FMD have not had enough power to have their stories heard – they have felt their narratives have been misrepresented, misunderstood and misjudged. Their protest has traditionally been interpreted by researchers and clinicians as resistance, reluctance, denial, lack of insight, or a personality disorder. For critical theorists individual problem solving without challenging the social order, is not the purpose [30]. It is argued that when information and knowledge are gathered and interpreted from within the existing order, the problem solving will only reproduce existing injustice and legitimise inequality and serve interests of the privileged groups [30].

Using critical theory made me appreciate that improving patients' experience in healthcare services might be difficult if done from within paternalistic frameworks where patients are seen as lacking insight and resisting sensible interventions. A shift in paradigm challenging the underlying assumptions on which the previous knowledge was based is needed to create a new order, where patients' perspectives are privileged and respected, and understanding of FMD and treatment needs is co-produced.

Reflections on the role of clinical psychology

The current study highlighted the role of psychological theory and practice in shaping treatments for FMD, and professionals' continuing attachment to psychological explanations of FMD which are so often contested by patients [10] and challenged by new neurobiological findings [19,31]. Incorporating insights from other disciplines seems to be slow and there is no consensus framework for psychological interventions for FMD. As the interest and research in FMD is rapidly growing, the time seems ripe for psychology to revise its current theories and practice and join in the development of new effective and acceptable treatments.

In mental health settings, clinical psychologists are encouraged to challenge the dominance of the medical model and to counterweight what has been described as colonisation of the biopsychosocial model by the medical model [32]. It might be that the opposite process has been happening for people with FMD where the biopsychosocial model has been colonised by psychological models. Patients have been raising concerns about the excessive focus on psychosocial factors but their voices have not been sufficiently validated in the past.

Psychological theory has been used in unhelpful ways and potentially perpetuating stigma and misunderstanding of people with FMD. Disseminating psychological knowledge in this area needs to be done thoughtfully and tentatively to prevent overly simplistic and

unfounded claims. It is often at the point of diagnosis when psychological factors are introduced and explained and which often leads to the communication breakdown [33]. Involvement in education of other professionals about the role and extent of possible psychosocial factors in FMD and ways of communicating it in a non-assuming and non-imposing way might facilitate access to psychological interventions, where appropriate.

The skill set of clinical psychologists places them in a unique position to address many of the identified issues. They are reflexive scientist practitioners [34] who are trained to critically appraise and evaluate research and current practice [35]. The British Psychological Society's Practice Guidelines emphasise that all interventions need to be based on provisional hypotheses and modified in the light of new data "to ensure compatibility with service user needs" [35]. Collaborative care and partnership towards mutually agreed goals [34] and supporting people to assert their needs and find their voice are at the core of clinical psychology's philosophy [32]. Clinical psychologists can play a significant role in challenging the disempowering narratives, systemic and interpersonal barriers to accessing effective treatments and facilitating organisational change through engagement in leadership, education.

However, a recent survey in Australia [9] reported 84% of psychologists admitted to insufficient education about FMD. This, alongside the quickly changing landscape of evidence for FMD, suggests that clinical psychologists could benefit from specialist training themselves. Additionally, the skills of critical analysis could be used to revisit and challenge some of the underlying assumptions about FMD in psychological interventions that might be facilitating paternalistic care or perpetuating unhelpful attitudes. Lastly, collaborating with professionals from other disciplines could promote broader perspectives on FMD, prevent psychological bias and contribute to development of novel theoretical frameworks that might advance the field of FMD treatments.

Conclusions

In conclusion, this research has highlighted the complexities of understanding and conceptualising FMD and the challenges it presents to patients, researchers and clinicians. The uncertainty and lack of consensus surrounding FMD are a source of misconceptions, stigma and interpersonal power struggles between healthcare professionals and patients. The helplessness and lack of control in the context of unpredictable and disabling symptoms has a detrimental impact on the wellbeing and quality of life of those affected by FMD and motivates them to seek hope and care from health professionals. However, the evidence base for effective treatments is limited and psychological therapies, frequently offered as the treatment of choice, have often been rejected by patients. Incorporating neurobiological as well as psychosocial models of FMD might improve the perception of relevance of psychological therapies for physical symptoms. Furthermore, a systematic and regular evaluation of acceptability of offered interventions is needed. Clinical psychologists are well placed to facilitate critical revision and development of psychological theoretical frameworks for FMD, to challenge disempowering narratives and contribute to systemic change through leadership and service delivery activities.

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Section Four: Ethics proposal

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Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: Living with functional movement disorders.

Name of applicant/researcher: Sylwia Bazydlo

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail: s.bazydlo@lancaster.ac.uk **Telephone**: (please give a number on which you can be contacted at short notice)

Address:

3. **Names and appointments of all members of the research team (including degree where applicable)**

Sylwia Bazydlo, Trainee Clinical Psychologist,
Dr Fiona Eccles, Lecturer, Research supervisor, Lancaster University
Dr Catherine Parker, Consultant Clinical Psychologist, Cumbria Partnership Foundation Trust

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant: Dr Fiona Eccles, Dr Catherine Parker

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:
Dr Fiona Eccles, Lecturer, Research supervisor, Lancaster University
Dr Catherine Parker, Consultant Clinical Psychologist, Cumbria Partnership Foundation Trust

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o
4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? n o
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Functional Movement Disorder (FMD) is a condition where a person's movement is affected and is believed to be caused by an error in the nervous system's functioning rather than a structural damage to the brain or muscles. Despite FMD being thought of as treatable, people with FMD have poor outcomes and accurate diagnosis is often delayed. There is a lack of sufficient evidence about effectiveness of currently provided psychological interventions to help people manage their symptoms and improve quality of life.

This study will explore their experiences of people living with FMD, their treatments, how they make sense of their condition and how it impacts their life. I will interview up to 12 people and analyse their responses. The findings will be summarised to capture important themes within and across individual stories. It is hoped to inform treatments and support that would respond better to the needs highlighted by the study.

2. **Anticipated project dates (month and year only**)

Start date: March 2019 End date: May 2020

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

I will be recruiting from 6 up to 12 people, as a typical sample for an Interpretative Phenomenological Analysis (IPA) study (Smith et al. 2009). Participants recruited will be aged 18 and over, any gender, and living in the UK (to ensure a fairly homogenous group in terms of received healthcare and support by the national health system) who have been diagnosed with any type of functional movement disorder at least 12 months prior to the interview (to ensure sufficient time and experience of living with the disorder and to be able to reflect on the course, treatment and impact of the diagnosis as well as the symptoms).
Participants would need to self-report that they have a diagnosis of Functional Movement Disorder (FMD) or Functional Neurological Disorder (FND) or Functional Neurological Symptoms Disorder or Psychogenic Movement Disorder or Somatoform/somatisation Disorder or Conversion Disorder or Functional Weakness or Functional Dystonia or other similar diagnosis that is found to be caused by a disturbance in functioning of the nervous system rather than structural damage in the brain or muscles. The participants would also need to experience at least one of the following symptoms:
- paralysis (or episodic paralysis) or weakness in an arm or leg
- muscles spasms affecting movement
- dystonia – involuntary muscle contractions that cause slow repetitive movements or abnormal postures
- myoclonus – sudden, involuntary jerking of a muscle or a group of muscles, affecting movement or posture
- tremor affecting movement or posture
- gait disturbances

Exclusion criteria:
- functional movement disorder as secondary to organic or structural (resulting from a damage to the brain or muscles) neurological disorder.

Participants with other medical conditions and other functional disorders in addition to FMD will not be routinely excluded. However, prior to arranging an interview, I will confirm that the movement disorder is their primary medical concern to preserve homogeneity of the sample.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

At the recruitment stage I will be collaborating with FND Hope – an international not-for-profit organisation who agreed to assist with the study. FND Hope has a registry of people who had already expressed their interest in taking part in research relating to FND and had submitted demographic and FND related information via the registry survey. There are currently 84 people registered on this list in the UK. Individuals who are believed to meet the inclusion criteria would be targeted and

contacted by FND Hope via email inviting them to take part in the current study. The email will include the participant information sheet and the consent form for information.

FND Hope will publicise information about the study on their website (https://fndhope.org/), social media and patient engagement platforms: Twitter, Facebook, Instagram and Health Unlocked (https://healthunlocked.com/). I will provide a link to the information about the study on https://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/research/.

As a contingency plan, if not enough participants were recruited, I would contact the Dystonia Society – a charity organisation supporting people with all forms of dystonia, including functional dystonia. I would ask for the link to the study to be posted on their website and social media sites. If there was still a need to recruit more participants, I would circulate the link to the study on Twitter via personal contacts. The Twitter account would be opened solely and exclusively for the purpose of the research study.

If they decide they would like to take part, the participants will need to contact me via email or phone. I would then contact them to discuss the study further. If they are happy to proceed, an interview will be arranged. At that point I would also ask them for their address in case of immediate risk becoming apparent during the interviews so that the emergency services could be contacted. I might also use their address to post the participant information sheet and the consent form if they don't have access to an email, with their agreement. The addresses will be stored on the main investigator's secure storage space on the Lancaster University's server. They will be encrypted, password protected and will be deleted once the interviews are completed unless the participants wished to have to study findings sent to them by post. In such case, the addresses will be deleted after the study findings were sent via post.

I would also ask about other medical concerns they might have that might be impacting their experience of the movement disorder to establish eligibility for the study

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Data would be collected through semi- structured interviews lasting around an hour each. Participants will be encouraged to talk about the issues that are most salient to them, so the interview schedule will serve as a guide rather than a comprehensive list of questions. The interviews would be conducted through the phone, Skype or Zoom. A face to face interviews might be possible if participants are based in Lancashire or Cumbria, within accessible distance for the researcher and a suitable, local community venue is available and accessible to the participants. There would also be a possibility of an interview via email or WhatsApp messaging if a face-to-face/audio/video medium would be a barrier for people in accessing the study (for example, if their speech was affected).

Additional demographic information will be collected: age, gender, living situation (alone or with others), occupational status (working or not), time since the diagnosis, duration of symptoms, type of symptoms, psychological treatments offered and accepted, comorbid conditions – to situate the sample and assist in the analysis of the data. This data will be recorded in a table of the study sample characteristics in an electronic version and stored on the main investigator's secure storage space on the Lancaster University's server, separately from the personal data and the interview transcripts.

The participants' addresses will be collected in case of immediate risk becoming apparent during the interviews so that the emergency services could be contacted. They will be stored on the main investigator's secure storage space on the Lancaster University's server. They will be encrypted, password protected and will be deleted once the interviews are completed unless the participants wished to have to study findings sent to them by post. In such case, the addresses will be deleted after the study findings were sent via post.

The study will adopt interpretative phenomenological analysis (IPA) as it is particularly suited to exploring under-examined topics (Smith & Osborne, 2015). Through an inductive analytical process, it would provide a detailed understanding of the participants' lived experiences of FMD and their subjective meaning making of that experience. To aid that process the interviews will be transcribed verbatim to create written transcripts. As I intend to focus on the individual's unique experience embedded in their context and perspective, IPA is ideal as it's idiographic in its nature and facilitates exploring particular perspectives in their specific contexts (Smith et al. 2009).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Interviews will be recorded on a digital audio recorder (using a recorder earpiece when conducting phone interviews to ensure best quality) and then transferred as soon as possible to and stored on the main investigator's secure storage space on the Lancaster University's server for the duration of the study. The transcribed interviews and copies of typed interviews held via email or WhatsApp will be anonymised and stored in the file with the interview recordings on the main investigator's secure storage space on the Lancaster University's server. Original emails and WhatsApp messages will be deleted immediately after copying them into the secure location. Participants will also be advised to delete the copies of interviews from their emails or WhatsApp.

Audio recordings of the consent and written consents will be encrypted, password protected and stored with a code to link them with their respective interview transcripts but in a separate file from non-personal data, such as interview transcripts.

Once the project has been completed and examined, audio recordings of the interviews will be deleted. The remaining files will be transferred securely using the university's encrypted file transfer software (currently Box) to the Research Co-ordinator at the Doctorate in Clinical Psychology programme and stored on the university's secure server.

If any participants request the interviews to be conducted via email exchange, they will be informed that those means cannot be entirely secure. They will be encouraged to use password protected attachments when sending emails to increase the security of data but will be advised that the security still could not be guaranteed. The contents of the emails would be uploaded to the secure space on the university server and the original emails deleted. Participants would be asked to also delete the email exchanges.

Participants' addresses and other contact details (email addresses, phone numbers, Skype ID) and table with information about email/phone exchanges (not including interview contents) will be encrypted, password protected and stored with audio and written consents. They will be deleted immediately after the interview is concluded unless the participants wish to be sent the study report with findings. In such case their contact details will be deleted after the study findings report is sent out to them.

The electronic data will be stored for ten years after which it will be deleted by the Research Co-ordinator at the Doctorate in Clinical Psychology programme under the direction of the university supervisor.

7. Will audio or video recording take place? ☐ no ☒ audio ☐ video
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

The interviews will be recorded on a digital audio recorder that cannot be encrypted so the audio data will be transferred immediately after each interview (when interviews are conducted from the researcher's home - phone/video link interviews) to a secure storage space on the Lancaster University server. When interviews are conducted face-to-face the data will be transferred onto an encrypted memory stick immediately after the interview. It will then be transferred to the secure storage space on the Lancaster University server as soon as possible – either when the researcher returns home or arrives at Lancaster University campus, whichever is the sooner.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings of the interviews will be stored on secure space on Lancaster University's server and destroyed after the research project has been completed and examined as part of the the Doctorate in Clinical Psychology qualification. Audio recordings of the consent will be encrypted, password protected and stored with a code to link them with their respective interview transcripts but in a separate file from non-personal data, such as interview transcripts. Audio recordings of the consent will be stored for 10 years.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder
8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The raw data will not be shared for confidentiality reasons. The transcripts of interviews are likely to contain individuals' unique and cohesive narratives that, if shared in their entirety, might compromise confidentiality even if specific identifiable data are removed. The data will be transferred to the Research Co-ordinator at the Doctorate in Clinical Psychology programme who will have it stored for ten years after which it will be deleted under the direction of the university supervisor.

8b. Are there any restrictions on sharing your data ?
Sharing of the raw data will not be appropriate so there will be no access to it for people who have not been working on the study.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Participants identified in the FND Hope Registry as eligible to take part will be emailed the consent form together with participant information sheet in the initial email inviting them to take part in the study so that they can familiarise themselves with the project and with the consenting process. Those who express their interest in the study in response to seeing an advertisement of the project, will be sent out the same information after they make an initial contact expressing their interest in the study.

Participants will be encouraged to voice their concerns, questions and any issues regarding the project, the consent and its withdrawal. They will be given the opportunity to do so via email, to request a telephone call to discuss it further and at the start of the interviews. The concerns, requests and other information included in email exchanges and phone calls will be recorded in a table to keep track of the exchanges with participants to ensure effective communication and transparent consent process.

They will be advised and reminded that they can withdraw their consent at any point in the study up to the data analysis stage after which point it might be impossible to extract the data. This advice will be included in the consent form, participant information sheet and re-iterated at the start of the interviews. In the process of seeking informed consent, the participants' attention would be drawn to potential upset and distress and we would discuss their current sources of personal and professional support to seek before or after the interviews.

The participants will be asked to read the consent forms prior to interviews. They will be informed they don't need to return it as it will be reviewed with them at the start of the interview. They will be asked to confirm they understand and agree to participate in the study. I will audio record the consent process into a standalone recording, separate from the interview recording (in the case of phone/video link interviews). Asking the participants to sign a written consent and return it prior to the interview would be impractical as we would rely on the prompt return of the forms to arrange or proceed with interviews which could cause long delays and disruptions. In the case of face-to-face interviews, the participants will be asked to sign a paper consent form at the start of their interviews. In the case of email/WhatsApp interviews, the participants will be asked to sign, scan and return the consent forms via email or WhatsApp message.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

There is a potential for distressing material to arise during interviews given the personal emphasis of the research question and many challenges associated with living with functional neurological disorders. In the process of seeking informed consent, the participants' attention would be drawn to potential upset and distress and we would discuss their current sources of personal and professional support to seek before or after the interviews.
Participants will be given the contact information of relevant support services as part of their participant information sheet.

Participants will be informed they can withdraw from the study at any point before and during the interview and then up to the data analysis stage when the themes are merged and after which data might not be possible to be extracted.

Participants will be advised they can stop the interview at any point to have a break, postpone to another time or cancel it altogether. I will be mindful of signs of distress in participants during the interview and remind them of the option to pause, postpone or withdraw. I will also seek participants' consent to continue discussing a topic/aspect that is the source of distress to them. In the event of participants becoming severely distressed and expressing thoughts of harm to themselves or someone else I will follow the process agreed with them prior to the start of the interview – I could contact the person named by them and in the case of immediate risk - the local emergency services. I would also discuss this with my field and university supervisors – Dr Fiona Eccles and DR Catherine Parker

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

There are no physical risks anticipated for the researcher when the interviews will be conducted via telephone or online from the researcher's home. The phone number that might be used for the participants to contact the researcher or to arrange interviews will be obtained from the Doctorate in Clinical Psychology programme and will not be the researcher's personal phone number. The researcher might use a personal mobile phone for conducting the interviews (when telephone interviews are requested by the participants) in which case a '141' number will be used to anonymise the caller's ID and the participants will be advised of it to ensure they accept the call. The choice of personal mobile phone for the interviews would be made to reduce the project's cost as phone calls are free of charge from the researcher's personal mobile phone. However, a DClinPsych programme's phone number will be used for the participants to be able to contact the researcher before or after the interview. When using Skype, a professional Skype ID will be created for the purpose of the interviews.

When interviews are conducted face-to-face, the researcher will adhere to Lancaster University Lone Working Policy. Interviews will be arranged in suitable community venues with reception facility or where other people would be working in physical proximity and will be aware of the researcher's presence and estimated time of the interviews. Researcher will also make sure that somebody else – a colleague or a friend is aware of the location and time of the interviews.

In case of any distress to the researcher as a result of the interviews, the research supervisors will be contacted for advice and support if needed.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits to participants from taking part in this study, however the participants might be interested in contributing to the evidence base that could shape the care and treatments they might receive in the future.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:
There will be no incentives to participate.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

There are limits to confidentiality regarding the content of the interviews and the participants will be advised of them at the beginning of the interviews, on the participant information sheet and on the consent form: In the case of significant risk being highlighted in the interviews regarding the participants or other people, it will be discussed with the field or research supervisor and an appropriate action agreed (unless there is an immediate danger to the participant or other people, in which case the appropriate emergency services will be contacted first).
At the start of the interviews participants will be reminded that internet is not a secure medium of communication and will be reminded of their right to withdraw from the study. The interviews will be transcribed by the researcher herself. The transcripts of the interviews will be anonymised and all identifiable information removed or changed. Whenever direct quotes are used to illustrate a theme/sub-theme or a reflection, all care will be taken for the person not to be identifiable from it and pseudonyms will be used.

The data from the study will be stored securely on the university's server with access to it by the researcher, the research supervisor and the research co-ordinator on the Doctorate in Clinical Psychology programme.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

I have consulted with two members of FND Hope who are or have been living with FMD to seek their views and advice regarding the design, recruitment and interview schedule of the research project. They have also provided initial feedback on participant information form and consent form. FND Hope will review the project protocol after it's been approved by the university ethics committee and will provide further feedback before the study commences. If any changes need to be made as a result of this, I would submit an application to the university ethics committee for approval of the amendment.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The findings will be written up into a thesis as part of the doctorate in clinical psychology. The findings will be summarised in a brief report and shared with FND Hope and potentially publicised on their website and social media sites. The report will also be sent to those participants who declare at the interview that they want to receive it. It is intended that the research will be submitted to a peer reviewed journal. The findings will be presented at a thesis presentation day at Lancaster university as part of the Clinical Psychology programme. If the opportunity arises, the findings would also be presented at academic conferences.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

none

SECTION FOUR: signature

Applicant electronic signature: Sylwia Bazydlo Date 14/02/2019

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☐x

Project Supervisor name (if applicable):Fiona Eccles Date application discussed 6/2/19

Submission Guidance

1. Submit your FHMREC application by email to Diane Hopkins (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    i. **FHMREC application form.**
    Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    ii. **Supporting materials.**
    Collate the following materials for your study, if relevant, into a single word document:
        a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
        b. Advertising materials (posters, e-mails)
        c. Letters/emails of invitation to participate
        d. Participant information sheets
        e. Consent forms
        f. Questionnaires, surveys, demographic sheets
        g. Interview schedules, interview question guides, focus group scripts
        h. Debriefing sheets, resource lists

    Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.
2. Submission deadlines:
    i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:
        a. existing documents/data only;
        b. the evaluation of an existing project with no direct contact with human participants;
        c. service evaluations.
3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

THESIS PROTOCOL

Living with functional movement disorders.

Principal Investigator: Sylwia Bazydlo, Trainee Clinical Psychologist, Lancaster University

University Project Supervisor: Dr Fiona Eccles, Lecturer in Research Methods, Lancaster University

Field Supervisor: Dr Catherine Parker, Consultant Clinical Psychologist, NHS Cumbria Partnership Trust

Background

Functional movement disorders (FMD) are part of a wider cluster of functional neurological disorders (FND) but refer specifically to neurological disorders of movement caused by a disturbance in functioning of the nervous system, rather than a damage to the brain or the muscles. Although thought of as treatable, the outcomes for FMD are poor with prevalence of the condition at 3%– 20% amongst the general movement disorder clinic patients (Hallett, 2006) and high levels of disability and psychological problems (Pringsheim & Edwards, 2017).

FMD were traditionally considered to be caused by psychological factors and has also been known as Psychogenic Movement Disorder or Conversion Disorder. People affected often fall between neurology and psychiatry or psychology without a clear and effective pathway for treatment, causing frustration and anguish to both the professionals and the service users (Pringsheim & Edwards, 2017). Due to uncertain aetiology, lack of sufficient understanding and adequate services people with FMD face stigma, isolation and lack of adequate care. Pharmacological and psychological approaches tend to focus on assumed

underlying psychological issues and trauma, though it has been noted that ‘compliance is a major concern’ (Thomas & Jankovic, 2004, p. 437) and that there is little evidence to guide treatment decisions (Ricciardi & Edwards, 2014).

In the last decade there has been a growing shift in the understanding of FMD reflected in the fact that the term functional rather than psychogenic or conversion disorder is increasingly proposed as a more adequate and acceptable diagnosis, as this acknowledges a variety of potential causes and a need for a multidisciplinary approach (Demartini, D'Agostino, & Gambini, 2016; Ding & Kanaan, 2017; Stone et al., 2011). As part of that shift, there is an emphasis on validating the service users’ experience of their symptoms as ‘real’ and offering appropriate, acceptable treatment. However, despite the growing interest and research in the FMD, there is no research exploring what the people affected experience when living with FMD and how they are affected by the treatment or its lack.

Previous studies have focused on quantitative measures of psychological profiles of individuals with the condition (Ekanayake et al., 2017; Tomic et al., 2017), their neurological (Voon et al., 2016) or psychological (Ludwig et al., 2018) predictive factors for the disorders or means for differential diagnosis to separate an organic disorder from a psychogenic one (Pastore et al., 2018; Scheidt et al., 2014). None so far asked the individuals with the condition an exploratory question to increase our understanding of the challenges faced and needs to be met when designing and choosing treatments. There are no current guidelines by the National Institute of Health and Care Excellence for the treatment of FMD. In a draft consultation guideline for suspected neurological conditions, NICE (2017) mentions functional symptoms as mimicking neurological disease, triggered by emotional and psychological factors and recommending referral for an unspecified ‘psychological support’.

Despite the recommendation and practice of referring people with FMD for psychological support or therapy in the hope of addressing the underlying emotional causes and reducing the physical symptoms, there is little evidence for effectiveness of any psychological therapy with FMD. There have been studies of cognitive behavioural therapy (CBT) for treatment of the wider category of Functional Neurological Disorders (FND) and the results are varied between the different studies and different treatment designs (Ricciardi & Edwards, 2014). Moreover, CBT or psychological input is often regarded by the service users as inappropriate and unacceptable form of treatment (Sharpe et al., 2011).

A multidisciplinary expert review made recommendations to reduce stigma for people with FND and improve access to adequate treatments (Rommelfanger et al., 2017). One of three identified pathways to achieve that is to empower people with FMD 'to be heard and drive changes in care' through gaining insight from the patient to inform treatment plans and goals (Rommelfanger et al., 2017).

The current study would address the gap in the research base, exploring the experiences of people with FMD and facilitating their perspectives to be heard. The findings from the project could contribute to reduction of stigma and would inform the design of appropriate psychological treatments that would be acceptable to people living with the condition.

Method

Design

Qualitative methodology using Interpretative Phenomenological Analysis (IPA) (Smith et al. 2009) to explore the subjective experiences of people affected by the disorder.

Participants

I will be recruiting from 6 up to 12 people, as a typical sample for an IPA study (Smith et al. 2009). Participants recruited will be aged 18, any gender, and over and living in the UK (to ensure a fairly homogenous group in terms of received healthcare and support by the national health system) who have been diagnosed with any type of functional movement disorder at least 12 months prior to the interview (to ensure sufficient time and experience of living with the disorder and to be able to reflect on the course, treatment and impact of the diagnosis as well as the symptoms).

Participants would need to self-report that they have a diagnosis of Functional Movement Disorder (FMD) or Functional Neurological Disorder (FND) or Functional Neurological Symptoms Disorder or Psychogenic Movement Disorder or Somatoform/somatisation Disorder or Conversion Disorder or Functional Weakness or Functional Dystonia or other similar diagnosis that is found to be caused by a disturbance in functioning of the nervous system rather than structural damage in the brain or muscles. The participants would also need to experience at least one of the following symptoms:

- paralysis (or episodic paralysis) or weakness in an arm or leg
- muscles spasms affecting movement
- dystonia – involuntary muscle contractions that cause slow repetitive movements or abnormal postures
- myoclonus – sudden, involuntary jerking of a muscle or a group of muscles, affecting movement or posture
- tremor affecting movement or posture
- gait disturbances

Exclusion criteria:

- functional movement disorder as secondary to organic or structural (resulting from a damage to the brain or muscles) neurological disorder.

Participants with other medical conditions and other functional disorders in addition to FMD will not be routinely excluded. However, prior to arranging an interview, I will confirm that the movement disorder is their primary medical concern to preserve homogeneity of the sample.

Data Collection/Procedure

At the recruitment stage I will be collaborating with FND Hope – an international not-for-profit organisation who agreed to assist with the study. FND Hope has a registry of people who have already expressed their interest in taking part in research relating to FND and have submitted demographic and FND related information via the registry survey. There are currently 84 people registered on this list in the UK. Individuals who are believed to meet the inclusion criteria would be targeted and contacted by FND Hope via email inviting them to take part in the current study. The email will include the participant information sheet and the consent form for information.

FND Hope will publicise information about the study on their website (https://fndhope.org/), social media and patient engagement platforms: Twitter, Facebook, Instagram and Health Unlocked (https://healthunlocked.com/). I will provide a link to the information about the study on the Doctorate in Clinical Psychology student research page: https://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/research/.

As a contingency plan, if not enough participants were recruited, I would contact the Dystonia Society – a charity organisation supporting people with all forms of dystonia, including functional dystonia. I would ask for the link to the study to be posted on their

website and social media sites. If there was still a need to recruit more participants, I would circulate the link to the study on Twitter via personal contacts. The Twitter account would be opened solely and exclusively for the purpose of the research study.

If they decide they would like to take part, the participants will need to contact me via email or phone. I would then contact them to discuss the study further. If they are happy to proceed, an interview will be arranged. At that point I would also ask them for their address in case of immediate risk becoming apparent during the interviews so that the emergency services could be contacted. I might also use their address to post the participant information sheet and the consent form if they don't have access to an email, with their agreement. The addresses will be stored on the main investigator's secure storage space on the Lancaster University's server. They will be encrypted, password protected and will be deleted once the interviews are completed unless the participants wished to have to study findings sent to them by post. In such case, the addresses will be deleted after the study findings were sent via post. I would also ask about other medical concerns they might have that might be impacting their experience of the movement disorder to establish eligibility for the study.

Participants will also be given an option of email exchanges or WhatsApp messaging instead of video/phone/face-to-face interviews if they would like to participate but would otherwise be unable to engage in video/phone/face-to-face communication, for example due to speech difficulties.

Participants will be sent the participant information sheet and the consent form to read before the interview. Participants will be informed they don't need to return the consent form. When the interview is conducted face-to-face, as I will review the consent form with them at the start of the interview and ask them to sign it if they want to proceed. In the case of phone/video link interviews I will read the consent form to them and ask them to confirm if

they understand and agree to participate in the study. I will audio record the consent process into a standalone recording, separate from the interview recording.

Data would be collected through semi- structured interviews lasting around an hour each. Participants will be encouraged to talk about the issues that are most salient to them, so the interview schedule will serve as a guide rather than a comprehensive list of questions. The interviews would be conducted through the phone, Skype or Zoom. A face to face interviews might be possible if participants are based in Lancashire or Cumbria, within accessible distance for the researcher and a suitable, local community venue is available and accessible to the participants. There would also be a possibility of an interview via email or WhatsApp messaging if a face-to-face/audio/video medium would be a barrier for people in accessing the study (for example, if their speech was affected). Additional demographic information will be collected: age, gender, living situation (alone or with others), occupational status (working or not), time since the diagnosis, duration of symptoms, type of symptoms, psychological treatments offered and accepted, comorbid conditions – to situate the sample and assist in the analysis of the data. The participants' addresses will be collected in case of immediate risk becoming apparent during the interviews so that the emergency services could be contacted. These will be destroyed once the interviews are completed.

Data Analysis

The study will adopt interpretative phenomenological analysis (IPA) as the approach as it is particularly suited to exploring under-examined topics (Smith & Osborne, 2015). Through an inductive analytical process, it can provide a detailed understanding of the participants' lived experiences of FMD and their subjective meaning making of that experience. To aid that process the interviews will be transcribed verbatim to create written transcripts. As I intend to focus on the individual's unique experience embedded in their context and perspective, IPA

is ideal as it's idiographic in its nature and facilitates exploring particular perspectives in their specific contexts (Smith et al. 2009).

Data Storage

Interviews will be recorded on a digital audio recorder and then transferred as soon as possible to and stored on the main investigator's secure storage space on the Lancaster University's server for the duration of the study. The transcribed interviews will be anonymised and stored as described above. Audio recordings of the consent and written consent forms will be encrypted, password protected and stored with a code to link them with their respective interview transcripts but in a separate file from non-personal data, such as interview transcripts. Once the project has been completed and examined, audio recordings of the interviews will be deleted. The remaining files will be transferred securely using the university's encrypted file transfer software (currently Box) to the Research Co-ordinator at the Doctorate in Clinical Psychology programme and stored on the university's secure server.

If any participants request the interviews to be conducted via email exchange, they will be informed that those means cannot be entirely secure. They will be encouraged to use password protected attachments when sending emails to increase the security of data but will be advised that the security still could not be guaranteed. The contents of the emails would be uploaded to the secure space on the university server and the original emails deleted. Participants would be asked to also delete the email exchanges.

Participants' addresses and other contact details will be collected to provide to local emergency services in the case of immediate risk becoming apparent during the interviews. Those details will be destroyed immediately after the interview is concluded unless the participants wish to be sent the study report with findings. In such case their details will be

stored as described above in an encrypted file with audio and written consents and destroyed after the findings are sent out to them.

The electronic data will be stored for ten years after which it will be deleted by the Research Co-ordinator at the Doctorate in Clinical Psychology programme under the direction of the university supervisor.

Ethical Considerations

There is a potential for distressing material to arise during interviews given the personal emphasis of the research question and many challenges associated with living with functional neurological disorders. In the process of seeking informed consent, the participants' attention would be drawn to potential upset and distress and we would discuss their current sources of personal and professional support to seek before or after the interviews.

Participants will be given the contact information of relevant support services as part of their participant information sheet. Participants will be informed they can withdraw from the study at any point before and during the interview and then up to the data analysis stage when the themes are merged and after which data might not be possible to be extracted. Participants will be advised they can stop the interview at any point to have a break, postpone to another time or cancel it altogether. I will be mindful of signs of distress or fatigue in participants during the interview and remind them of the option to pause, postpone or withdraw. I will also seek participants' verbal consent to continue discussing a topic/aspect that is the source of distress to them, if this should arise. In the event of participants becoming severely distressed and expressing thoughts of harm to themselves or someone else I will follow the process agreed with them prior to the start of the interview – in the case of immediate risk I will contact the local emergency services. I would also discuss this with my field and university supervisors.

Dissemination

The findings will be written up into a thesis as part of a doctorate in clinical psychology for the principal investigator. The findings will be summarised in a brief report and shared with FND Hope and potentially publicised on their website and social media sites. The report will also be sent to those participants who declare at the interview that they want to receive it. It is intended that the research will be submitted to a peer reviewed journal. The findings will be presented at a thesis presentation day at Lancaster University as part of the Clinical Psychology programme. If the opportunity arises, the findings would also be presented at academic conferences.

Service User involvement

I have consulted with two members of FND Hope (who are or have been living with FMD) to seek their views and advice regarding the design, recruitment and interview schedule of the research project. They have also provided feedback on drafts of participant information form and consent form. FND Hope will review the project protocol after it's been approved by the university ethics committee and will provide further feedback before the study commences. If any changes need to be made as a result of this, I would submit an application to the university ethics committee for approval of the amendment.

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APPENDIX 4-A

INTERVIEW TOPIC GUIDE

1. What diagnosis have you been given and when?
   - What sorts of symptoms/problems do you experience?

2. Sense making of the disorder and the experience of having it
   - How would you describe it/explain it to someone? /what would you compare it with?
   - What's your understanding of the condition and your symptoms? What explanation seems to have most sense in relation to your difficulties? Has that changed?
   - How do others understand it? (family, friends, health care staff)

3. What is the impact of your condition on your functioning and wellbeing?
   - on work, leisure, relationships (family life, intimate relationships, friends) relationship with - on how you view yourself?
   - on your mental health and wellbeing – how was it before you had the condition?
   - Is there anything you think people aren't talking about when speaking about their condition and its impact?

4. What is your experience of getting a diagnosis and treatment?
   - Experience of treatments so far - What's been helpful, why, and how? What's not been helpful? What do you think would be more helpful?
   - What is your understanding and experience of psychological treatments for functional movement disorders?
   - If accessed psychological interventions – what was the impact on distress and on severity or frequency of symptoms? What's not been helpful and why? What would be more helpful?

5. What do you wish health professionals knew or understood that you know now?

6. If recovered or recovering: what do you think helped the recovery the most? If not recovering – what do you think are the barriers to your recovery? What would help it?

7. Anything else that is important, and I have not asked about?

APPENDIX 4-B

Health & Medicine | Lancaster University

Consent Form

Study Title: Living with functional movement disorders.

We are asking if you would like to take part in a research project exploring experiences of living with functional movement disorders. Before you consent to participating in the study, we ask that you read the participant information sheet and this consent form. You do not need to return the forms. If you consent to take part in the study, we will review the statements below at the start of the interview and I will ask you to confirm that you agree to each of them – orally (if your interview is on the phone/via internet video link) or in writing (if your interview is face-to-face). I will audio record the consent process if we are not meeting face-to-face. If you have any questions or queries before consenting please speak to the principal investigator, Sylwia Bazydlo at s.bazydlo@lancaster.ac.uk or tel. 07508406248

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐
8. I consent to anonymised information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that the researcher will discuss data with their supervisors as needed. ☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their supervisors. ☐
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
12. I consent to take part in the above study. ☐

APPENDIX 4-C

Participant information sheet

LIVING WITH FUNCTIONAL MOVEMENT DISORDERS.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Sylwia Bazydlo and I am a student on the Clinical Psychology Doctorate programme at Lancaster University, LancaCter, United Kingdom. I would like to invite you to take part in a research study about living with functional movement disorders.

Please take time to read the following information carefully before you decide whether or not you wish to take part.

What is the study about?
This study aims to explore experiences of people living with functional movement disorders: their views, thoughts and feelings.

Why have I been invited?
You have been approached because the study requires views and thoughts of people who have had a diagnosis of any form of functional movement disorders for at least 12 months. This includes diagnoses such as: Functional Movement Disorder (FMD), Functional Neurological Disorder (FND), Psychogenic Disorder, Somatoform/Somatisation Disorder, or other similar diagnoses.

I would like to hear from you if, as part of your condition, you are experiencing symptoms affecting your movement or posture, such as: paralysis or weakness, muscle spasms, dystonia, myoclonus,, tremor or gait disturbances.

What will I be asked to do if I take part?
If you decided to take part in the study, you would need to let me know on s.bazydlo@lancaster.ac.uk or 07508406248. I would then contact you to talk more about the project. If you are happy to go ahead with it, we would then arrange a suitable time for the interview. At that point I would also ask you about other medical concerns you might have that might be impacting on your experience of the movement disorder to ensure your participation in the study would be appropriate and possible at this time.

The interview can be held via WebEx, Skype, Zoom or telephone – whichever is best for you. A face to face interview might be possible if you're based in Lancashire or Cumbria and a suitable venue is available and accessible for you.
During the interview you will be asked about what it is like for you to have a functional movement disorder, its impact on your life and your experience of care and treatments. The interview will last up to approximately one hour and will be audio recorded.

You will be asked to read the attached consent form before the interview. There will be no need to return the consent form. If we meet in person, I will give you a copy of the form to sign before we start the interview. If the interview is held over the phone or internet video link, I will read its contents to you and ask whether you confirm to understand and agree to participate in the study. I will audio record your consent in a separate file from the interview. In the case of email/WhatsApp interviews, I will ask you to sign and scan the consent form and email it or send via WhatsApp to me prior to the interview.

If you would like to take part in the study but there are barriers to taking part in a video/phone/face-to-face interview, please let me know and we can discuss other means such as email exchanges or WhatsApp. However, whilst WhatsApp uses encryption to increase security of the data, you need to be aware that email exchanges are less secure means of communication.

What are the possible benefits from taking part?
There are no direct, immediate benefits for participants, but it is hoped the results will inform care and research relating to functional movement disorders, helping those who live with FMD.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part. Your participation is voluntary.

What if I change my mind?
If you change your mind, you are free to withdraw your participation in this study. If you want to withdraw, please let me know, and if possible, I will extract information you contributed to the study and destroy it. However, once your data has been anonymised and pooled together with other people's data, it might not be possible to extract it.

What are the possible disadvantages and risks of taking part?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Will my data be identifiable?
I will remove any personal information from the written record of our interview so that you are not identifiable from it. Any personal information collected will be stored separately from the interview data in an encrypted and password protected file to preserve your anonymity and confidentiality.

Please note that although internet applications and tools (such as Skype) are widely used in research, it cannot be guaranteed to be completely secure means of communication.

How will we use the information you have shared with us and what will happen to the results of the research study?
The results of the study will be summarised in a report and shared with FND Hope and will form a part of my doctoral thesis for Doctorate in Clinical Psychology programme. I might present the results at professional conferences and submit for publication in an academic or professional journal to inform other researchers and clinicians working in this field.

When writing up the findings from this study, I might use direct quotes (e.g. from my interview with you) but they would be anonymised which means you would not be identified.

If something you tell me suggests that you or somebody else might be at risk of harm, I will need to share this information with my supervisors. If possible, I will inform you of this. If I think you might be at immediate risk of harm, I might contact the emergency services in your local area to ensure that you can access immediate help. To make it possible, I will ask you to provide your address before the start of the interview.

How my data will be stored

The data collected for this study will be stored on a secure university server and only the researchers involved in this study and the research co-ordinator at the Doctorate in Clinical Psychology will have access to it. They will be kept for 10 years after which they will be deleted.

- Your interview will be transcribed to a typed version by the researcher herself and made anonymous by removing any identifying information including your name.
- Audio recording of your interview will be deleted once the work has been examined. Audio recording of your consent or a written signed consent form will be stored separately from non-personal information (such as your views about a topic) for 10 years.
- Your personal details, such as telephone number, address or email address will be deleted/destroyed after the interview is completed. However, if you would like to hear about the study findings, your address or email address will be kept until the findings are sent out to you. After that time, they will be deleted.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study

What if I have a question or concern?

If you have any queries or if you are unhappy with anything that happens concerning your participation in the study, please contact myself,

Sylwia Bazydlo: s.bazydlo@lancaster.ac.uk tel. 07508406248

Or the project supervisors:
Dr Fiona Eccles tel. 01524 592807
Dr Catherine Parker tel. 01228 814781

Or the Head of Research at the Doctorate in Clinical Psychology:
Professor Bill Selwood: b.sellwood@lancaster.ac.uk tel: 01524 59399
Division of Health Research, Lancaster University

If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact:

Professor Roger Pickup: **r.pickup@lancaster.ac.uk tel: 01524 593746**
Associate Dean for Research
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Sources of support

If you feel distressed either as a result of taking part in the study, or in the future, the following resources may be of help. It may also be appropriate in such situations to speak with your GP.

FND Hope Support Groups via FND Hope website: https://fndhope.org/

Mind
Info line: 0300 123 3393
Website address: http://www.mind.org.uk/

The Samaritans
Info line: 08457 90 90 90
Website address: http://www.samaritans.org/

Thank you for considering your participation in this project.

APPENDIX 4-D

Letter of approval from the Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Applicant: Sylwia Bazydlo
Supervisor: Fiona Eccles
Department: Health Research
FHMREC Reference: FHMREC18

15 April 2019

Dear Sylwia

Re: Living with functional movement disorders.

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R.E. Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.