

What are the experiences of people living with functional movement disorders (FMD)? An Interpretative Phenomenological Analysis study.

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Abstract

Introduction: Functional neurological disorders (FND) are medical conditions that involve problems with the functioning of the nervous system. Functional movement disorders (FMD) are a subcategory of FND. Qualitative research in this area has been limited, meaning we have a limited understanding of the subjective experience of living with FMD. This research aimed to address this gap.

Method: Eight participants with FMD were interviewed using semi-structured interviews. Data was analysed using interpretative phenomenological analysis.

Results: Three superordinate themes and fourteen subordinate themes were identified. *'Unexpected and progressive losses'*: participants experienced many losses (e.g. bodily control, identity) as a result of having FMD. Their distress was compounded by a period of uncertainty whilst trying to get a diagnosis and unhelpful interactions with healthcare professionals. *'False dawns'*: participants had positive diagnosis experiences, although they felt a diagnosis did not change anything and they perceived treatment options to be unsuccessful. *'Living with 'it''*: participants still experienced a loss of control of the body. Some participants did not feel better and had not yet accepted living with FMD, whereas others felt better and had accepted living with FMD.

Discussion: The findings are consistent with qualitative research on other neurological disorders (Parkinson's disease and multiple sclerosis) and medically unexplained conditions (chronic fatigue syndrome and non-epileptic seizures). Novel findings for the FMD evidence-base are: conceptualisation of identity, sense of separateness from body part(s) affected, experiences of self-blame, shame and embarrassment, fear of losing one's mind, the belief of being judged negatively by others, working in a positive diagnostic framework and processes involved in acceptance. The findings may facilitate a more accurate understanding of patients' experiences of FMD that could be used to inform healthcare, emphasising the importance of a timely diagnosis, developing a warm therapeutic relationship and suggesting the application of third-wave cognitive behavioural therapy approaches.

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Introduction

This chapter will begin with defining functional neurological disorders (FND). I will then define functional movement disorders (FMD), which are a subcategory of FND and this is the condition that the research study is interested in. I will then explain how FND are diagnosed, the current understanding of the aetiology and current treatment. I will then present the qualitative literature on illness experience. Firstly, I will briefly outline the research strategy for the literature review on FMD. The research on FMD qualitative studies was limited, therefore, this section will present qualitative research investigating illness experiences in other conditions that are similar in presentation to FMD. Parkinson's Disease (PD) and multiple sclerosis (MS), chronic fatigue syndrome (CFS) and non-epileptic seizures (NES). Then I will present the qualitative research on FMD. I will end this chapter by discussing the relevance of qualitative research on FMD.

Overview of functional neurological disorders

FND is a diagnosis for neurological symptoms that cannot be explained by neurological disease and are not the result of intentional feigning (Van et al., 2015). A functional diagnosis acknowledges something is not functioning properly within the nervous system (Tremolizzo et al., 2014). Many terms have previously been used to describe such symptoms such as conversion disorder, hysteria, somatisation disorder, medically unexplained symptoms and psychogenic (Stone, 2009). FND is now considered the most acceptable term to use as such language is moving away from the concept of feigning and psychiatric co-morbidities and is received more favourably by patients.

Within neurological services the most common diagnoses for new referrals are headaches (19%), FND (16%) and epilepsy (14%) (Stone et al., 2010a). FND is an umbrella term for a range of neurological conditions such as functional seizures, functional speech disturbance and functional stroke. This patient group has been described as the most difficult to help by UK neurologists (Carson, Stone, Warlow,

& Sharp, 2004) and FND have been described as 'a crisis for neurology' (Hallett, 2006). This research focused on FMD which are a subcategory of FND (Edwards & Bhatia, 2012). FMD is the recognised term used within most publications, but it may also be known as motor subtype of FND (mFND). This study will use FMD.

Functional movement disorders

FMD include abnormal 'motor' or movement symptoms such as tremor, dystonia, gait disturbance, (Stone, 2009), parkinsonism, tics, limb weakness and complete paralysis (Wilshire & Ward, 2016). These functional symptoms can mimic the symptoms of organic movement disorders (van der Salm, de Haan, Cath, van Rootselaar, & Tijssen, 2013) such as Essential Tremor, PD, Tourettes and stroke. Patients with FMD experience motor symptoms as involuntary (Stenner & Haggard, 2016) or lacking in self-agency (Voon et al., 2010). The onset is often sudden and may occur after physical injury (Schrag, Trimble, Quinn, & Bhatia, 2004; Stone, Warlow & Sharpe, 2012; Wilshire & Ward, 2016). FMD represents 3% of diagnoses in movement disorders clinics and up to 20% in specialised clinics (Hallett, 2006). FMD are more common in women and they can occur at any age but are more common in young adults than children or the elderly (Nowak & Fink, 2009).

FMD are challenging to live with as the persistence of physical symptoms can cause distress and disability (Stone, 2009). A common comorbidity of functional presentation is pain and it can be in the form of associated fibromyalgia, chronic spinal pain, complex regional pain syndrome or migraine (Espay et al., 2018). Patients with FMD experience a higher frequency of pain compared to those with an organic movement disorder (Espay et al., 2018; Stone, Warlow, & Sharpe, 2010b). The experiences of pain are a common grievance for patients (Schrag et al., 2004). In addition, psychiatric comorbidities such as depression and anxiety may occur in FMD (Crimlisk et al., 1998; Feinstein, Stergiopoulos, Fine, & Lang, 2001). Research has shown affective disorders such as depression and anxiety are more common in patients with FMD than in patients with organic movement disorders (Anderson et al., 2007; Schrag et al., 2004; Stone et al., 2010b). FMD are associated with a lower quality of life (QoL) that is similar to patients with PD (Anderson et al., 2007). Quantitative measures are useful for providing statistical evidence, for

example the higher rates of psychiatric disorders within this population; however, such methods struggle to capture and consider the lived experience of a condition from the patient's subjective experience.

A significant difficulty of living with an FMD is that symptoms may persist for decades (Hallett, 2006). A systematic review of studies since 1985 found that at least 50% of patients with FMD were still symptomatic at long term follow-up (Gelauff, Stone, Edwards, & Carson, 2013). Furthermore, patients who have experienced chronic adversity are more likely to have a severe disability and poorer outcomes (Singh & Lee, 1997). Even when patients have a good understanding and acceptance of the diagnosis many will still continue to experience severe symptoms regardless of treatment (Espay et al., 2018). Long-term follow up data (3-5 years), however, has shown that about half of patients reported improvements in their symptoms, although most patients remained unemployed due to illness (Jankovic, Vuong & Thomas, 2006).

Indicators of a good prognosis for FMD include a short duration of illness, an experience of anxiety or depression that responds to psychiatric treatment, good physical health, positive social life perceptions and if the patient perceives their condition to be effectively managed by the clinician (Jankovic et al., 2006). Also, prognosis has been found to be better for patients who have had a good pre-morbid functioning who developed a sudden-onset of symptoms triggered by acute stress (Singh & Lee, 1997).

Unfortunately, there are limited appropriate health service provision and research interest in FMD (Edwards & Bhatia, 2012). Also, patients with FMD will often experience poorly delivered diagnoses that hinder their understanding of the condition and this results in inappropriate treatments and iatrogenic harm (Espay et al., 2018; Van der Salm et al., 2013). One study found that patients with FMD experienced inconsistent patterns of care and subsequently they felt dissatisfied with their treatment; this resulted in more referrals and greater potential for iatrogenic harm (Crimlisk et al., 2000). The authors suggested the inconsistent patterns of care could be attributed to two factors: doctors may consider this client group to be too complex, and/or may see them as misusing valuable time. Alternatively, inappropriate treatment pathways may be due to the lack of

systematic evidence to guide treatment decisions (Ricciardi & Edwards, 2014). This lack of direction means that clinicians may experience some difficulties in effectively managing the condition and consequently this will inevitably have implications for patient care.

Diagnosing functional neurological disorders. FND have been traditionally classified as conversion disorders of motor subtype within the Diagnostic and Statistical Manual of Mental Disorders (DSM)-4 (American Psychiatric Association, 2000). The diagnosis of conversion disorder required the identification of a psychological stressor and the exclusion of malingering (Ricciardi & Edwards, 2014) which was in line with the Freudian idea that symptoms originate from psychological conflict (Van der Hoeven et al., 2015). The concept of psychological conflict will be discussed further in the aetiology section. In addition, the International Classifications of Disease (ICD-10) classified FND as a dissociative disorder and it was located within the psychiatry section, which supported the dominance of psychiatric models (Stone, Hallett, Carson, Bergen, & Shakir, 2014). A significant change in our understanding of the condition can be seen within both the DSM-5 and ICD-11. The DSM-5 is now using the term 'functional neurological symptom disorder' and diagnosis no longer requires the presence of a psychological stressor and the exclusion of malingering (American Psychiatric Association, 2013). The ICD-11 uses the term 'dissociative neurological symptom disorder' and the condition appears in both psychiatric and neurological categories (World Health Organization, 2018). The symptoms are described as involuntary and incongruent with a recognised disease of the nervous system.

There have been some significant issues within the diagnostic process of FND. Patients have often been misdiagnosed and received inappropriate treatment, and some have experienced a poorly delivered diagnosis, which may then hinder their understanding of the condition (Espay et al., 2018). Patients with FND are not dissimilar to patients with a 'pathological defined disease' in terms of distress; and thus, investigations should be undertaken quickly, and a diagnosis should be delivered sensitively with "a clear explanation of what is wrong (and not just what is not wrong)" (Stone, 2009, p. 189). The consequences of a poorly delivered diagnosis include patient distress, iatrogenic harm from inappropriate

treatments, costly and unnecessary evaluations and poor patient outcomes (Espay et al., 2018).

Within the last decade there has been a shift to using a positive diagnosis process as opposed to diagnosing only after excluding all other possible diagnoses (Dreissen, Cath, & Tijssen, 2016). For example, the diagnostic criteria for identifying FND are moving towards the use of positive clinical signs such as distractibility, entrainment, Hoover's sign and suggestibility (Wilshire & Ward, 2016).

Demonstrating these physical signs can support patients to understand how the diagnosis is being made, which can move their attention away from the concept of negative test results (Ricciardi & Edwards, 2014). The demonstration of positive physical signs helps to reassure patients of the accuracy of their diagnosis, and this approach is imperative to the delivery of a good diagnosis (Edwards & Bhatia, 2012; Stone, Carson, & Sharpe, 2005). The discussion and demonstration of positive physical signs helps explain how symptoms are produced and thus how they may get better, and can have a powerful therapeutic effect (Stone & Edwards, 2012).

To increase favourable outcomes, the delivery of a diagnosis should confirm the diagnosis, convey that the diagnosis was made through positive neurological examination signs and not diagnosis exclusion, and convey the potential for reversibility of symptoms with treatment (Espay et al., 2018). A timely and clear diagnostic explanation may be of particular importance for FND as persistently 'normal' test results drive further worry and uncertainty about the ongoing symptoms, and a lack of explanation may increase patient's attention to symptoms and create unhelpful illness beliefs (Ricciardi & Edwards, 2014). Whereas as a positive diagnostic framework can ensure the patient leaves the consultation with: validation of their neurological symptoms, confidence in the diagnosis and a sense of partnership with the neurologist (Espay et al., 2018). A study found that neurologists believe that acceptance of the diagnosis is an essential part of recovery and the most important factor in determining a favourable prognosis (Espay et al., 2009).

Another shift in the diagnosis process is focusing on how the diagnosis is communicated. Research has investigated the effectiveness of a communication strategy for delivering an FND diagnosis. A study investigated the effectiveness of a

NES communication strategy, the strategy consisted of a booklet for patients and a crib sheet for neurologists (Hall et al., 2010). The crib sheet prompted neurologists to cover certain aspects of the diagnosis in order to be more comprehensive in explanation. The crib sheet covered the key domains of patient' illness representations (e.g. genuine symptoms, label, cause and maintenance factors, treatment and expectations). The participants reported that the approach was acceptable; 94% reported that their questions were answered, 90% of patients felt listened to, and only 14% and 4% respectively reported feeling confused and angry. The development of communication strategies such as these has the potential to reduce the risk of poorly delivered diagnoses and increase positive outcomes for patients. The way a diagnosis is communicated can play a key role in treatment, therefore the delivery of an FND diagnosis should replicate what happens with any other diagnosis in neurology (Stone, Carson, & Hallet, 2016).

The delivery of an FND diagnosis is also now moving beyond identifying physical symptoms and considering the importance of the therapeutic relationship. Clark (2006) suggested physicians need to go beyond looking for symptoms and need to listen to the patient's life stories: "expand the history to include every aspect of the patient's life, understand what it means to suffer with these symptoms and help the patient find an answer to the question 'What good does life hold for me?' " (Clark, 2006, p.358). As the evidence base stands there is little information on people's experiences of living with FMD. Physicians must consider how to deliver a diagnosis of FND clearly and compassionately. Patients benefit if the delivery of the diagnosis is non-judgemental, empathetic and validating of their distress, as opposed to feeling blamed for behaving in this way and treated as illegitimate patients that are malingering (Clark, 2006). This approach of compassion is crucial to developing a trusting patient-physician relationship (Jankovic, 2011). A therapeutic approach may be necessary in supporting the patient through the process of acceptance of a diagnosis (Espay et al., 2009).

Aetiology of functional neurological disorders. This section will introduce the theories and some of the research on FND and its subcategories, specifically FMD and non-epileptic seizures (NES). Over the years many theoretical

explanations for FND have been developed. Psychodynamic and psychological models have been commonly used to understand FND, but there has been a shift towards using neurobiological models. Uncertainty still remains regarding aetiology and FND are considered a grey area between neurology and psychiatry (Edwards & Bhatia, 2012).

Jean-Martin Charcot (1889) identified hysteria as a 'functional disorder' in that no structural lesion could be found, although it was hypothesised that there was an undetectable physiological abnormality (as cited in Kanaan, Armstrong, & Wessely, 2012). Following on from Charcot's ideas a psychodynamic explanation was developed. It was proposed that an experience of trauma (for example physical and/or sexual abuse in childhood and adult life and recent life events) caused mental conflict in the subconscious and this caused the development of a FND. This occurs via a process whereby mental conflict causes dissociation and distressing memories or thoughts are excluded from conscious awareness; however, psychological tension remains at an unconscious level and this is resolved through the expression of physical symptoms (Wilshire & Ward, 2016), which is known as primary gain. Symptoms may then be reinforced, for instance through sympathy and/or attention from others and this is referred to as the theory of secondary gains (Nowak & Fink, 2009).

Research has shown that the frequency of stressful life events (e.g. family, social and occupational environments, illness, death, rape, and injuries) increase during the onset of FND (Roelofs & Spinhoven, 2007; Stone, Sharpe, & Binzer, 2004). Furthermore, a study in India similarly found that an important precipitating factors are family and social issues (e.g. bereavement, dispute with family member, loss of job) (Pandey & Koul, 2017). Research has also investigated whether there is a link between childhood abuse and functional symptoms. NES research, another subtype of FND has found an association between child sexual abuse and seizures (Sharpe & Faye, 2006; Stone et al., 2004). Furthermore, Roelofs, Keijsers, Hoogduin, Näring, and Moene (2002) looked at the association of childhood abuse and FMD in a questionnaire survey and found that 85% of participants with functional paralysis reported experiences of childhood sexual/physical abuse. In addition, another study used questionnaires and a standardised clinical interview

(DSM-5) with patients with FMD and found that they reported higher rates of emotional abuse and neglect, childhood trauma, greater fear associated with traumatic event and more traumatic episodes compared to the control group (patients with specific organic hand dystonia), (Kranick et al., 2011). The evidence base indicates that there are some links between childhood trauma and stressful life events and functional symptoms. In contrast to these studies showing links between trauma and functional symptoms other studies have found contradictory evidence. For example, patients with FMD do not report psychological stressors occurring at the time of onset (Espay et al., 2009; Stone & Edwards, 2011). In addition, a study showed that a significant proportion of patients with FMD score within the normal range on psychological questionnaires (Van der Hoeven et al., 2015). It appears people can have FND without trauma, thus there may be other risk factors. These findings support the new DSM-5 criteria and challenge the psychodynamic perspective that symptoms always originate from psychological conflict. Furthermore, the different findings support the notion that we do not really understand the cause of FND.

A second major aetiological explanation for FND is described within a cognitive model. Leventhal's Common-Sense Model (CSM) of self-regulation suggests that it is the individuals' illness beliefs that will inform the coping strategies used and appraisal of their success (Cameron & Leventhal, 2003). The CSM underpins the cognitive behavioural therapy (CBT) model of FND (Cameron & Leventhal, 2003). It suggests that unhelpful illness beliefs (for example "something is physically wrong") results in unhelpful coping behaviours (for example safety behaviours, avoidance, symptom vigilance) and these both interact with the individual's emotions and physiology forming a vicious cycle of symptoms and disability (Carson, Ludwig, & Welch, 2016). These unhelpful beliefs cause both the distress and aberrant attentional focus on the body and this is believed to produce and maintain functional symptoms. There is some support for this model Ludwig, Whitehead, Sharpe, Reuber, and Stone (2015) assessed illness perceptions in patients with FMD and NES using the Illness Perception Questionnaire (IPQ). They found that both groups reported a low level of personal control over symptoms, limited understanding of their symptoms and a tendency to reject a psychological

cause. The IPQ is a quantitative measure and therefore, unlike qualitative methods such measures can provide limited data on the subjective experience of what it is like to live with an illness.

The CSM focuses only on how illness beliefs drive coping behaviours and it does not account for how people make sense of experiences to arrive at the behaviour. Furthermore, this issue is evident in research using the IPQ. It could be argued that maybe the CSM and the IPQ are insufficient to explore 'meaning making' in illness experiences. Thus, qualitative research looking at 'meaning making' in FMD could support better application of psychological theories; as currently the limited knowledge on illness experiences of FMD results in difficulties in applying theories to this client group. A person's experience of a phenomenon is a multifaceted concept and a questionnaire reduces such experiences to standardised items.

The integrative cognitive model (ICM) was developed by Richard Brown, a psychologist, and Markus Reuber, a neurologist and international expert on NES. The model was established to explain medically unexplained symptoms, in particular, dissociative seizures (Brown, 2013). The ICM uses a single explanatory framework to bring together existing psychological theories (dissociation, psychodynamic, CBT) on medically unexplained symptoms (Reuber & Brown, 2016). An important concept in this model is that functional symptoms either involve a disturbance of voluntary control or the activation of inaccurate illness beliefs or a distortion in consciousness (Brown, 2013). For example, the model proposes that dissociative seizures result from "the automatic activation of a mental representation of seizures (the "seizure scaffold") in the context of a high level inhibitory processing dysfunction" (Brown & Reuber, 2016, p.2). In other words symptoms occur in the context of chronic stress, arousal and other factors that require high level processing which then trigger unhelpful illness beliefs or perceptions (Reuber & Brown, 2016). Attentional processes are implicated within the activation and selection of mental representations (Brown, 2013). These attentional processes are either focusing on physical symptoms to avoid emotional or interpersonal conflict (psychodynamic model) which increases the activation of mental representations or checking and/or worrying about symptoms (CBT model)

(Brown, 2013). These processes are believed to increase the frequency of symptoms, induce further reactions and thus maintain a vicious cycle of symptoms (Brown, 2013).

Leading models of understanding FND are now shifting towards understanding the neurobiological mechanisms. A neurobiological model 'predictive coding account' (Edwards, Adams, Brown, Pareés, & Friston, 2012) has been proposed to explain the underlying mechanisms for functional neurological symptoms. The model focuses on the role of abnormal self-directed attention and abnormal beliefs about movement. It is thought that these are responsible for disturbances in motor and sensory functioning. The processes of sensory feedback during movement and attention to movement become represented in higher-level cognitive processing, for instance illness beliefs. There is empirical evidence of sensorimotor and attentional disturbances to support this model (Macerollo et al., 2015; van Poppelen et al., 2011).

It is also worth considering that many of our existing theoretical explanations for FND have been developed to make sense of a presentation that is 'medically unexplained'. Yet it is possible that a medical explanation has not yet been found and with the advancement of medical knowledge it may become a medically *explained* disorder (Edwards & Bhatia, 2012).

Treatments for functional neurological disorders. Developing interventions for this patient group is more difficult due to the unknown aetiology of FND. The cognitive model of FND has been useful in informing CBT interventions with clients, with FND. Unfortunately, CBT interventions have not been widely studied in FND but research has looked at the application of CBT with functional neurological symptoms in general (Ricciardi & Edwards, 2014) and provided support for the intervention. Speckens (1995) conducted a randomised control trial (RCT) with people with NES and found that at the 6 months follow up patients with NES showed a higher recovery rate and reduced intensity of symptoms compared to the control group. Furthermore, RCT pilot studies of patients with NES receiving CBT have shown a reduction in seizures and patients scores in psychiatric and psychosocial scales improved (Goldstein et al., 2010; LaFrance et al., 2010). Within the Goldstein et al. (2010) study the significant reduction in seizures did continue at

follow up, therefore, CBT may not be as effective in the long term. A narrative review found that there is some evidence to support the use of specific forms of CBT and physiotherapy with people with FMD (Ricciardi & Edwards, 2014). Nonetheless, a Cochrane review found there was not much reliable evidence to support the use of CBT in the treatment of NES and it proposed a need for more RCT (Martlew, Pulman, & Marson, 2014). It is possible for symptom improvement although there is a need for more high-quality treatment studies to better develop and inform treatments for people with FMD (Ricciardi & Edwards, 2014).

A more novel approach to working with FMD is evident in the application of third-wave CBT approaches. A case study has shown Acceptance and Commitment Therapy (ACT) to have promising outcomes. The participant showed improvements on psychometric scores for psychological flexibility, functioning and mood (Graham, Stuart, O'Hara, & Kemp, 2017). The authors propose that third-wave CBT approaches may be useful to improve functioning as opposed to controlling or attempting to eradicate symptoms. The unknown aetiology of functional disorders makes symptom elimination difficult, therefore, qualitative research on the experiences of living with FMD may inform the use of models other than CBT to support the individual with living in the context of illness.

Qualitative literature search

A systematic search of PubMed, Embase, Psych Info and CINAHL was completed as part of the literature review. Also, Google Scholar was used as an additional database to identify articles of relevance. The search was conducted to identify qualitative studies investigating the experience of living with FMD. I identified two key concepts to focus the literature search: FMD and illness experience. These key concepts provided a framework to identify what the search terms should be. The following search terms were used for concept one (FMD); FMD, conversion disorder, psychogenic disorder, psychogenic movement disorder, motor conversion disorder. The following search terms were used for concept two (illness experience); qualitative, interview, narrative, phenomenology, interpretative phenomenological analysis, grounded theory, thematic analysis, discourse analysis and focus group. To ensure no articles were missed these additional search terms

were used; patient satisfaction, illness experience, patient experience, lived experience, illness perception and subjective experience. To ensure the search strategy was comprehensive the search terms were truncated (e.g. psychogenic disorder*) or combined (e.g. motor conversion disorder or conversation disorder or psychogenic movement disorder). The search identified 991 articles. The titles and the abstracts of the articles was reviewed to establish whether they were appropriate. Articles were discarded if they were not a qualitative study on FMD. The search did identify qualitative studies on NES and these were kept. Six of the articles involved qualitative research with NES and one article was a qualitative study on FMD. This indicated there was limited research on FMD using qualitative approaches. The literature was identified using a comprehensive strategy, however, there are some limitations to the review strategy. Firstly, within concept 1 (FMD) the term FND was not included, therefore, it could be possible that the search may have missed some papers. Secondly, the literature review did not use a more formal comprehensive method, for example, a systematic literature review. Consequently, the literature review may not be an exhaustive summary of the current literature. Thirdly, the qualitative research papers were not critiqued using a formal appraisal tool, for example the critical appraisal skills programme check list.

The experience of illness

Qualitative research is a popular methodological approach to investigate illness experiences, however, the systematic review only uncovered one qualitative study on FMD. This study did not investigate illness experiences. A qualitative research project on the experiences of living with a FMD is therefore timely and qualitative approaches can provide a rich understanding of the meanings that individuals attribute to their experiences (Willig, 2013). The limited qualitative research on FMD means that this section will need to refer to qualitative research investigating illness experiences in other conditions that are similar in presentation to FMD. Looking at illness experiences in other similar conditions will support the project to answer the research question, as these findings will provide more context to try and understand the illness experience of FMD, support the development of the

interview schedule and inform the analysis. Furthermore, looking at illness experiences in other conditions will provide an understanding of whether there are similarities or differences in the experiences across these conditions and how these experiences may compare to FMD.

The neurological conditions that will be considered are PD and MS. PD is a progressive neurodegenerative movement disorder that tends to affect adults aged over 50, and MS is a chronic inflammatory disorder that usually presents in younger adults and frequently includes abnormalities of movement too. Additionally, CFS and NES will be included as, similar to FMD, they are both medically unexplained conditions. Qualitative research on these conditions has provided an important insight into the experience of diagnosis, activities of daily living, physical and psychological functioning, identity, coping and the process of adjustment and stigma. Furthermore, these findings have resulted in recommendations to improve patient care. The review of these conditions will demonstrate the importance of gaining data on patient experiences through qualitative methodology and thus, the clinical implications for practice. This section ends considering the qualitative literature on FND in general and in particular NES, as the closest conditions to FMD. It will also consider the one existing qualitative study on FMD. It is evident that the knowledge gap regarding the experience of living with FMD is limited and a focus on NES literature intends to demonstrate the relevance of research needed in FMD.

Qualitative research with neurological conditions. This section will review the research and present the most prevalent themes on both PD and MS. These neurological conditions have clearly defined underlying disease processes. PD manifests with reduced speed of movement, tremor, rigidity and postural instability, accompanied by a slow short-stepped, shuffling gait pattern (Morris, Huxham, McGinley, Dodd, & Iansek, 2001). Although medications can treat many of the symptoms, PD is a progressive condition with a steady decline in function over many years. People with MS can experience symptoms such as limb weakness and numbness, visual and cognitive impairment, vertigo, ataxia, fatigue and bowel and bladder dysfunction (Goldenberg, 2012). These symptoms usually occur in an unpredictable 'relapsing-remitting' pattern for many years – i.e. they may last for a few weeks at a time, in different combinations, and then recover (fully, or partially)

with many 'stable' months or years between the relapsing symptom periods. In the majority of cases the relapsing-remitting pattern of symptoms eventually changes to become steadily progressive after a number of years.

Patient experiences of living with a progressive condition. The loss of physical functioning and the experience of mental health problems such as anxiety and depression are common in PD and MS (Dauwerse, Hendriks, Schipper, Struiksma, & Abma, 2014; Mozo-Dutton, Simpson, & Boot, 2012; Soleimani, Bastani, Negarandeh & Greysen, 2016). People with MS report no longer feeling able to trust or depend on their body to act as reliably or expected (Mozo-Dutton et al., 2012). In addition, in PD the loss of physical ability impacts on an individual's ability to carry out routine activities and independence (Soleimani et al., 2016). The illness experience of both conditions can lead to difficulties in maintaining relationships and thus, social isolation (Haahr, Kirkevold, Hall, & Østergaard, 2011; Barker, das Nair, Lincoln, & Hunt, 2014). People with MS can struggle to care for their family and home, impacting on family relationships (de Ceuninck van Capelle, Visser, & Vosman, 2016). Furthermore, when living with PD the family can impact upon a person's QoL, either being a source of support or support being absent (Dauwerse et al., 2014). A meta-synthesis found that adjustment and coping appeared to be a key theme in maintaining QoL when living with MS (Barker et al., 2014). The use of positive and practical coping strategies can support the preservation of a normal life and develop acceptance (Reynolds & Prior, 2003; Dennison, Yardley, Devereux, & Moss-Morris, 2011). In contrast, other people with MS cope by protecting themselves from thoughts about an uncertain future as illness progression is a frightening reminder of the disability that can be experienced (Dennison et al., 2011).

Identity. The experience of PD and MS can impact on a person's sense of self and result in a loss of identity (Barker et al., 2014; Irvine, Davidson, Hoy & Lowe-Strong, 2009) due to changing roles within the home or workplace and a loss of productivity in society (Habermann, 1996; Irvine et al., 2009; de Ceuninck, Visser & Vosman & Vosman, 2015). An individual's self-concept can influence their decisions, behaviours and general QoL. People with PD who have a negative self-concept can experience loss of motivation and willingness for self-care, however,

self-care increases significantly for those with a positive sense of self (Soleimani et al., 2016), therefore, the negative effects of identity loss can be reduced. A meta-synthesis of MS found that adjustment to changed identity and the family are important factors in identity reconstruction (Barker et al., 2014). Furthermore, a systematic review in PD found that identity loss can be managed by being able to maintain or develop a social identity (Soundy, Stubbs & Roskell, 2014).

Stigma. The experience of living with these conditions can be associated with stigma. A systematic review of qualitative literature on PD found that people experience stigma in relation to how others perceived them (Soundy et al., 2014). Furthermore, people with MS report experiencing difficult attitudes (e.g. misunderstanding their symptoms) from others towards their illness (de Ceuninck van Capelle et al., 2016). In addition, people with MS attempted to avoid stigma by not using mobility aids, as such aids are perceived as a symbol of disability and thus stigmatising (Dennison et al., 2011).

Clinical Implications. The qualitative studies on PD and MS provided clinical recommendations, however, these recommendations are not evidence based as these studies were not RCT. Living with PD is influenced by many inter-related factors, therefore, to improve patients QoL and the care provided, all these factors must be considered (Dauwerse et al., 2014). Clinical interventions for PD may involve adapting skills to manage daily living, improving mood, increasing social connections and self-belief (Soleimani et al., 2016). Clinical interventions for MS may benefit from considering the role of identity to inform better management of the condition (Irvine et al., 2009; Mozo-Dutton et al., 2012). Rehabilitation interventions for MS may need to focus on supporting people to maintain and discover active roles and engagement in meaningful activities to preserve aspects of identity (Reynolds & Prior, 2003). Furthermore, MS interventions may even benefit from incorporating the family to support an individual's identity reformation (Barker et al., 2014). In addition, MS research has found that clinicians need to acknowledge the meaning of family and the support available for families (de Ceuninck van Capelle et al., 2016).

Qualitative research with medically unexplained conditions. This section will firstly summarise the most prevalent themes from the research on CFS, then NES and ends with FMD.

Chronic Fatigue Syndrome. CFS is a long-term illness. Some of the symptoms of this condition are cognitive processing issues, sleep difficulties and severe fatigue (Carruthers et al., 2003). It is a medically unexplained condition associated with profound fatigue and reduced physical activity.

Diagnosis. A meta-synthesis found that gaining a diagnosis can be a difficult experience; for some a diagnosis is not perceived as a legitimised condition due to the lack of illness acknowledgement from healthcare staff, family and friends (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012). In contrast the concept of 'legitimacy' is not present within the PD and MS literature. This may be because these are organic disorders and when living with a medically unexplained symptoms like CFS one may be more prone to additional distress.

Symptoms. A meta-synthesis identified that the debilitating symptoms impact on physical, social, educational, occupational and economic functioning; resulting in multiple and profound losses (e.g. roles, relationships and financial stability) (Anderson et al., 2012) and consequently leading to isolation (Dickson, Knussen & Flowers, 2007). The lack of illness acknowledgement (e.g. not being diagnosed or believed) can cause an individual to 'fight' symptoms and attempt to retain previous levels of functioning and roles (Edwards, Thompson, & Blair, 2007).

Coping and Adjustment. Individuals can perceive the condition as an 'invisible illness' and they can find it difficult to explain the illness to others which results in fear and difficulties in knowing how to cope (Edwards et al., 2007). Additionally, individuals can develop coping strategies (Anderson et al., 2012) and achieve acceptance (Edwards et al., 2007).

Identity. The illness experience of CFS can result in loss of identity due to the loss of confidence and self-esteem when valued roles are lost (Anderson et al., 2012); however, people can experience positive transformational growth when they adjust to the trauma of living in a dysfunctional body. Furthermore, this process can be supported by psychological interventions (Arroll & Howard, 2013).

Stigma. A meta-synthesis found that people experience stigma from medical professionals, family and friends and the condition is often attributed to affective disorders and psychological factors, thus delegitimising patients' experiences (Anderson et al., 2012). The unknown aetiology of CFS results in both patients and others struggling to understand and manage the condition thus perpetuating stigmatisation (Anderson et al., 2012). Experiences of stigmatisation and limited knowledge of the condition has led to delays and prevention of a diagnosis (Anderson et al., 2012). Delegitimising experiences can leave patients in a prolonged period of distress and negatively impact on the therapeutic expectation of doctor-patient relationships (Dickson et al., 2007).

Clinical Implications. The qualitative studies on CFS provided clinical recommendations, however, these recommendations are not evidence based as these studies were not RCT. The research on lived experience and meaning-making of CFS can only enlighten the understanding of a contentious and uncertain disorder (Arroll & Senior, 2008). There is a need for more accurate diagnoses and treatment recommendations (Anderson et al., 2012). Furthermore, the delegitimatising experiences delay support and if people were to receive advice on illness management in the early stages they may become less distressed (Edwards et al., 2007). Thus, publicising the impact of the condition could increase insight and authenticate CFS as an illness and it may even benefit the understanding of other health conditions (Dickson et al., 2007). Furthermore, to provide better care dominant narratives held by clinicians must be challenged as such views can be detrimental to the care delivered (Anderson et al., 2012).

Non- epileptic seizures. Qualitative approaches have been widely implemented to understand peoples' experiences of other kinds of FND, such as NES; and yet there has only been one qualitative research study with people with FMD. The limited research in FMD means we currently do not have a good understanding of the subjective lived experiences. The literature review found two areas of interest for qualitative studies in NES: the experience of receiving a diagnosis and living with functional symptoms. This section will present some of the common themes in the NES literature as it demonstrates what is already known

about patient experiences of other types of FND and therefore, is relevant context to the development of the research project.

Patient experience of living with NES. A systematic synthesis review identified 21 qualitative studies published after 1996 that investigated patients' experiences of living with NES (Rawlings & Reuber, 2016). The review found that many patients experienced uncertainty surrounding NES, often resisted psychological explanations, reported negative experiences with professionals, sought validation of their experiences and often reported feeling ignored or doubted and perceived NES to be a significant burden. Some of these themes are also present in CFS. The authors recommend that further research is required with other groups (men, young people, non-western patients) that were not represented in the studies and that participants should be interviewed at more than one time point to explore whether meanings change over time. This review has provided a helpful insight into the experience of living with NES and therefore a qualitative study into FMD could also deepen our understanding of this condition.

The experience of living with NES and epilepsy has also been investigated (Rawlings, Brown, Stone, & Reuber, 2017a). Participants with NES described their symptoms and how they and others have reacted to their condition, whilst participants with epilepsy portrayed themselves as coping and 'fighting' to live a 'normal' life. The discrepancy in experiences indicates that adjusting to living with functional symptoms could be more difficult and therefore it could be argued that patients with functional symptoms are a more vulnerable population. Therefore, it is necessary for research to focus on different kinds of FND (e.g. FMD), other than NES to ascertain a clear understanding of how experiences may differ or be similar for a potentially vulnerable population.

Impact on daily life. Common themes regarding the impact on daily life are the restrictions NES places on an individual's life, social isolation, family and friends as a source of support and valuing employment whilst recognising an inability to work (Karterud, Risør & Haavet, 2015; Wyatt, Laraway, & Weatherhead, 2014; Rawlings & Reuber, 2016) and experiencing mental health difficulties (Thompson, Isaac, Rowse, Tooth & Reuber, 2009; Rawlings, Brown, Stone, & Reuber, 2017b). Some patients are unable to perceive their condition as 'legitimate' and this can

impact upon their QoL as they withdraw socially, therefore, healthcare professionals play a key role in supporting patients to understand the legitimacy of their condition. (Karterud, Haavet, & Risør, 2016). Before healthcare professionals can support patients they too must be able to perceive the condition as 'legitimate'. This may be a challenge as NES can be associated with stigma and others not believing in the condition, which will be discussed later in the stigma section. Qualitative research into FMD could supplement the research in NES and begin to promote insight into FND in general, as a legitimate condition. The findings could be utilised to attempt to shift healthcare staffs understanding and attitudes, which may then enable them to better support patient's perception of the condition.

Adjustment. Adjusting to a diagnosis was often achieved through acceptance (Thompson et al., 2009). Acceptance can be achieved through being believed and being given a diagnosis that makes sense (Karterud et al., 2015). This demonstrates the importance of healthcare professionals' attitudes at the early stages of illness. A diagnosis can be a validating and empowering experience (Rawlings & Reuber, 2016; Thompson et al., 2009). Some participants no longer perceived their seizures as a shameful or an embarrassing condition, however, acceptance was not a linear process (Wyatt et al., 2014). It has been recommended that individuals need more time and resources to understand the diagnosis and additional support after it has been received (Thompson et al., 2009). It could be hypothesised that acceptance may improve the individuals' QoL, therefore, the experience of this process needs to be understood by those who support this client group. A qualitative research project on FMD could be valuable to provide this type of in-depth data.

Stigma. A systematic synthesis found that patients with NES reported negative experiences with healthcare professionals such as not being believed, their voice not being heard, not being taken seriously and that healthcare professionals are unwilling to appreciate subjective knowledge (Rawlings & Reuber, 2016). In addition, these experiences are further validated by a piece of research that found that healthcare workers reported a poor understanding of NES compared to epilepsy; and healthcare workers believed that patients with NES

have more 'personal control' over seizures (Worsely, Whitehead, Kandler, & Reuber, 2011). Consequently, these negative experiences have led to participants reporting experiences of stigma from others and the subjective phenomenon of stigma can be a barrier to accessing healthcare (Rawlings et al., 2017b; Wyatt et al., 2014). Raising professionals' awareness of functional symptoms and the complexities of working with this population is imperative to reduce stigma and encourage engagement in services (Wyatt et al., 2014). Therefore, a project on FMD could play a vital role in addressing stigma within the healthcare setting.

Functional movement disorders. Whilst qualitative research interest has been established in NES there has been limited qualitative research in FMD. The literature search found one qualitative study on FMD. The study aimed to explore the value of qualitative psychiatric interviews as part of the diagnosis process to enhance the understanding of psychological features of FMD (Epstein et al., 2016). Participants (n=36) were recruited from the Human Motor Control (National Institute of Health). They all had a diagnosis of FMD and the sample varied with the type of FMD. Participants completed a qualitative psychiatric interview and a structured diagnostic psychiatric interview based on DSM diagnostic criteria. The interviews explored patients' understanding of their illness and the conceptualisations of their emotions in coping with stressors. The interviews generated data on patients' understanding of their illness and impairments with emotional processing compared to assessment using the DSM diagnostic criteria. The data was grouped into themes: 'minimization of emotional impact of trauma', 'symbolic conversion of psychological stressors into a specific movement disorder', 'emotional states converted into physical symptoms and expressed in somatic language', 'secondary gains from symptoms' and 'avoidance of, or inability to recognise emotional states'.

Unfortunately, there is insufficient explanation of the analysis used to develop these themes. It appears that a specific qualitative approach, such as grounded theory (GT), interpretative phenomenological analysis (IPA), discourse analysis (DA) or thematic analysis was not implemented. Furthermore, the theme names appear to resemble the diagnostic criteria and it could be argued that the themes have been developed from an objective (for example, the psychiatrist view)

as opposed to subjective perspective (for example the participants view). The aim of the study was to demonstrate the value of exploratory psychiatric interview rather than investigate subjective experiences and this may explain the themes produced. Consequently, the study is limited in being able to present data on the subjective experiences of living with FMD. This research project will provide an additional contribution to the evidence base as it will be the first study to use a specific qualitative technique, IPA to explore the experiences of living with FMD. Furthermore, the study will be attempting to gain a broader insight into the person and their experiences.

Implications for FMD. The research findings from the other conditions (PD, MS, CFS and NES) have demonstrated there are common issues and difficulties across these groups. Furthermore, the research findings have been used to provide clinical recommendations with the aim of improving patient care. In contrast there is limited qualitative research on FMD. It is possible these key issues and difficulties that are common across these groups may also be experienced by people with FMD. Currently there is anecdotal evidence from websites (FND Hope and FND action) and the experience of healthcare professionals, however, there is a need for a body of systematic research to verify how the experiences may be similar or different. Furthermore, considering the important clinical implications from the research discussed on other conditions it demonstrates a need for research on the illness experiences of living with FMD. Especially as the research on PD and MS has progressed to consider the importance/and or the impact of family, and yet clinically we are still struggling to support and understand the individual with a functional presentation. It appears the process of qualitative research informing clinical practice with functional presentations is still within its infancy.

Working with functional symptoms can be a challenge for psychologists as there is no clarity or direction on which psychological interventions to use. Also, there are difficulties in applying theories due to the limited knowledge about this patient group's lived experiences. Predominantly the psychological theories have focused on explaining aetiology. Potentially qualitative research could highlight how patients make sense of their illness experience and such data could support healthcare professionals as they try to find treatment methods that can improve

QoL, even while we do not know what has caused the FMD. This may provide some direction for psychological interventions and alternative ways of working, other than within a CBT approach. A more novel approach of working with FMD may be using ACT to improve QoL (Graham et al., 2017). A strength of this model when applied to working with functional symptoms is that the effectiveness of an intervention does not rely upon an assumption regarding the cause (Graham et al., 2017). This indicates that maybe the way forward in working with functional symptoms is not necessarily finding the answer to why it happens, but how to support people to live a more meaningful life. The latter is a question that potentially qualitative research may provide some insight on.

The qualitative research has also demonstrated the need to publicise the legitimacy of medically unexplained conditions (for example CFS, NES) and to challenge stigma (Dickson et al., 2007; Wyatt et al., 2014), thus authenticating illness status, which may then improve QoL. In addition, CFS research has indicated that overcoming stigma may be crucial to promote accurate diagnosis and treatment recommendations. Furthermore, the NES research has recommended that raising professionals' awareness of functional symptoms and the complexities of the condition is imperative to also reduce stigma and encourage engagement in services. Potentially, a research project on FMD may uncover a similar theme and such findings can build on the current evidence base of stigmatising experiences when living with medically unexplained conditions.

The research on understanding patients' experiences of NES may provide important implications for diagnosis, treatment and prognosis (Rawlings et al., 2017b). Considering these implications, a preliminary understanding of patient's experiences of FMD is imperative and research interest needs to shift towards understanding service users' experiences of other kinds of FND. Even more so now, as research is beginning to question whether NES should remain part of the broader diagnosis of FND. A review comparing NES with other functional symptoms found aetiological and mechanistic differences indicating some support in the conceptualisation of NES as a separate condition (Kanaan, Duncan, Goldstein, Jankovic, & Cavanna, 2017). Of the eight studies reviewed, five studies were for a difference and three were against. It is important to note that these were small

studies with the possibility of type 2 errors; therefore, the authors recognise support for this hypothesis is weak, but propose that the initial findings demonstrate a new direction for research. Furthermore, they suggest that teasing these conditions apart may have important implications for diagnosis and treatment as services that conceptualise all functional symptoms as the same condition may run the risk of applying the same generic psychological approach. Therefore, patient experiences of NES may not resonate with patients' who have an FMD and this demonstrates a need for qualitative research on FMD.

The possible value of qualitative research on illness experiences of FMD:

1. Potentially address and/or raise the profile of the issue of stigma.

2. Improve Healthcare: the findings may support clinicians to develop and hold empathy for a complex client group and enhance their ability in perspective taking, which is imperative to develop and maintain a therapeutic relationship. Also, a qualitative research paper could provide useful reading on the context of living with functional symptoms and thus a useful clinical aid that provides some psychoeducation for clinicians.

3. Improve psychological interventions and theoretical frameworks: clinicians can approach this client group with many theoretical assumptions and provide treatment with this informed perspective. Due to limited research clinicians predominately work within a trauma-based model and believe that the trauma needs to be addressed to alleviate the symptoms. However, service user perspectives on living with FMD could potentially encourage clinicians to consider a more person-centred approach to inform treatment rationale. For instance, the research into PD, MS and CFS have indicated that interventions would benefit from focusing on identity and acceptance to improve QoL. Therefore, when working psychologically with FMD, it might not be too dissimilar than working with other presentations.

Research Questions

Research question: "What are the experiences of people living with functional movement disorders (FMD)?" The additional research aims were:

1. To understand the nature of the impact of FMD on an individual's life.

2. To gain insight into how individuals make sense of, or understand, their experiences.

Method

In this chapter I will first describe and justify the methodological approach used for this research project and will then provide an outline of the study design, participants, measures, procedure and data analysis. The quality checks used within the analysis process will then be presented. This section will end with the researcher's reflexive statement.

Methodological approach

The research question aimed to explore peoples' experiences of living with FMD therefore, the most suitable approach for this study was qualitative methodology. Three qualitative approaches were considered; grounded theory (GT), discourse analysis (DA) and interpretative phenomenological analysis (IPA). I will describe each approach and then justify why they were discarded (GT and DA) and why IPA was chosen.

Consideration of other approaches. GT was developed by two sociologists, Barney Glaser and Anselm Strauss. GT is "the discovery of theory from data-systematically obtained and analysed in social research" (Glaser & Strauss, 1967, p.3). GT is used to generate a theory about a phenomenon and it is grounded in the data (Glaser & Strauss, 1967). A number of key strategies are used to generate the theory. Comparative analysis is used to generate two key elements of the theory: the generation of conceptual categories and their properties, and generating hypotheses about the categories and their properties (Glaser & Strauss, 1967). The researcher must engage in a process of constant comparative analysis (Glaser & Strauss, 1967); moving back and forth between the identification of similarities and differences between the emerging categories (Willig, 2013). Theoretical sampling is used to generate the theory (Glaser & Strauss, 1967). Further data is collected in light of emerging categories and the emerging theory is checked against 'reality' through using sample incidents that may elaborate or challenge the interpretations (Willig, 2013). Negative case analysis requires identifying instances that 'do not fit' to elaborate or qualify emerging theory (Willig, 2013). The researcher must be theoretically sensitive to enable the generation of theory (Glaser & Strauss, 1967).

The researcher must move from the descriptive to analytic level by interacting with the data, for example asking questions of the data and modifying interpretations (Willig, 2013). The criteria for judging when to stop is theoretical saturation, which means no more new categories emerge from the data (Glaser & Strauss, 1967).

GT as a method of data analysis examines the interaction and meanings as related to the social context in which they actually occur (Pidgeon, 1996). The analysis produces knowledge of processes within the data and its theoretical assumption of the world is to focus on 'process' and 'change'; considering the way humans manage and negotiate social situations and how their actions contribute to social processes (Willig, 2013). The researcher creates a model by identifying similar experiences within the data, thus generating support for the model's assumptions and finding out if others share this experience. GT researchers focus more on understanding social processes as opposed to personal experiences (Brocki & Wearden, 2006), therefore, its application to phenomenological questions is limited (Willig, 2013).

DA is one way of studying language (Gee, 2011). There are two main versions of DA; Discursive Psychology and Foucauldian discourse analysis (Willig, 2013). They both share the same interest: the role of language in the construction of social reality (Willig, 2013). When using Discursive Psychology researchers are interested in how people use discursive resources to achieve interpersonal objects in social interactions (Willig, 2013), whereas Foucauldian discourse analysis is used to explore discursive resources and investigates the way in which discourses construct subjects and objects, thus creating versions of reality, identity and society (Willig, 2013). The approach is more suited to research questions that explore how people use language to create social realities or the function and implication of dialogue.

Interpretative phenomenological analysis. In this section, I will provide an overview of what IPA is, its theoretical underpinnings, criticisms and benefits of the approach.

What is IPA? The chosen method of analysis was IPA. IPA researchers are interested in exploring how participants make sense of their social and personal

world (Smith & Osborn, 2007). IPA is used when researchers want to provide a detailed examination of personal lived experience with a focus on how people make sense of their significant life experiences (Smith, Flowers, & Larkin, 2009). Researchers aim to understand the participants world and describe what their world is like and thus, IPA seeks to provide an insider perspective on the phenomenon under investigation (Smith et al., 2009). IPA researchers are interested in the 'personal meaning making' participants hold in relation to particular experiences and events (Smith & Osborn, 2007). A participants account reveals something about their private thoughts and feelings and these are implicated in their experiences; and thus, IPA produces knowledge of what and how people think about the phenomenon under investigation (Willig, 2013). The essence of IPA is the analytic focus on understanding how participants make sense of their lived experiences and how the analyst makes sense of what the participants is thinking and feeling (Smith et al., 2009). The phenomenological analysis produced is therefore an interpretation of the participants experiences (Willig, 2013). My epistemological position for this research project is not situated in exploring language or generating a theory to explain the phenomenon under investigation. Instead it is interested in understanding how people make sense of their lived experiences thus, IPA is an approach that lends itself well to the research question.

IPA has three key theoretical underpinnings; phenomenology, hermeneutics and ideographic. Phenomenology is a philosophical approach and it is the study of experience (Smith et al., 2009). Phenomenologists are interested "in thinking about what the experience of being human is like" (Smith et al., 2009, p.11) and how we understand our experiences of the world (Smith et al., 2009). In the early twentieth century Husserl established the development of phenomenology with the aim "to return to things themselves, as they appear to us as perceivers" (Willig, 2013). Husserl's reference to 'things' refers to the experiential content of consciousness (Smith et al., 2009). Phenomenology is a philosophical approach aimed to produce an account of lived experiences in its own terms rather than by pre-existing theoretical preconceptions (Smith & Osborne, 2015). This process for the researcher requires "bracketing one's preconceptions and allowing phenomena to

“speak for themselves” (Pietkiewicz, 2012, p.2). Husserl believed that an *phenomenological attitude* could be achieved through *bracketing* (Smith et al., 2009). Heidegger’s approach to phenomenology differed to Husserl’s as he advocated the study of phenomenology through a hermeneutic lens (Smith et al., 2009). Hermeneutics is the second theoretical perspective in IPA. The word is derived from the Greek word ‘to interpret’ (Pietkiewicz, 2012, p.2). Heidegger believed humans exist in a world of objects, relationships and language, and our position in the world is ‘temporal’ and always in ‘in-relation’ to something; therefore, the interpretation of people’s meaning-making is the essence of phenomenology (Smith et al., 2009). IPA is informed by hermeneutics and “shares the view that human beings are sense-making creatures, and therefore accounts which participants provide will reflect their attempts to make sense of their experiences” (Smith et al., 2009, p.3). The process of hermeneutics requires interpretative engagement with the data, the researcher is trying to make sense of the participants trying to make sense of their experience (Smith & Osborne, 2015). The researcher aims to understand the experience from the individual’s perspective and then responds to the material with critical questions (Pietkiewicz, 2012). The researchers’ role in trying to understand the participants experience is known as double hermeneutics (Smith et al., 2009). The third theoretical perspective is ideographic. IPA is idiographic in that it examines each case individually then moves towards more general claims (Smith & Osborne, 2015). This allows for more in-depth analysis with a focus on the ‘particular’ for instance, how a particular phenomenon has been understood from the perspective of a particular person, in a particular context (Smith et al., 2009).

Criticisms of IPA. IPA researchers access to experience is reliant on what participants’ can tell us about their experiences (Smith et., 2009). Therefore, IPA may be difficult to use when people struggle to articulate their experiences (Willig, 2013). Additionally, IPA has been criticised for its reliance on the use of language. When an experience is described it is a version of that experience rather than a true account, therefore, direct access to someone’s experience is impossible (Willig, 2013). IPA researchers do not contest this as their aim is to engage with the individual’s reflections on the significance of an event and their understanding of

that account (Smith et al., 2009). IPA has been criticised for limiting our understanding of a phenomenon as it does not explain why a phenomenon occurs (Willig, 2013). Even though IPA does not aim to develop a generalisable theory the comparison of IPA studies on a certain phenomenon may "provide insights into universal patterns or mechanisms" (Pietkiewicz, 2012, p.4). IPA research has the potential to inform theory. IPA studies tend to have a small sample size in comparison to quantitative methods which limits the transferability of the data to a wider population. Consequently, the findings might only apply more strongly to people with similar characteristics. Studies have been published with a sample of one, four or nine (Pietkiewicz & Smith, 2014). Some would argue this to be a limitation although IPA studies can have larger samples, for example, fifteen participants (Pietkiewicz & Smith, 2014). IPA intentionally does not provide nomothetic data that is generalisable instead it provides detailed and rich data from an idiographic perspective (Smith et al., 2009) and thus, "sacrificing breadth for depth" (Smith & Osborn, 2007, P. 56). IPA in-depth analysis derived from a small sample and its idiographic stance has the potential to inform theory and make important contributions to the evidence base. Readers of IPA research can use this understanding to enhance their understanding of existing nomothetic research (Smith et al., 2009).

Benefits of using IPA. IPA has been widely implemented as a methodological design within health psychology research (Brocki & Wearden, 2006). A review of IPA research found that the biggest area of interest for this approach was illness experience (Smith, 2011). In addition, IPA has been suggested to be a valuable research method to examine topics that are complex, emotionally laden and ambiguous; such as pain, a phenomenon that is elusive, difficult to articulate for patients and involves complex psycho-somatic interactions (Smith & Osborn, 2015). Similarly, to the phenomenon of pain, FMD are too a phenomenon of complexity with an elusive nature that involves persistent and unexplained symptoms that both professionals and patients struggle to comprehend. Therefore, IPA appears to be an appropriate approach to explore the experience of living with a complex condition (for example FMD).

A strength of IPA is its broad focus on lived experiences. IPA aims to provide a rich and detailed account of the phenomenon under investigation and allows the exploration of similarities and differences between participants' experiences (Smith et al., 2009). This feature is not present in all forms of qualitative methodology. Therefore, IPA could potentially provide a diverse insight into the experiences of this phenomenon and findings that broaden our understanding of the illness experiences of FMD.

Data collection in qualitative research. There are many methods of data collection in qualitative research: structured interviews, semi-structured interviews, focus groups and on-line interviews. A structured interview consists of a set of closed-ended questions that are asked in a specific order. The interviewer should not deviate from these questions to explore the participants answer further and so are less flexible than semi-structured interviews. This method of data collection was not suitable for this study as phenomenological research aims to enter the participants world, thus, the questions should be open-ended and non-directive (Willig, 2013). Focus groups can be used to collect data in IPA research. This method "uses the interaction among participants as a source of data" (Willig, 2013, p. 34). Focus groups generate data on 'attitudes' and 'opinions' from a large group of people, however, the presence of multiple voices can make it more difficult to capture the phenomenological aspects of IPA (Smith et al., 2009). The research question was interested in subjective experiences and not group concerns, therefore, a focus group was not an appropriate method. On-line interviews were dismissed due to the following limitations; the loss of non-verbal communication can potentially lead to misunderstandings or misinterpretations of communication and it can be more difficult to develop a rapport with participants (Willig, 2013), all of which may potentially reduce the richness of data.

IPA research requires a flexible data collection method as the researcher is interested in analysing in detail how participants make sense of their experiences (Smith & Osborn, 2007). Semi-structured interviews are the most common method for data collection in phenomenological research (Willig, 2013). Furthermore, semi-structured interviews are advocated as the best way to collect data for IPA research

(Smith & Osborn, 2007). This style of interviewing encourages a dialogue between the researcher and the participant as the researcher will adapt questions and probe for further information depending on the participants' responses (Smith & Osborn, 2007). This approach encourages a dialogue where the participant tells their story in their own words (Smith et al., 2009). Semi-structured interviews were chosen as the data collection method for this study.

Method

Design. The chosen research design for this study was qualitative methodology. The data was collected using one-to one semi-structured interviews, which were conducted face-to-face. This type of interview enabled a detailed and in-depth exploration of peoples lived experiences. The interviews were transcribed and then analysed using IPA.

Sampling. In line with sample size recommendations for IPA, I aimed to recruit a sample of 6-8 participants to interview. There are no stringent rules on sample size for IPA studies, however, IPA studies are usually small, which enables a detailed analysis of each of the participants' accounts (Pietkiewicz & Smith, 2014). IPA studies have been published with a sample size of one, four, nine or fifteen participants (Pietkiewicz & Smith, 2014). Turpin et al. (1997) have recommended a sample size of 6-8 participants for clinical psychology doctoral programmes in Britain (as cited in Pietkiewicz & Smith, 2014). This informed the sample size for this study.

The study aimed to recruit a sample of adult participants who had FMD. The term FMD includes a range of movement disorders, for example tremor, dystonia and limb weakness. It was considered whether the sample would be exclusive, for example only one type of FMD (e.g. only tremor), or more diverse, for example different types of FMD. When considering homogeneity of the sample, I initially presumed it should be exclusive, however, this clinical population is small and successful recruitment of an exclusive sample would be difficult and thus, unfeasible. Consequently, it was decided the sample could be diverse and consist of participants with different types of FMD. IPA requires a homogenous sample

where participants are similar in some way. The sample for this study was situated in homogeneity based on three factors; all the participants were adults, they had a diagnosis of FMD and they shared the experience of living with FMD.

Recruitment criteria. The study had the following inclusion and exclusion criteria. Inclusion criteria: aged 18 years old, a diagnosis of FMD made by a neurologist and capacity to consent. Exclusion criteria: under the age of 18 years old, no diagnosis of FMD, unable to speak English, actively suicidal or no capacity to consent.

Recruitment. Participants were recruited from the Leeds Teaching Hospitals NHS Trust (LTHT) adult neurology department. The field supervisor, Doctor Alty was a consultant neurologist at this service and was responsible for recruiting participants. Doctor Alty sub-specialises in Movement Disorders and had developed a 'delivering the FND diagnosis' style that captured the ethos of working within a positive diagnostic framework (see Appendix A). She developed her skills over many years by attending training sessions delivered by international experts in the field of FND and through supervised consultations observed by senior consultants. She believes the information obtained from a patient's history is important to inform the delivery of the diagnosis and recognises that the way a diagnosis is delivered is crucial in establishing a therapeutic relationship. She is mindful that patients have often experienced significant delay or misdiagnosis, which can leave them feeling mistrustful and/or angry. Therefore, she believes in providing patients with a different experience in hope of restoring the patient-doctor relationship. She has based her approach on the core principles of building a therapeutic relationship: being calm, gentle, validating and actively listening. It is important to note that I did not receive this information until after analysis was completed as I did not want this knowledge to contaminate the analysis process.

Recruitment started in September 2018. Doctor Alty identified potential participants from her clinical caseload and the recruitment strategy had two strands. The first required her to approach potential participants in person at their routine neurology appointment or during their inpatient admission. The participants were told that there was a research study happening in the department and asked if they were interested in hearing more. If they wanted to

hear more about the study she explained the principal researcher would contact them to discuss participation and the administration team would post out the research invitation letter (see Appendix B) and PIS (Appendix C). Her secretary was responsible for passing on the potential participants contact details to me either by email or telephone. These details were kept on an electronic document on the university secure server. Alternatively, participants could also directly contact me via email or telephone or they could contact the consultant's secretary by telephone. The second strategy required her to identify outpatients from her clinical caseload and the secretary posted out the research invitation letter and PIS. Potential participants had to contact the principle researcher either by email or telephone or the secretary if they were interested in participating. Participants had the responsibility of making the first contact because they had not been directly seen by their clinical team to introduce the research, therefore, it would not be ethical to 'cold call' them. A recruitment flowchart of participant's numbers identified and recruited, as well as reasons for those not recruited are presented in figure 1.

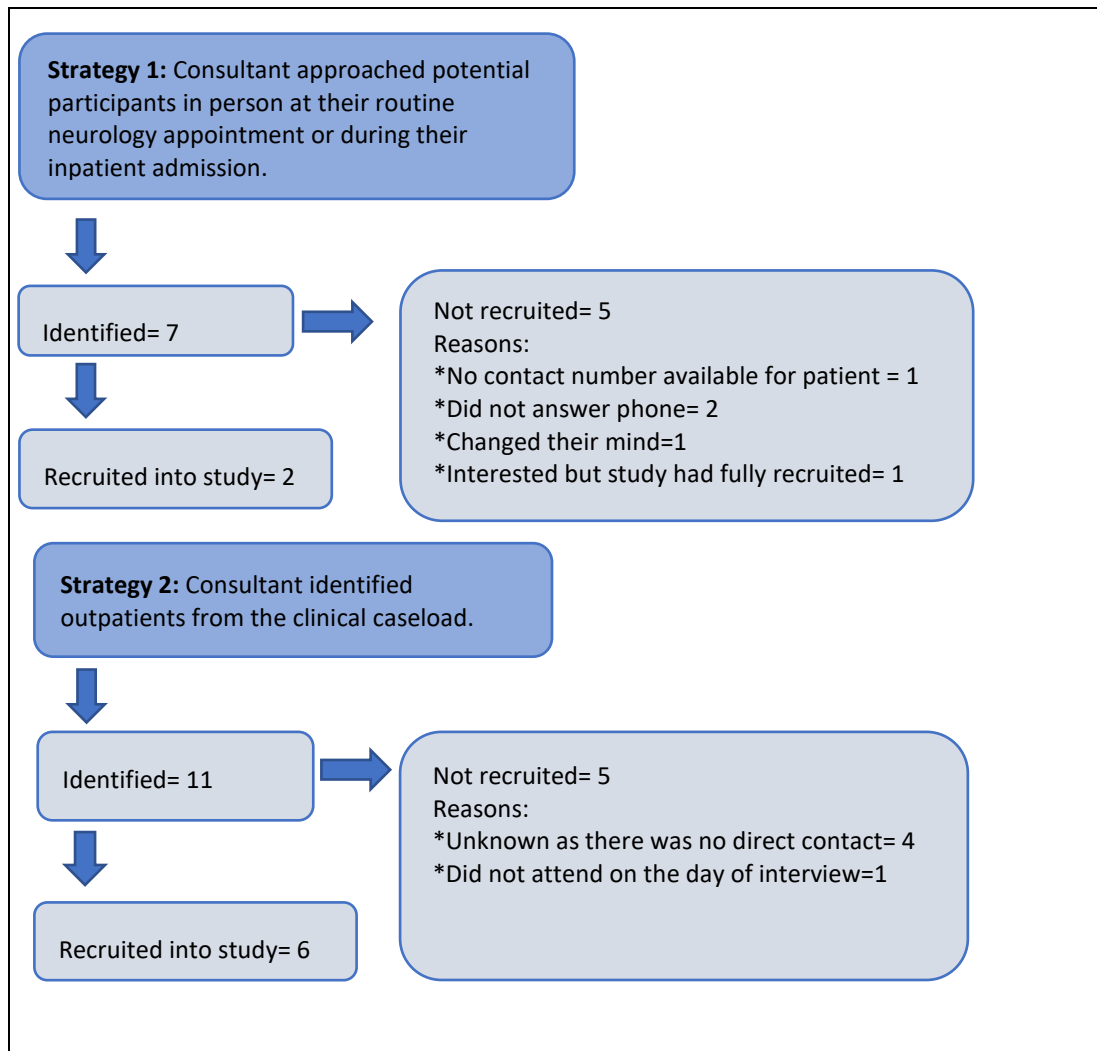


Figure 1: Recruitment flowchart

Informed consent was initially sought by providing potential participants with the PIS during the recruitment process. The PIS provided detailed information to enable participants to make an informed decision as to whether they took part in the study. Once participants had decided to take part they had the opportunity to ask further questions during our initial contact. I then contacted participants 24 hours later to arrange an interview date. This provided a sufficient reflection period with regards to consenting to taking part in the research. Both recruitment strands arranged the interview appointment through the participants preferred method of communication, either email or telephone.

Materials. The data was collected using a semi-structured interview schedule (see Figure 2 and see Appendix D for the full schedule including the prompts and probes). A semi-structured interview provides a flexible approach that generates rich data as interviewees can also lead discussions. The interview

schedule was developed in collaboration with project supervisors; one was experienced in qualitative methodology and the other was experienced in working with this population. The charity *FND Hope* was consulted on the development of the schedule. Two of their employees, who had FND, were given the opportunity to provide feedback on the schedule and they were satisfied with the schedule. The interview was trialled on peers and they did not make any suggestions for improvement. I also practised the schedule on other colleagues and did a role play to test out how usable it was in practice.

1. Can you tell me what interested you to take part in the study?
2. What was life like before you had the condition FMD?
3. Can you please tell me about your story from the beginning?
 - a. What did you first notice?
 - b. When you started to have these symptoms what was going through your mind at time?
4. Tell me about getting the diagnosis?
5. Can you tell me whether you received any treatment?
6. Then what happened, what was life like once you had received the diagnosis, so the first 6 months?
7. So, what is life like living with a FMD?
8. What does having FMD mean to you?
9. What advice would you give someone who has been diagnosed?

Figure 2: Interview schedule guide

To explore participants' experiences the interview schedule was based on a narrative approach for two reasons; to elicit stories based on time points within their life and to encourage participants to tell their life stories. Successful exploration of experiences required a schedule that could engage participants. Therefore, the schedule started with broader questions and moved towards more specific questions. This funnelling technique (Smith et al., 2009) provided a logical order that enabled participants to warm up to the process of the interview and sharing information. Furthermore, to support this notion of exploration the schedule consisted of open-ended questions to guide the interview. I collected additional information using a demographic and other information questionnaire (see Appendix E). All this data was self-reported by the participant. This information was intended to support data analysis and inform pen portraits.

Ethical Considerations.

Participant and interviewer wellbeing. Participation in the study was unlikely to cause distress, but participation could bring to the fore existing distress. Participants were discussing personal experiences, therefore, these responses are expected and proportionate to the content. To manage any potential distress participants were informed before taking part in interview that they can take breaks, stop the interview at any time or decline to answer questions. These measures were intended to reduce the risk of exploring topics that participants did not wish to discuss or elaborate further on. As a researcher it was possible I may have experienced distress from listening to participants' experiences, therefore, this was managed by using supervisors for a debrief if required. Although, I never needed to use this support. An additional consideration was safety when conducting home interviews and I adhered to the Leeds University Lone Working Protocol. Supervisors or the admin team were informed when I arrived and when the interview had finished.

Confidentiality and data protection. The PIS explained that anonymised extracts from the interview would be used in the final write up and that the interview would be recorded using an encrypted dictaphone. All recordings were deleted from the dictaphone and transferred to secure server on the University of Leeds computer network. The interviews were kept as an audio file. The interviews were transcribed by a professional transcriber who worked at the University of Leeds. They signed a confidentiality agreement. The interview data was anonymised from the point of transcription to prevent identification of participants; their name, places (for example, name of hospital, place of work) and third-party names (for example, family, friends or pets) were all anonymised. All participants have been given a pseudonym.

Payment. After the interview had finished all participants were offered the choice of a £20 voucher or £20 in cash as a gesture of good will; thanking them for their time and to compensate any travel expenses. All of the participants accepted the payment. Five participants chose cash and three participants chose vouchers.

Interview Procedure. The participants were offered the choice of being interviewed at either Leeds Teaching Hospitals NHS Trust (LTHT) adult neurology department (n=2), the University of Leeds (n=1) or their home (n=5). All the interviews were face to face and the majority were completed in one session, apart from one interview which was completed in two sessions because all of the topic areas of the interview schedule had not been completed. The length of the interviews varied.

Firstly, I reviewed the information in the PIS with the participant. Participants were then given the opportunity to ask questions. They then provided consent to take part in the study by reading and signing the consent form (see Appendix F). I then completed the demographic and other information questionnaire with the participant. The interview then began and was recorded using a dictaphone.

The majority of the interviews were predominantly guided by the participants. My role was to prompt for further explanation and detail, as well as ensuring the key topic areas of the interview schedule had been covered, therefore, the interviews were not prescriptive. My approach for the interviews was for it to be more of a conversation, doing my best to encourage participants to lead the conversation and tell their story.

At the end of the interview a debrief was provided. All participants were given the opportunity to reflect on their experience of taking part in the study and I was able to check out the participants wellbeing. Participants were given a debrief sheet with signposting information (see Appendix G). When the participant had left I immediately made a note of my reflections on the interview. At a later time point I also listened to the early interviews to evaluate my interviewing style and promote engagement with the data in preparation for analysis. Consequently, there were no changes to the interview content or procedure as a result of this process.

Transcription of interview. Interviews were transcribed verbatim by a professional transcriber. The transcript also included non-semantic content (for example, laughing). Pauses are represented as [. . .]. I checked all of the

completed transcripts for accuracy by listening to the audio file whilst reading the transcript.

Ethical approval

Full ethical approval was given by Leeds West Research Ethics Committee (Yorkshire & The Humber) on 21 August 2018 (see Appendix H).

Data analysis

The interview transcripts were analysed in accordance with the principles of IPA. IPA involves reading the interview transcripts in search of themes. Firstly, the data was manually coded in terms of what was considered to be interesting and significant aspects of the text. This facilitated the identification of potential themes from the data. These emerging themes were given a provisional name. As further reading of the transcript continued the themes were further developed. Individual themes for all the participants were then identified. These individual themes were then used to inform the group analysis. This process is based on IPA analysis guidelines by Smith et al. (2009) (Appendix I).

These guidelines were slightly adapted. The guidelines advise to complete the first three stages and then identify the individual themes for that transcript before moving onto the next transcript. Instead I completed the first three stages for all the transcripts and then I returned to identify the individual themes for each transcript. This allowed me to have a sense of each transcript within the total data set and therefore, it prepared me for finding themes. See table 2 below for the amended procedure. The amended stages have been highlighted.

Stage	Process	Example
1.Read and re-reading	Read and reread the transcript to become familiar with the account.	N/A
2.Initial noting	Examine semantic content and language use on an explanatory level. Note anything of interest or significant. Produce a comprehensive set of notes. Commentary will involve descriptive comments that are close to the participants explicit meaning and interpretative comments indicating the researchers understanding of how and why the participants has these concerns.	Appendix J
3.Developing emergent themes	Analytic shift to working with the initial notes. Analyse exploratory comments to identify emerging themes. Provisional theme name that captures what is important.	Appendix K
4. Moving to the next case	Repeat the process above with the other transcripts.	N/A
5.Searching for connections across emergent themes	<i>Individual themes:</i> map how themes may fit together. Develop 'super-ordinate' themes by clustering similar themes together. Extract oppositional relationships between emergent themes and identify contextual and functional elements within analysis. Produce a graphic representation of the emergent themes (see figure 3).	Appendix L
6. Looking for patterns across cases	<i>Group Analysis:</i> look for patterns across cases by laying out each table of themes for each participant. Produce a table of themes for the group, illustrating how themes are nested within super-ordinate themes for each participant.	Appendix M

Table 1: Amended IPA procedure based on Smith et al. (2009) guidelines

To ensure rigor in the analysis the data was subjected to audit checks. The purpose of the audit was to ensure the analysis was done correctly and to a satisfactory and rigorous standard. The analytical process was audited by the supervisors of the project. All supervisors had a specialism, there was an expert in IPA and GT, and two experts in FMD. The expert in IPA was able to ensure and assess whether the analytical techniques of IPA were applied appropriately. The auditors saw and we discussed (at length) the raw data (transcript, codes and interpretations), the reduction and organising of data (quotes and process notes), data refinement (emerging themes and process notes) and the development of themes (quotes and process notes).

An audit task facilitated by me was checking the transcripts against the original recordings for errors. The audit tasks carried out by the supervisors for the individual analysis were: 1. *Transcripts*: annotated transcripts were looked at to provide feedback on coding and interpretations, 2. *Emerging themes document*: they looked at the emerging themes against the interpretations and quotes, 3. *Individual theme story board*: this overview of the data set was checked to see whether the theme names represented the set of experiences. The audit task carried out by the supervisors for the group analysis was: 1. *Story board document*: supervisors checked the accuracy and appropriateness of whether theme names reflected the experiences as well as the narrative of the themes.

Quality checks

To evaluate the quality of the research I used Elliott, Fischer, and Rennie's (1999) guidelines for good qualitative research (see table 3). The table shows the criteria for the evaluation and I have evidenced how I applied the criteria to the study.

Elliott et al. (1999) criteria	Applied	Incorporation of criteria to the study
1. Owning one’s perspective: the researcher should share their values and assumptions to enable the reader to interpret the analysis and consider alternative interpretations.	Yes	Reflexivity journal kept. Reflexive statement to show my position in relation to the research topic. Role play of interview schedule. Interviewed about my experience of doing the interviews. <i>(see table 4: description of how strategies informed my understanding and analysis).</i>
2. Situating the sample: describe the participant and their life situation to enable reader to decide the applicability of findings.	Yes	Pen portraits of each participant. Table of demographics. Table of diagnosis information. Description of service characteristics.
3. Grounding in examples: provide examples of the data to demonstrate the analytic procedures used and the understanding developed. This will allow the reader to evaluate the data and the researcher’s interpretation.	Yes	Quotations have been provided to support the themes that have been found; therefore, this will enable the reader to evaluate my interpretations.
4. Credibility Checks: the researcher must refer to colleagues’ interpretation of the data to check whether their accounts are credible.	Yes	Achieved in the data analysis phase. Supervisors provided credibility checks. They saw extracts of the interviews and we talked at length with regards to the coding process, emergence of individual themes, development of group themes and refinement of themes. I also presented the themes and interviewed extracts to peers.
5. Coherence: analysis should be presented in a way that shows coherence and integration (e.g. a narrative story, map or framework).	Yes	The analysis is presented as a story based on chronology of events. A clear structure to the section was achieved by re-reading and refining each written draft. Supervisors provided support in checking the coherence of the analysis.
6. Resonating with the reader: findings should resonate with the reader by furthering or clarifying their understanding and appreciation of the topic.	Yes	Research strategy: throughout the data analysis process I received feedback from a Consultant Neurologist and Clinical Psychologist who work in this field.

Table 2: Guidelines for the evaluation of qualitative research (Willig, 2013)

Reflexivity in IPA

An important process within qualitative methodology is *reflexivity* (Pietkiewicz & Smith, 2012). Reflexivity refers to “recognising the importance of the researcher’s

perspective” (Willig, 2013, p. 97). IPA requires the researcher to have a *reflexive* attitude (Willig, 2013) and this is because the researcher is trying to make sense of the participants trying to make sense of what is happening to them, this is known as double hermeneutics (Smith & Osborne, 2015). The analysis is both phenomenological (i.e. participant’s view) and interpretative (i.e. researcher’s own conceptions and standpoint), therefore, the researcher is implicated in the analysis (Willig, 2013). Researcher reflexivity is an important quality check as this process can reveal any potential influences that shaped the data.

The reflexive process began before data collection. To explore my assumptions I reflected on my interest and position on FND by writing a reflexive statement. This is presented in the next section. I kept memos on the research process, for example, memos on my response to the development of the interview schedule and literature review. I practised the interview schedule with other colleagues and I role played being a participant. I made a note on my reflections of these experiences. During data collection I continued to keep memos and at the end of each interview I reflected on my experience of the interview. I made a note of my impressions and a summary of what I thought was important regarding their accounts. The function of this was to support the analysis process. It was anticipated the memos may support my understanding of the data.

Before data analysis began I considered repeating the role play exercise. I was curious as to whether my portrayal of a participant would have changed in light of the interviews, however, I thought it would be more useful to do a reflexive interview about my experiences of doing the interviews as I did not have the condition myself. The purpose of this was to provide an insight into my position and whether this had changed during the research process. The interview was done before I started data analysis and the function of this was to *bracket off* my pre-conceptions but also to provide transparency when judging the quality of the research findings. I was interviewed by another trainee psychologist. I had developed the interview schedule and this was checked by my supervisor and amended in response to their suggestions (see Appendix N). The interview was recorded to form part of the reflexive diary. During data analysis memos were also kept. All these strategies were an attempt to capture and develop insight into my

pre-conceptions as they had arisen during the research process. My reflexive stance functioned to allow transparency of how themes may have been influenced by my subjective interpretive position. See table 4 for the reflexive strategies used. There were benefits to using various reflexive strategies in the early stages of the research process. The strategies supported me to notice how my assumptions may influence the analysis and my understanding of the condition across the research process.

Reflexive Strategy	Example of how these strategies informed my understanding
<i>Reflexivity journal</i>	<p>First draft of the interview schedule: I noticed the questions were quite specific. They reflected the themes found in the literature review of other qualitative research. For example, asking how they have adjusted to living with the condition. I was developing questions based on what I thought it was like to live with the condition. A potential consequence of this was preempting the findings. The schedule was amended to a narrative framework. This structure encouraged participants to tell their story, therefore, bringing what they thought was important, not what I thought was important.</p> <p>Memo note: participants spoke about feeling embarrassed because of other people, for example, they stare. I felt angry at the public for being so judging and if they were kinder then people may feel better about going out, and thus live more meaningful lives. During the data analysis phase I noticed my anger building. I was thinking the world needed to be kinder. The process of reflecting and the support of supervision enabled me to notice these were the participants assumptions (subjective experiences) as we had no observable data on others. The feelings of embarrassment reflected the shame they held towards themselves.</p>
<i>Role play of interview schedule</i>	<p>On reflection my portrayal was a surface level account: They would struggle to do every day things; but I could not articulate the impact this would have as I did not know to what extent they struggled to do things</p> <p>I portrayed experiences with doctors to be negative. This might have been informed by the literature I had read on NES.</p> <p>I struggled to really understand and describe what it feels like to have the symptoms; both emotionally and physically.</p> <p>I imagined they would feel low in mood but nothing else beyond this.</p>
<i>Reflexive interview: experiences of doing interviews</i>	<p>Supported me to identify any new understandings into the condition. I was shocked by how difficult everyday life was and how incapacitated people were, for example, needing help to dress and how much of a struggle it was to get through the day. I did not expect to find that people avoided going out because they felt embarrassment. I was surprised by the anxiety people experienced. I was not prepared for how difficult it was to observe people's symptoms. I think this increased my levels of empathy and my appreciation of how difficult their lives are.</p>

Table 3: Reflexive strategies

Initial reflexive statement

I do not have an FND and I do not know anyone in my personal life who has this condition. My interest in FND is professional and I have never worked clinically with this population. The first time I met a client with a FND (NES) was whilst I was shadowing a clinical psychologist therapy session. This was also the first time I had even heard of the condition. Within the clinical team (Multi-disciplinary team in a mental health service) many considered this presentation to be one of feigning and some professionals struggled to hold and maintain empathy towards the client. The

team's perspective conflicted with how I was feeling. I remember when I saw the client having a functional seizure. I felt sympathetic towards their suffering and I was able to hold compassion. When considering our differing perspectives I was curious as to whether the concept of 'feigning' is relevant to the discussion of clinical care. In my opinion, either way the distress is real and the behaviour is communicating that something is not right for this individual. My only other experience of FND was whilst I was working within a community mental health team. A team member would often express a dismissive attitude towards the client's presentation. At the time, I was on the Doctorate in Clinical Psychology course, therefore unlike the case discussed above I was more confident to engage the staff member in a reflective conversation about this. On reflection from these experiences, I recognise that as I was not directly working with the clients it might have been easier for me to have held this perspective.

My initial interest in FND was around how the condition can evoke strong reactions within professionals and at times we can often forget there is a person behind the label who is experiencing distress. My experiences left me thinking how complex and challenging this condition was to understand and 'treat' as medical interventions were limited and the psychologist mainly worked from a trauma perspective. The client in the first case did not share the psychologist's understanding of their symptoms being an expression of trauma that needed to be worked through. Furthermore, I was curious as to how this condition could impact on the therapeutic relationship, compared to neurological conditions with an established pathology such as MS or stroke; and so, I perceived living with a FND to be lonely if they face a path of clinical care where they are doubted. I perceived this population to be a vulnerable group, therefore, my compassion and empathy may possibly influence the research findings and how I conduct and behave in the interviews. In addition, I believe some professionals can have a negative attitude towards the condition, so I may be more driven to show this condition in favourable light to challenge such attitudes.

What did I think my results would look like?

Looking back at what I expected to find, I feel my thinking was quite naïve. I did not have many expectations and I wonder whether this reflected my novice position on FND. Before this project I had no clinical experience of working with this patient group and my knowledge of the condition was very limited. I expected people to talk about struggling to do things, for example hobbies and daily tasks, but I did not expect people to completely lose the ability to do these things. I anticipated people may experience difficulties with their mood, but I did not foresee how strong the feelings of anger, fear, worry and confusion would be. My only expectations around the diagnosis process were that people would report not feeling believed and a diagnosis was validating. This was based on my knowledge of the NES literature. I expected people would find ways of coping and adapting to the condition. I presumed this would be an indication of 'acceptance'.

Results

This chapter will present the results. Firstly, the details of the final sample and then the participants' demographic and clinical information. The pen portraits for all the participants will then be introduced. Each portrait will describe the participant's motivations for taking part in the study, their story, then the individual themes generated by each participant will be presented followed by an account of how the interview experience was for the participant and myself. Finally, this section will end by presenting the group analysis. Each superordinate theme and the subordinate themes will be described and extracts from the transcripts will be provided.

Final sample

The study successfully recruited 8 participants. Please see table 5 for their demographic information and table 6 for information on their clinical presentation. This information was self-reported by the participants.

Participant pseudonym	Age	Gender	Ethnicity	Employment	Current physical health problems	Current mental health problems
P1. Zoe	20s	Female	White British	Yes	Yes	No
P2. Rita	30s	Female	British Indian	Yes	Yes	No
P3. Jude	50s	Female	White British	No	Yes	Yes
P4. Mary	40s	Female	White British	No	Yes	No
P5. Dan	30s	Male	White British	Yes	Yes	No
P6. Tina	50s	Female	British	No	Yes	Yes
P7. Sundip	60s	Female	British Indian	Yes	No	Yes
P8. Anne	70s	Female	English	No	Yes	No

Table 4: Table of demographics

Participant Pseudonym	FMD sub-type	Previous Management	Symptoms duration before FMD diagnosis
P1. Zoe	Tremor and dystonia	Physiotherapy Drugs	2-3 years
P2. Rita	Tremor	Physiotherapy Psychology	10 months
P3. Jude	Dystonia	Botulinum toxin	10-15 years
P4. Mary	Tics and tremor	Drugs	10 years
P5. Dan	Dystonia	Drugs	Under 4 years
P6. Tina	Tremor	None	8 year
P7. Sundip	Tremor and dystonia	Botulinum toxin	1 year
P8. Anne	Dystonia	Botulinum toxin	16 years

Table 5: Clinical information

Pen portraits

In this section I will present a pen portrait for each participant. The purpose of the portraits is to provide context to the group analysis. I have provided information on whether participants were diagnosed by the field supervisor of this project (Doctor Alty, NHS Consultant Neurologist or a different doctor (private doctor or NHS Consultant Neurologist)).

Participant 1. Zoe is in her twenties. She was aware that there is limited research on FND and this motivated her to participate in the study. She hoped the sharing of her experiences would improve other people’s knowledge of what it is like living with this condition. The interview lasted 110 minutes and was completed in one session at the University of Leeds. She described her symptoms as: tremors, headaches, visual disturbances, fatigue, pins and needles, spasms, back pain and shortness of breath. She received her diagnosis of FMD from a private Doctor and then later transferred her care to Doctor Alty.

Life before symptom onset: life was “*completely normal*” and she was “*healthy, fit and active*”. She enjoyed competing in competitions and socialising

with friends. She reported doing well at school and college and had a full and structured routine. She described her relationships with immediate and extended family to be distant. She reported no experiences of mental health difficulties.

Onset of symptoms: when she was 17 years old she suffered a fall resulting in a spinal injury. She believed this was the trigger for the symptoms and *"life just changed; it was no longer the same"*. At the time of the injury she was seen in the orthopaedics and physiotherapy departments. A couple of months after she had been discharged she had a bad chest infection which persisted for some time. She then developed an array of symptoms. She first visited her GP, but she felt they were limited with regards to the support they could provide and the symptoms were managed with drugs. She went back and forth between the GP practice and the accident and emergency department on multiple occasions (when there was an *"influx of symptoms"*). The GP did a series of investigations, but test results came back as *"reasonable"*. She saw a few different GPs at her practice and eventually she found a doctor that recognised something was not right and referrals were made. She then encountered two foundation (F1) doctors and Doctor Alty who began testing. She started the diagnosis process with Doctor Alty in the NHS but then she saw a private doctor to speed up the process. She was diagnosed two to three years after the onset of symptoms by the private doctor and then transferred back under the care of Doctor Alty.

Management: the private doctor diagnosed her with FMD and admitted her to a short stay ward. Medical professionals viewed her condition as a psychological problem and she was offered pharmacological treatment. She disagreed with this, declined treatment, discharged herself from the ward and transferred to the care of Doctor Alty again. She received physiotherapy and found this to be a helpful treatment.

Life now: she lives with her family. She now is studying a different subject and alongside this works at a hospital. She described having good support from friends and extended family. She has other health issues. She described being *"in a good place"*, *"happy"* and in a better position of managing the condition. She still has difficult days where she will feel tired, achy, be less active and require rest. She

is focused on finishing her degree and beginning her new career. She is much closer to some members of her extended family because of the illness experiences. Initially, she felt they did not believe she was unwell, however, when her symptoms got worse, they realised something was not right. Therefore, they provided more support and thus *“improved relationships with sort of extended family”*.

Individual themes:

World starts to crumble
<i>In constant war with your own body</i>
<i>Defeated and hopeless</i>
<i>Stripped of self</i>
<i>Frustration in not being listened too</i>
<i>Cutting off; it's not worth feeling</i>
Spiralling down, up and then back down
<i>Silenced</i>
<i>Breaking the silence</i>
<i>No longer “in a hole anymore”</i>
<i>Bittersweet</i>
“A normal life but just with extra baggage”
<i>‘it’ slows me down</i>
<i>“made me the strongest person”</i>
<i>“I’ve got a knack for it”</i>
<i>Got to make the most of life</i>
<i>“Pulled your finger out”</i>

Table 6: Zoe’s individual themes

Experience of interview: Zoe very much led the interview. Her openness, honesty and ability to reflect on her experiences provided a rich account. At the end of the interview she was surprised by how much she had talked and how open she had been about her feelings and experiences. I found this interview experience to be easy as she was able to take ownership of the interview. She was friendly and warm. I left the interview feeling positive and happy as she was coping well and living a life she appeared to find meaningful.

Participant 2. Rita is in her thirties. She had decided to take part in the research as she was aware that there is limited research on FND. She felt that research was important to improve others understanding on what it is like living with the condition. Our interview lasted 75 minutes and was completed in one session at the NHS neurology clinic room. She has a tremor in the hand. She received her diagnosis of FMD from Doctor Alty.

Life before symptom onset: she described herself to be an active individual. She enjoyed keeping fit, cooked "*whipping up meals left, right and centre*" and socialising. She travelled independently, had a full-time job in healthcare and she managed the home and family life. In her words she was "*getting on with life*". She was married and she had children.

Onset of symptoms and diagnosis: she tripped and fell at work and she suffered a back injury. Four weeks after this accident she then developed the tremor. In the interview Rita only spoke about her experiences with Doctor Alty and it is unclear as to whether she saw anyone else prior to this. She was diagnosed by Doctor Alty 10 months after the onset of symptoms.

Management: she had therapy and saw a psychologist. She reported psychology was a useful experience as it supported her to accept the tremor, however, she was upset when it had finished. She did not find physiotherapy helpful. The sessions were not frequent enough and it was difficult to practice the exercises as she did not have the equipment at home.

Life now: she is still married and has children. She had to stop working in healthcare due to symptoms. She is now working in the family business. Self-employment has given her more flexibility to manage the demands of work and her physical health. She has a good network of social support from immediate family and friends, in addition she uses a blogging site. She does have other physical health conditions. Since her illness experience she had appreciated having more time to spend with her family. She described herself as feeling "*happy*". She now does other gentler physical activities. Cooking can be a challenge, but she is finding ways to continue with this. The tremor can still cause disruption to her daily life but she feels better able to cope with it and manage the symptoms.

Individual themes:

"just a tremor can change your life so much"
<i>"A mind of its own"</i>
<i>Mind dealing with the unknown</i>
<i>Life "a big waiting game"</i>
<i>Body can't keep up with life</i>
<i>Frustrated in repeating same story</i>
<i>Ashamed of unsightly self</i>
<i>Loss of self "just this poorly person"</i>
Slowly building an understanding and moving forwards
<i>Floating in uncertainty</i>
<i>Slowly build a picture</i>
<i>Bittersweet</i>
Assimilating it into my life
<i>Fitting in with my life</i>
<i>It is part of me and my life</i>
<i>Starting to feel more comfortable around others</i>

Table 7: Rita's individual themes

Experience of interview: Rita very much led the interview. She was open, talkative and had great insight into her experiences. Her account was rich in reflection and she did not shy away from talking about difficult experiences. Her story was told in a coherent way and she was able to give lots of specific examples, therefore, the experience of this interview for me was straight forward. I felt there was an emotional rapport between us both. I left the interview feeling hopeful and happy about her current situation and I think this possibly reflected where she currently was within her life.

Participant 3. Jude is in her fifties. She was interested in taking part in the study because she wanted the opportunity to share how she feels. Our interview lasted 120 minutes and it was completed in one session at her home. She has dystonia in the hand. She received the diagnosis of FMD from Doctor Alty.

Life before symptom onset: she described herself as a *"normal person"*. She was sociable and enjoyed going out with friends. She loved to dance and swim. She worked in healthcare and valued working *"loved the job"*. She was married for a long period and had children.

Onset of symptoms and diagnosis: she began to progressively struggle to write as her hand went into spasm. She noticed a tingly feeling, numbness and her fingers swelled, therefore, she struggled to use her hand. Initially she thought these

experiences were due to getting older. Over time the symptoms got worse. She was struggling to write and doing tasks such as stirring a cup of tea or buttering a piece of bread. She described her hand as having no strength. Considering these difficulties a friend prompted her to seek medical assistance. Jude kept on visiting her GP with regards to her concerns about the symptoms however, they kept on telling her nothing was wrong. She eventually (length of time unknown) got a referral to a hospital (department unknown) and a doctor (type of doctor unknown) diagnosed her with writer's cramp. The doctor managed the symptoms with drugs (type unknown). She lived with the diagnosis of writer's cramp for around 12 years. She noticed no improvement in her symptoms and this prompted many more visits to the doctors (type unknown). Eventually she was referred to hospital again and she went under the care of Doctor Alty, who started to investigate the symptoms. She was diagnosed with FMD by Doctor Alty.

Management: she was prescribed botulinum toxin injections. Initially this was an effective treatment and the spasms did stop however, treatment success was only short-term.

Life now: Jude was single and lived alone. I do not know the reason for separation. She is a grandmother. She had to take early retirement due to ill health. She reported having a good social network of friends, however, she did not consider her family support to be as strong. She is suffering with other physical health conditions and she reported currently having anxiety and depression. She had to stop working and although she did "*miss it*", she recognised that no longer working made it easier to manage the condition. Her hobbies of dancing and swimming have ceased and she is struggling to find replacement hobbies. She is still socialising with her friends and they go out for meals or to the pub.

Individual themes:

“dropping to pieces”
<i>Confused by uncontrollable body</i>
<i>Fighting to carry on but “everything just got on top of me”</i>
<i>Deterioration of body and life</i>
<i>Frustration in not being listened too</i>
<i>Suffering in silence</i>
<i>Feeling desolate</i>
“in the end I was right” but nothing changes
<i>Silenced</i>
<i>Bittersweet</i>
<i>Making sense of my state</i>
Struggling to hold onto me and my life
<i>Wanting ‘it’ to go away</i>
<i>“Stuck in a rut”</i>
<i>“Just got to live with it”</i>
<i>I feel “full of shame” and damaged</i>

Table 8: Jude’s individual themes

Experience of interview: Jude was keen to tell her story and she very much led the interview. She was skilled at reflecting on her experiences, thoughts and feelings. She felt comfortable enough to be open and honest, and at times she became upset during the interview. I left the interview feeling sad. This may have been a parallel process of where she currently is in her life. In that, I was able to empathise with her experiences or I may have experienced her feelings directly through the way she communicated with me. In addition, I think the home environment possibly gave me a greater sense of her loneliness as she spoke about spending a lot of time within the home.

Participant 4. Mary is in her forties. She was interested in taking part in this study because she wanted others to know “*how it is to be me*”. Our interview lasted 125 minutes and it was completed in one session at her home. She described having limb tics (involuntary movements of her arms, legs, neck and stomach) and then developed a tremor. She received a diagnosis of FMD from an NHS Consultant Neurologist.

Life before: employment was something she valued “*I loved going to work*”. Before having to take early retirement 5 years ago she had worked in the education sector and in healthcare. In her own time she enjoyed active hobbies, for example abseiling, walking and dancing. She described herself as bubbly, energetic and

confident. She was diagnosed with other two health conditions (fibromyalgia and arthritis) at around 20 years old.

Onset of symptoms and diagnosis: the first time she noticed the symptoms she was watching TV and her arm jerked causing her to spill a drink in her face. At the time she realised something was seriously wrong but she presumed it was a symptom of the fibromyalgia. She decided to see a doctor (type unknown) and experienced a lengthy process of seeing various doctors who she reported did not really understand what was wrong. She was eventually referred to a consultant neurologist that was able to help. She saw this doctor and a number of neurology registrars, one of which was Doctor Alty. She was given the diagnosis FMD. She then saw Doctor Alty again as a Consultant Neurologist when the vocal tics started. She was diagnosed with FMD ten years after the onset of symptoms.

Management: the initial treatment she received was pharmacological. This treatment lasted for around ten years and during this time she experienced *“horrendous side effects”*. She did not find this treatment pathway to be helpful as she thought that the doctors did not *“really know what they were treating”*. Consequently, she stopped treatment. She is now not receiving any treatment, although, she is in the process of seeing whether CBT or physiotherapy would be helpful interventions.

Life now: Mary lives with her partner. I did not have the information as to when this relationship started. She reported having good support from her family and friends. She reported that living with the condition was much easier now as she was no longer contending with work and the symptoms. She had found a new hobby which she enjoyed. She still frequently experiences the symptoms but reported feeling happy.

Individual themes:

"Dark days"
<i>The unpredictable force is degrading and dangerous</i>
<i>I am an embarrassment to myself and others</i>
<i>Push, push, push all the time</i>
<i>"walking in treacle"</i>
<i>"What is the point of me"</i>
<i>Loss of hope and left with nothing</i>
"in the end I was right" but nothing changes
<i>Silenced</i>
<i>Breaking the silence</i>
<i>Need to get off the conveyor belt of false hope</i>
Choosing to live and letting go
<i>The body is "life limiting"</i>
<i>"it's scary being unpredictable"</i>
<i>"Just part of me"</i>
<i>Breaking the body freed me</i>
<i>Pushing self to live a meaningful life</i>

Table 9: Mary's individual themes

Experience of interview: Mary was very reflective and insightful about her experiences, feelings and thoughts. Her openness and willingness to share her experiences meant that the interview was very much led by her. Something that I had not anticipated was the shock I experienced when I saw the symptoms present during our interview. She looked like she was in great distress and discomfort. At times this was hard to observe.

Participant 5. Dan is in his thirties. He was interested in taking part in this research because he wanted "to help" by sharing his experiences. Our interview was completed over two sessions at his home. Session one was 110 minutes and session two was 90 minutes. He has dystonia and he experiences muscle twitches of his arms, legs, neck and face. Later on he then developed seizures. He was diagnosed with an FMD by Doctor Alty.

Life before symptom onset: Dan reported that he spent his time going to work, managing and spending time with family and friends, going out for meals and engaging in hobbies. He liked to watch football, TV and go for walks. After the onset of his other physical health conditions he did have significant periods of sick leave from work. He worked at a transport company. Dan was married and he had children.

Onset of symptoms and diagnosis: at the time he was experiencing many difficulties within his personal life. His relationship with his wife was under strain, his son was going through difficulties at school and he was on the verge of losing his job due to health reasons. When he first experienced the symptoms he thought he was having a stroke and he was admitted as an emergency to hospital. He spent some time in hospital undergoing various tests and a stroke was eliminated. Doctor Alty was his Consultant upon this admission and he remained under her care. He reported having lots of trips to the hospital for investigations and then a diagnosis was provided. He also developed seizures.

Management: he reported not receiving any treatment currently. It is unclear whether he received treatment in the past as this information was difficult to make sense of from the interview transcript. He spoke about previously receiving input from psychology but it was not clear whether this was a referral for the FMD or something else.

Life now: he is still married and he lives with his wife and children. He is currently in employment and works for a transport company. He described himself as having a network of friends and family for support. He also has other physical health conditions. The seizures have reduced in frequency. The dystonia still presents, but the frequency of episodes can vary from days, weeks to months. Therefore, he feels the dystonia is not currently having a big impact on his life as he is continuing to work and do the things he wants to do. In addition, he feels that he is in more control of his symptoms and this ability to better manage his symptoms has made living with the condition easier.

Individual themes:

Living with unpredictability and worry
<i>Losing control of the body</i>
<i>The unknown unsettles the mind</i>
<i>Less of a man</i>
A time of uncertainty
<i>Frustrated being left and floating in uncertainty</i>
Uncertainty over the unknown but I won't be defeated
<i>It's frustrating that people are not satisfied with my answers</i>
<i>Uncertainty creates doubt</i>
<i>I can control this, it will not defeat me</i>
<i>"Sailing in the sea of the unknown"</i>
<i>Stop worrying and carry on living</i>
<i>No control of this thing in my body</i>

Table 10: Dan's individual themes

Experience of interview: Dan was open and willingly to share his experiences. There were moments where he became upset. The interview was very much led by him. At times he struggled to reflect upon his experiences. His account focused on what the cause of the condition was and descriptively describing examples of the symptoms. The interview was sometimes hard to manage as he could sometimes go off topic, therefore, it would be difficult to understand the narrative of his story and use prompts for further information. This may have impacted on the richness of the account.

Participant 6. Tina is in her fifties. She decided to take part in the research because she thought it might be help other people. The interview lasted 89 minutes and was completed in one session at the NHS neurology clinic room. She has a tremor in her hands, legs and head. She received the diagnosis of FMD from Doctor Alty.

Life before symptom onset: Tina was married and lived with her husband. She liked to play bingo, go walking, dancing and spending time with the grandchildren. She had always been in employment. She had 25 years of experience of working in retail. She came from a family that valued working and she too shared this. She enjoyed working but had to take early retirement due to fibromyalgia. During retirement she was struggling with her physical health and as a consequence she was feeling low in mood and lost interest in going out of the house.

Onset of symptoms and diagnosis: Tina experienced many stressful events many years before the symptoms presented. Her aunt and uncle passed away. In addition, her dog passed away and they brought a new dog which became ill. She described these events as *“traumatic”* and she wondered whether this triggered the tremor. When the tremor first began in the hands she feared it was Parkinson’s disease. She initially saw her GP who referred her to a neurologist, but no diagnosis was given. She was given drugs to manage the symptoms but the drugs did not help her. She underwent a series of investigations, but still no diagnosis was given. She eventually was referred to Doctor Alty and was diagnosed with FMD eight years after the onset of symptoms.

Management: she currently is not receiving any treatment. She reported she has not received any treatment in the past.

Life now: she has been married for 40 years and lives with her husband. She described her husband as being very supportive. She has a network of friends for support. She has other physical health conditions that developed before FMD and she struggled with these. She described her mood as *“up and down”*. She still does not have interest in her old hobbies. Managing the home is difficult and she struggled with daily task such as personal care and eating. She oscillates between good and bad days.

Individual themes:

Frustrated and scared
<i>Embarrassed and frustrated by uncontrollable body</i>
<i>Fearing the worst and the future</i>
<i>Frustrated by a limited body</i>
<i>Trying to make sense</i>
A long wait
<i>Bittersweet</i>
<i>Frustrated and scared by not knowing</i>
I still feel no different
<i>Uncontrollable body is a danger to me</i>
<i>Adjusting to needs of the body</i>
<i>Ashamed of body</i>
<i>Determined to be self sufficient</i>
<i>Angered by useless self</i>
<i>Pushing self to live is exhausting</i>
<i>All alone and lost interest in meaningful activities</i>
<i>I feel like a burden</i>

Table 11: Tina's individual themes

Experience of interview: Tina was friendly, warm and shy. It took her some time to warm up to the interview process and to talk about herself. She found it difficult to reflect on her feelings but she was more insightful about her cognitions. She struggled to remember her experiences of living with FMD in the past, as the onset of symptoms and diagnosis and management process was a long time ago. Her account was more detailed regarding the here and now experiences. At the end of the interview she told me that she is usually not very good at talking about herself. I found this was the most challenging interview experience and I felt that I led the interview much of the time. I initially struggled to encourage her to reflect on her experiences, however, as the interview progressed she became more responsive in expanding on her answers and reflecting. I think she did a tremendous job in letting me into her world.

Participant 7. Sundip is in her sixties. She expressed an interest in taking part in the research because she wanted to share her experiences. Our interview lasted 107 minutes and it was completed in one session at her home. She has a tremor in her hands and a spasm in her legs. She received her diagnosis of FMD from Doctor Alty.

Life before symptom onset: she was widowed and raised her young children alone. Employment was something she valued in her life and she had always worked. She had 23 years of experience of working as a social worker and 15 years

of experience of working for the council within a different role. She enjoyed making clothes and crochet.

Onset of symptoms and diagnosis: she first noticed suddenly struggling to write at work. She could not understand why as she had not experienced any injury and there had been no pain in her hand. Initially she thought this was a temporary experience, but slowly her ability to write got worse. The first time she experienced the spasms she thought it was a stroke. She first visited her GP and she found their advice unhelpful. The GP suggested she avoided writing at work and use other methods. She returned to the GP with the view of getting a referral for further investigations. She was then referred to a hospital, underwent a series of investigations and then discharged with no diagnosis; however, she was not happy with this outcome and requested to see a doctor that was higher up. She was then diagnosed with carpal tunnel and surgery followed a week later. She went back to the GP (time period unknown) as there was no improvement in her symptoms. The GP then referred her to Doctor Alty. She was diagnosed with FMD approximately one year after the onset of symptoms.

Management: she received botulinum toxin injections. Initially this worked and she was able to write, however, the benefits were temporary and treatment stopped.

Life now: she is currently widowed and lives alone. She has regular contact with her children and they are supportive. She works for a charitable organisation, although she is struggling in the role because of the condition. She reported feeling low in mood. In addition, she is unable to pursue her hobbies and she is socialising less now. She is actively looking for new hobbies, but unfortunately she had not found anything.

Individual themes:

Feeling desolate and scared
<i>Hand not corresponding with mind</i>
<i>Weighed down by worry</i>
<i>Wanting to be normal and fearing to be seen as anything but</i>
<i>Fear of losing mind</i>
<i>Saddened by deteriorating body</i>
Sorrow and Hope
<i>Silenced</i>
<i>Breaking the silence</i>
<i>Bittersweet</i>
I want my old life back
<i>Powerless to tame body</i>
<i>Trying to survive but ready to shut down</i>
<i>'It's' getting in my way of living</i>
<i>I'm not normal</i>
<i>Defeat is inevitable but I'll keep fighting for as long as I can</i>
<i>Flickers of perfect self but stuck with imperfect self</i>

Table 12: Sundip's individual themes

Experience of interview: Sundip was excited to be a part of the study. She was skilled at reflecting on her experiences, thoughts and feelings and this enabled her to lead the interview. I found her to be very warm and friendly. I felt a very strong emotional rapport with her. I wonder whether this might have been because she was an Indian woman who was of a similar age to my parents. I felt moved by her experiences and at times upset. I left the interview feeling sad as I felt her loneliness.

Participant 8. Anne is in her seventies. She decided to take part in the research because she wanted *"to see what it was all about"*. Our interview lasted 89 minutes and it was completed in one session at her home. She has dystonia and it presents in her eyes and voice box. Her eyes will close and she will produce vocal noises that prevent her from talking. She received her diagnosis of FMD from an NHS Consultant Neurologist.

Life before symptom onset: she described herself as enjoying life. She liked to walk, go on holidays, shop and go to a theatre or club. She was married and had children. She then divorced and remarried. She had worked in the hair dressing and care industry.

Onset of symptoms and diagnosis: she was out shopping with her first husband and then suddenly her *"eyes went"* in the middle of the road. The issue

with eyes continued. She saw her GP immediately. She was given drugs to manage the symptoms and was referred for a brain scan, but no abnormalities were found. She was then referred to another doctor, but she reported not getting on well with them and thus, she stopped seeing the doctor. She was then referred to another hospital and discharged as nothing was found to be wrong. The symptoms persisted for many years and she returned to the same hospital and saw a new doctor. She described this doctor as being good and this doctor gave her the FMD diagnosis. She then went under the care of Doctor Alty. She was diagnosed sixteen years after the onset of symptoms.

Management: she received Botulinum toxin injections for a long period of time. Initially, this was an effective treatment however, the improvements were not sustained. Consequently, the doctor decided to stop the treatment. Anne agreed with this doctor's decision; however, she felt that the treatment was still effective for her voice box.

Life now: she is still with her husband and she has grandchildren. She has other physical health problems. She is now retired. She does not feel comfortable going out of the house as the physical characteristics of the condition are visible to others and she has stopped going on holidays. She described herself as trying to "just get on with life" and cope.

Individual themes:

Fearing the body and fearing to be seen
<i>My body scares me</i>
<i>Bewildered and fearing the worst</i>
<i>Embarrassed by being different</i>
Breaking the silence
<i>Silenced</i>
<i>Breaking the silence</i>
<i>Bittersweet</i>
Losing the fight, self and left just existing
<i>The body is still controlling me</i>
<i>Incomplete acceptance</i>
<i>Hatred of self</i>
<i>Restricted and deprived living</i>

Table 13: Anne's individual themes

Experience of interview: before the interview started Anne told me that she was not one for talking. Initially she was very quiet and consequently I had to direct

the interview. She became more comfortable as the interview progressed. She was more open and talkative, and this enabled her to take ownership of the interview and lead. She struggled to remember details about the past, therefore, her account is much stronger on the here and now. At the end of the interview she was surprised by how much she spoke. During the interview there were many occasions where we had to stop and wait for the symptoms to pass. At times, I found it difficult to watch. She looked like she was in great pain and I empathised with how upsetting this must be for her.

Group analysis

This section will present the results from the group analysis. The **superordinate themes** will be presented in bold with a summary of the theme. The **subordinate themes** will be presented in *italics*. A description of each subordinate theme will be provided and participants' extracts used to further illustrate the themes. The group analysis produced three superordinate themes and fourteen subordinate themes. Figure 3 demonstrated the themes generated and table 15 shows the frequency of themes across participants.

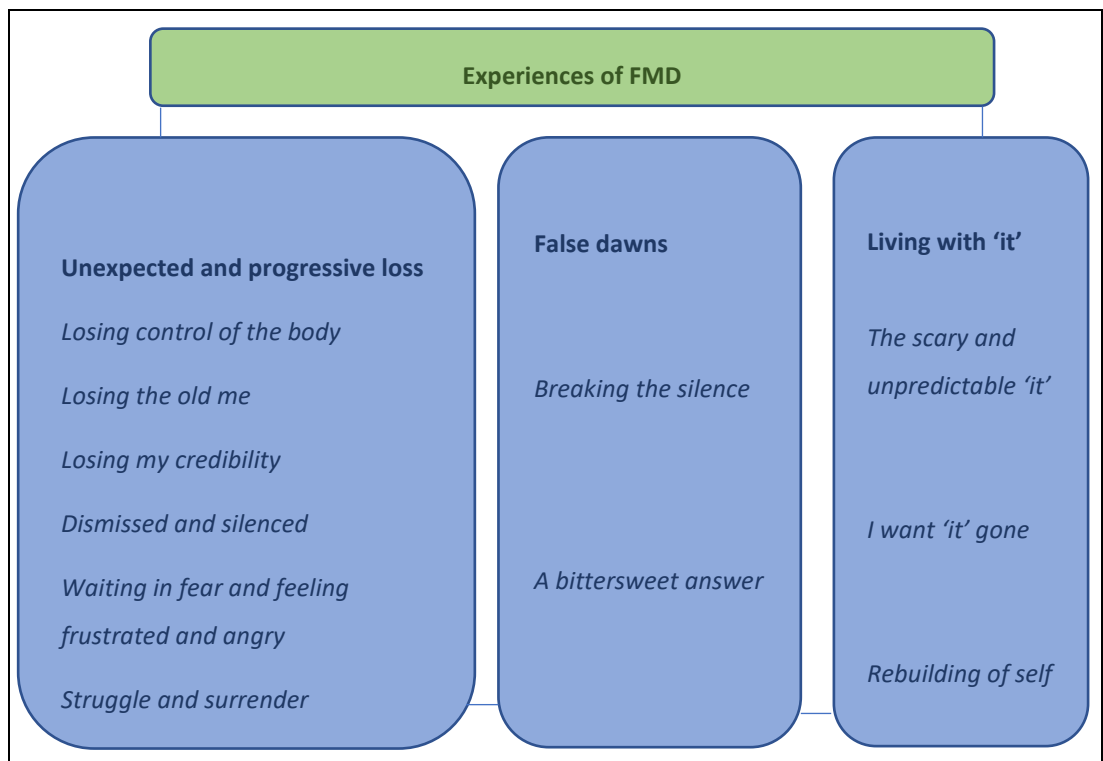


Figure 3: Thematic map of the group analysis

Participant	1	2	3	4	5	6	7	8
Unexpected and progressive losses								
<i>Losing control of the body</i>		x	x	x	x	x	x	x
<i>Losing the old me</i>	x	x	x	x	x	x	x	x
<i>Losing my credibility</i>	x	x	x					
<i>Dismissed and silenced</i>	x		x	x			x	x
<i>Waiting in fear and feeling frustrated and angry</i>		x			x	x		
<i>Struggle and surrender</i>	x		x	x				
False Dawns								
<i>Breaking the silence</i>	x		x	x			x	x
<i>A bittersweet answer</i>	x	x	x	x		x	x	x
Living with 'it'								
<i>The scary and unpredictable 'it'</i>	x		x	x	x	x	x	x
<i>I want 'it' gone</i>			x		x	x	x	x
<i>Rebuilding of self</i>	x	x		x				

Table 14: Frequency of themes across participants

The three **superordinate themes** (see table 16) reflect the experience of significant time points within the participants' story: life during onset of symptoms (superordinate theme 1), diagnosis and treatment (superordinate theme 2) and life in the here and now (superordinate theme 3).

Unexpected and progressive losses
<i>Losing control of the body</i>
<i>Losing the old me</i>
<i>Losing my credibility</i>
<i>Dismissed and silenced</i>
<i>Waiting in fear, frustration and angry</i>
<i>Struggle and surrender</i>
False Dawns
<i>Breaking the silence</i>
<i>A bittersweet answer</i>
Living with 'it'
<i>The scary and unpredictable 'it'</i>
<i>I want 'it' gone</i>
<i>Rebuilding of self</i>

Table 15: Table of superordinate themes

Unexpected and progressive losses. This theme is situated in the time point of life during the onset of symptoms. The participants experienced strange unexplained symptoms that had arisen suddenly 'out of the blue'. The participants reported a progressive loss of control of body parts. Whilst living with these symptoms' they were also trying to get a diagnosis. Within this period they felt very distressed and experienced a range of strong emotions.

Participants recognised something was wrong and described experiencing extreme feelings of fear and confusion. Some were concerned their symptoms were an onset of a serious medical condition such as stroke or PD and this added to their fear. The participants described experiencing many losses. They lost their ability to be able to physically do things and their body became a barrier to living a meaningful life. Before the onset of symptoms they lived with positive beliefs about their self but afterwards they did not feel able to be the person they were. These new identities were experienced to be very shameful and embarrassing. They felt angry and frustrated with the new and somewhat weaker identities. They felt desolate and mourned the loss of self and thus, some resisted these new identities. Amongst all of this, they had different diagnostic experiences. Most experienced a period of 'diagnostic delay' – waiting for a diagnosis to be confirmed, or being told they did not have a neurological disorder as all investigations were normal. During the diagnostic process some participants felt scared, anxious and frustrated by the long wait. Whilst other participants reported an experience of where they felt the doctors and family and friends did not believe them and they felt angry, upset and they were left without help.

Losing control of the body

Seven participants described how they would frequently lose control of their bodies. Participants experienced the loss to be a complete absence of control. For example, *"I just couldn't control it"* (Dan, line 1189), *"me hands don't do what I want 'em to do"* (Jude, line 832). Participants often experienced the body part affected by symptoms to be something separate to them as the body would act according to its own volition. Mary said *"it's not like it belongs to me"* (Line 531), *"that force of the jerk and it, I never knew where it was going"* (Line 164). Rita described her body as *"it's almost like it's just got a mind of it's own"* (Line 1060) and this was a *"weird"* (Line 1062) experience as she would be watching her arm and she was unable to make it still *"arm is just going"* (Line 1058). Sundip experienced a sense of separation from her body. Whilst trying to write her hand would be acting independently of her *"it would be going somewhere"* (Line 239). Participants experienced the symptoms to be an external force that took control of

their body. Participants often referred to the body part affected by symptoms as 'it'. It appeared they were no longer identifying with this body part as being a part of themselves, it was seen as separate and thus, externalised to 'it'.

The loss of control was sudden, unexpected and unexplained. Participants experienced extreme feelings of fear and confusion as they were faced with something they did not understand. Sundip was confused by the notion that her mind was not corresponding with her body *"it wasn't moving but my mind was telling it move"* (Line 555). This confusion led to her living in a state of anxiety as she was constantly thinking *"What is, what is it, why, why is this thing happening to me? I was questioning myself all the time..."* (Line 975). This was a common experience amongst participants as they were often trying to make sense of this unusual experience. Participants' also felt scared. The loss of control and not knowing what was happening to them fuelled this fear. Anne's account of the symptoms demonstrated this *"...me eyes just went like that... middle of the road. There was traffic at back of us, traffic in front of us... and I couldn't see a thing...on the next day... my eyes started going again. I started screaming [chuckles] cause I didn't know what was happening to me. . . and I was so frightened."* (Line 255). Rita's fear was also firmly rooted in the loss of control of her body. Losing control of her body was scary but also not knowing why then resulted in further worry and fear

"...it's quite frightening to see something like that, to have control of all your body parts and then all of a sudden you've got your dominant arm trembling that's a big, like, shock almost... I don't have any control over my arm... I think that's what I found so scary, the fact that there was no control at all over my arm and: "What is going wrong?"..." Why is this happening and what's wrong with my brain?" (Line 1114).

Participants' inability to make sense of what is happening to them and the feelings of fear then led to more confusion, worry and fear. They described being worried about their future health and circumstances. Participants feared these symptoms were progressive. They were extremely worried for the fate of their future selves and this worry led to more worry and feelings of distress. Dan feared for his health *"... I was thinking is this gonna lead to any more serious things: loss of sight, death,*

you know something that my triggering other serious things in my body” (Line 1341). Rita feared for her future and the inability to make sense of her experiences meant she was living in a state of uncertainty and this left her feeling vulnerable “quite vulnerable because then obviously your mind races and you think: “Well, what if the next thing is my leg?” ... “What if I can’t walk?” ... “Oh, what’s going to happen next?” If something like this just happens from being okay one hour to then suddenly trembling” (Line 1114). The fear of symptom progression, uncertainty and lack of agency appeared to have kept the anxiety going. The extreme feelings of worry caused participants to perceive that their life will fall apart and this made them feel hopeless. Tina feared she may have PD and she worried about being dependent on others. She feared losing her independence as this meant losing her privacy and dignity. “...I wa’ scared ... having somebody looking after me and things like that; cause I-I I’ve got a umm, me bladder’s umm, like incontinent and that. I have to wear a towel all time” (Line 218).

Losing the old me

All the participants talked about experiencing losses in their lives that they ascribed to the condition and consequently they described a loss of identity. Regardless of the time it took to get the diagnosis participants all shared this experience of losses.

Participants were losing the ability to function within their daily lives. Mary struggled with basic daily tasks *“I would have to be helped to dressed...brush my teeth. Er, I was struggling to hold a pen umm, being a [job role] that’s not best thing not to be able to do...” (Line 1148). Jude’s job required her to write and this was a challenge as the symptoms affected her hand. The difficulties in writing caused her to become very anxious at work “I were panicking cause of all this writing... I didn’t want to get into trouble...” (Line 547). On her days off from work she had no respite from the anxiety. At weekends she would look at the work rota (“program”) and *“Panic set in. I used to hate it when I got my program...Cause obviously open it (the shift rota)...and panic all weekend thinking what am I going to do...” (Line 500). Zoe experienced a big shift in her lifestyle and isolation.**

“gone from sort of this completely normal life....being very active, no limitations...to something completely different... you couldn’t go out and do things with friends. So they, so they start drifting away. And then you can’t do much of your hobbies...So you sort of see y-your world sort of crumbling down a little bit....looking back now, I probably did have a little bit of depression” (Line 384).

Participants felt angry as they could no longer undertake activities they found meaningful or enriching. Participants grieved for their old lives and felt resentful about their circumstances. Jude was angry that important parts of her life had disappeared *“I hate it...don’t do aerobics, don’t dance... I want to dance. I want to swim... just love it... part of my life.”* (Line 1269). This notion of grieving for losses resonated with Zoe *“...lost everything that you used to be; everything that makes you who you are, you’re not the same person anymore and you don’t have anything left of that lifestyle other than memories... you just spend your whole day resenting your life and grieving the life you used to have before.”* (Line 1139). Being unable to live their old lives led participants to become self-critical. They saw themselves in an unfavourable way and this led to them feeling desolate. At times self-criticism appeared to become contempt towards the self, which resulted in some participants (Mary, Zoe, Rita) to question the purpose of their existence. The participants no longer valued themselves.

“you just feel helpless... a burden...What is the point of me when I’m like this... like a waste of a life [pauses] I was no use [. . .] to anybody. I couldn’t do anything...I was [sighs] having weeks, months off work at my worse times... I just thought I was worthless. Umm, and there was no real point” (Mary, line 219).

“...another diseased body...that wasn’t contributing to society no more...my family’s very much, you know you work your way through life...and I believe that and I, I couldn’t do that anymore. So I didn’t feel like I were contributing anything...it was horrid. You just felt worthless. There’s no point to you being there” (Zoe, line 1729).

The participants’ loss of functioning had left them feeling like ‘a shadow of their former selves’ as they no longer held positive meanings about themselves. In essence, the loss of functioning signified a loss of who they were.

Seven participants discussed that an integral part of losing who they were was also the loss of roles. Participants seemed to encounter new roles and thus a new identity was born out of the context of illness. These new identities were perceived to be somewhat weaker in comparison to their old selves: the 'mad person' (Jude and Sundip) the "lazy person" (Sundip), no longer the person that helps others (Mary), a 'weak man' (Dan), "another diseased body" (Zoe) and 'the unattractive woman' (Anne). These new identities were experienced to be shameful and embarrassing. Rita and Jude's experiences have been provided to illustrate this in more depth.

Rita identified with being the "poorly person". She had lost her social roles within the workplace and at home. She described how her husband had to take over her duties within the home "*...I'd stopped doing the vacuuming which my husband had to do every week because that was my job...*" (Line 118). In addition, she talked about how he had to work extra hours "*to compensate for the fact that we'd had the loss of a wage because of me.*" (Line 483). She felt ashamed that she was unable to contribute to the home. Furthermore, she blamed herself and considered herself to be a 'problem'. This uncompassionate perspective left her feeling guilty and inadequate "*doing all the extra duties that he wouldn't normally have to do because of me being in a situation...*" (Line 463). She valued having a career, being in a privileged position where she could help others and financially contribute to the income of the household "*...going to work and feeling as though I'm really making a difference to patients as well as bringing some money in for the house, so all those factors I think really played on my confidence...I was just this poorly person at home and I didn't want to be that, I wanted to get on with my daily life again*" (Line 890). Her new identity prevented her from being who she was and she lost her self-worth "*...all just a big change for someone who was working full-time, going to work, coming home and making a difference to people's lives and now all of a sudden I'm a patient.*" (Line 190). She no longer saw herself as useful and this made her feeling angry "*a feeling of bitterness almost... "I can't believe that I'm here, on a bus, not working, not doing something positive, I'm just here, just waiting!"...just waiting for the bus... just waiting for that diagnosis...*" (Line 630). She was ashamed of being poorly, dependent and having what felt like no

real purpose any more “I was useless, like there was no real reason for me” (Line 901). She rejected this identity as it prevented the survival of her old self and she was “...just wishing it would go away...” (Line 880). This disdain towards the self and loss of self made her to feel frustrated and angry.

Jude also experienced a loss of role within the workplace. She struggled to write and subsequently was moved to the “*store cupboard [office]*”. She felt ashamed of the new role as she described being treated like an “*apprentice*” (Line 1560) and given “*the jobs nobody wanted to do...*” (Line 1495). She was embarrassed by the status of her new position and ashamed by her loss of skills and her inability to be able to still do meaningful jobs “*I felt embarrassed cause I couldn’t do a proper job; it were just like, like licking stamps, like rubbish. Just felt like, I, just, shove me in here, pay me for sitting on my backside...*” (Line 1519). For Jude, being in the ‘store cupboard’ signified she was of no use and thus, she placed herself into the new identity of the old woman and this made her feel angry at her loss of self

P: Peed off...Just thought I were ready for knacker’s yard.

I: ‘knacker’s yard’, what does that mean?

P: knacker’s yard: where you go when you’re old and hagged [. . .]

knacker’s yard: where everything’s like an old wreck like um [. . .] like a car?

[chuckles] a knacker’s . . . yeah, sell-by date’s gone.” (Line 1487).

Jude talked about how her ex-husband and children would call her “*...lazy and idle...*” (Line 676). At the time she was still unable to get a diagnosis and therefore, she forced herself to keep going and maintain this social role “*...just covered it up and did everything as I should have done . . . as a good wife’s supposed to be*” (Line 326). She described experiencing others to be uncompassionate towards her and this may explain why she was uncompassionate to herself. She had internalised the external criticism and adopted the shameful identity of the ‘lazy and idle person’ “*...just thought I was a lazy, idle, cow . . . even though I worked every day, went shopping, cooking, cleaning and ironing, I were still ‘lazy’; but it wasn’t cause I couldn’t be bothered, it was because I couldn’t do it; physically I couldn’t.*” (Line 2446).

Both Jude and Rita were angry and frustrated with their new identities and they would direct these emotions towards themselves. This self-blame may have been a consequence of not having a diagnosis for a prolonged period of time. The only way they could make sense of the situation was to blame themselves for their inadequacies.

"...just felt stupid; felt silly and people didn't understand; frustrated cause I couldn't do things. Frustration...I couldn't open a can of things, I'd get right frustrated, start crying...chuck things and get right angry with me-self, with nobody else. Just get peed off with me-self." (Jude, line 1144).

"...I'd think to myself: "Well, why isn't my mind sound enough to (.) not cause that, or my brain not sound enough to cause that?" so I was almost, like, blaming myself for it, um, blaming my body for it, thinking: "You know, why have I got such a rubbish body? Why is it developed this tremor?" So, yeah, I think it was a lot of self-blame, really low confidence, low self-esteem..."(Rita, line 321).

For three participants (Rita, Anne, Mary) the feelings of embarrassment and shame about their new selves led to the avoidance of others. Mary said she *"did less...I went out less... I just didn't want to do anything that was going to embarrass me"* (Line 1056). There was shame in not being able to control her body and being incapacitated and subsequently this led to feeling embarrassed that others would judge her negatively *"slight embarrassment... so sometimes I'm in the restaurant and I can wave or clap...I feel stupid..."* (Line 572).

Losing my credibility

Three of the participants talked about the difficulties experienced in trying to explain to other people what was wrong with them. The participants described that others struggled to believe that something was wrong with them because they were unable to explain what was happening. Living with the unknown threatened their credibility.

Zoe felt frustrated by the repeated conversations. The circular conversations of explaining and others being confused left her feeling like they did not believe. She thought others were judging and doubting her and subsequently she felt very anxious around others and mistrustful of them.

"...they're just like, 'Well I just don't get it. Why can't they find out what's wrong?' 'Well you tell me!'...you're just explaining yourself all the time...it just makes you feel horrid because then friends and family that have always been there are like second-guessing you...you can just feel them thinking, 'Oh what, what an earth is she on about' . . ." (Line 1270).

The doubt of others caused her to doubt herself. This self-doubt left her fearing that she may be losing her mind. *"You second-guess yourself all the time...you're just being really sensitive to everything little thing. These little things happened before but you just never noticed..."* (Line 955). She experienced others to be mistrustful and thus she felt alone *"...they're [family] just like, 'Well nothing can be wrong with ya because they [doctors] said it's fine.' Um, so then you lose trust in everybody. Um, you do just feel alone"* (Line 1055). Rita's hand did not tremor all the time, therefore she was worried as to whether her work colleagues believed her. She felt suspicious about the judgements they may be making *"if you look at me now, I look absolutely fine there's nothing wrong with me. So, it's almost like: 'Well, do they believe me?'"* (Line 1231). Rita was embarrassed by her tremor but at the cost of her own dignity she felt driven to persuade others she was ill *"I was a spectacle in a way...everyone wanted almost to see us and you'd have to show them it to prove to them you had got a tremor, just in case everyone thought: 'Oh, does she really have tremor?'"* (Line 1204). The paranoia of negative judgement was internalised to be a character assassination and thus an attack on her self-worth *"...it kind of tarnishes your self-worth a little bit... because you feel as though people might not believe you and you're not trustworthy."* (Line 1251).

Dismissed and silenced

Five of the participants described having unsatisfactory experiences when attempting to get a diagnosis. They reported the doctors did not listen to their concerns and were dismissive of their experiences and thus they did not feel believed.

"I sometimes think that they think you're putting something..." (Anne, line 681).

"it was like they didn't believe you... 'Well none of it makes sense so you can't be experiencing all these.'... 'We'll do a, some bloods and your obs and things

and like.’ ‘Oh well, they’re reasonable.’ ... just fobbed you off a little bit.” (Zoe, line 775).

Participants felt silenced by the medical community as often they were going back and forth for several or many years. Participants were angry and disappointed as they felt like they were ‘getting nowhere’ and they were left living with the unknown, feeling alone and desolate. Sundip’s tremor caused her difficulties with writing at work. She thought the GP’s response to her situation was unhelpful and she felt upset and alone with the problem

“I was kind of depressed that I didn’t know what to do, where to go... My GP said to me...can you type?’ I said, ‘Yes, I can type.’ She said, ‘Well why don’t you just type and not write.’ I said but sometimes... I have to sign cheques ...and I said I can’t sign... I said, ‘But no, I’ve to sign,’ I said, ‘that’s not the solution.’ So anyway I came back [home] and umm, it carried on and I felt quite down about it.” (Line 242).

The experience of loneliness also resonated with others *“... just don’t know what to do...You’re sort of looking everywhere for an answer and there isn’t one. So you just sort of left alone...you just feel horrid because there’s just nothing you can do...”* (Zoe, line 927). Participants felt angry and disappointed with their interactions with healthcare professionals. An example of this was when both Sundip and Anne were taken into hospital for testing and then discharged without a diagnosis *“...I didn’t think it was right...that they just discharged me when [. . .] when there were something the matter with me”*. (Anne, line 763). This experience of injustice fuelled the feelings of anger. Mary was angered by the doctors not knowing position *“...it was umm anger...not knowing, enough, never seems enough of an answer from a doctor. It-it is just the, ‘I’m sorry. We don’t know enough.’ So we have to continue to live [. . .] the way we do – with nothing: no medication, no [. . .] help, no [. . .] explanation.”* (Mary, line 16). She felt disappointed in medical professionals and hopeless. The doctors not knowing position also made Zoe feel angry towards herself *“you have nothing in to put your anger onto, other than yourself, you know when you don’t have a diagnosis.”* (Line, 1752). The absence of a diagnosis and access to a doctor that believed her led to the experience of self-blame.

Three of the participants thought they were losing their mind and this was a consequence of not being believed and not being listened to. This fear of 'madness' was an upsetting experience as they questioned whether they were losing touch with reality. To be 'mad' was experienced as a fear of being fragile and vulnerable in the world.

*"I thought I were going fr****g mental. I were going, thought there was something wrong with me. I knew there was something wrong but I couldn't put my mind to it. I kept going to doctors. They kept saying nought's wrong with me. 'There is something wrong. There is. There is.' Nobody'd listen."* (Jude, line 885).

"you start to second guess yourself. 'Am I actually getting these symptoms or is it all in the head. Am I just being too sensitive, you know; am I just searching for things that are wrong trying to help a diagnosis?...you sort of lose faith and then you don't want to go because you don't want to have that experience again..." (Zoe, line 892).

"Am I going mad? Am I going crazy? What's happening to me...why isn't my mind doing what I'm telling it to. Why isn't it holding isn't it holding the pen, why isn't it writing? You know how am I going to manage with my life, if you are not going to do anything about it?" (Sundip, line 895).

Waiting in fear, frustration and angry

Three participants (Rita, Tina, Dan) had a very different experience when attempting to get a diagnosis. Doctors were not dismissive, but it still took a long time to get a diagnosis and this was a distressing period.

These three participants were waiting from 10 months to 8 years and during this wait they felt frustrated, worried, confused and scared. It took Tina eight years to be diagnosed and she felt frustrated being left living in uncertainty. This time was spent worrying and fearing what it could be *"... it took quite a while for me to...find out...what I had...I wan't sure if it were like Parkinson's or something else...it were quite frustrating really...that I couldn't sort of get a diagnosis..."* (Line 8). Rita felt scared, confused and alone whilst waiting for her diagnosis (10 months) *"...really confusing...you go onto all these websites and start researching so much*

and then you start scaring yourself almost about the things that you read and whether that would apply to me or not... an alienating time as well when you don't know what's going on..." (Line 16). Feeling confused was a common experience. Dan explained whilst a stroke was eliminated the doctors were unable to diagnose what was wrong, therefore, for him, living with the unknown meant living in a state of confusion and panic for four years "*...sheer panic . . . worry, panic, worry [pauses] utter confusion..."* (Line 1401).

This group of participants (as within the *dismissed and silenced theme*) also felt frustrated by the doctors 'not knowing' position. Dan explained the doctors were "*very per-perplexed. They were not sure what was going on. They couldn't, they couldn't figure out exactly what was causing these.*" (Line 233). The doctors apparent lack of knowledge was frustrating "*...frustrated with [. . .] with the hospital, if I'm honest with you... [. . .] ... it's talked about a lot, about probable diagnosis, possible diagnoses of what we think it is; this is what we guess it is... but not, this is what we definitely think it is.*" (Line 773). The impact of this not knowing position left Rita feeling like 'a medical mystery' and thus, she felt alone and isolated "*...feels like you're floating around almost, like you're this rare thing that nobody knows about, which is really annoying because you just wish that people knew about it and knew exactly how to deal with it and what bracket you truly fall under..."* (Line 417).

Struggle and surrender

The experience of losses and living in a body with limited motor functioning resulted in three (Zoe, Jude, Mary) participants fighting to get through the day. It had taken these participants a considerable amount of years to receive a diagnosis. It took Zoe 2-3 years, Jude 10-15 years and Mary waited for 10 years. Life was described as "*you're sort of in a constant war with your own body..."* (Zoe, line 963). These participants struggled to keep up with their roles, responsibilities and commitments. For example, Mary had to push her body to keep up with her lifestyle "*I was trying to push myself all the time..."* (Line 1024) because she considered herself "*not right for retirement*" (Line 1294). Participants were actively fighting and trying to resist change. During this fight there was no consideration

given to their body and they were just fighting to get through and survive the day. The fighting was their attempt to continue living their old lives and restore their previous selves; however, maintaining their identity was hard as they struggled to keep up with their old lives. These participants felt they had to try and fight because they believed if they were successful they would get their identities back. During this time of uncertainty they were conflicted as to who they were: the old self or new self, the patient or not. The fight to survive was a struggle, for example Jude explained “... *everything just got on top of me... couldn't do me job properly, that were getting worse...I had-had to still do all work, two shifts: work on a morning then go home do tea, go back out after teatime...*” (Line 249). For Jude, not being to stop meant she had to continue with fulfilling her expected social roles, but this left her feeling like she was “*dropping to pieces*” (Line 2240). The consequence of no one believing her meant she was alone and in distress “*I used to just go in shower and cry*” (Line 658). In all cases they surrendered and relinquished their old identities. Mary and Jude described feeling relieved when they stopped working as they realised it was the right decision. Mary's permission to stop fighting came at the cost of physically pushing her body too far “*I was literally at breaking point of [. . .] of my body not umm [pauses] not being able to literally do... and that's when I knew I was ready*”. (Line 1204).

The fight may have endured as it also provided participants with small flickers of being their old self. Jude would often take work home and spent hours trying to write neatly. She was fighting the feeling of being incompetent at her job but also the shame and embarrassment associated with being an adult who could not write “*I'd feel a bit better so people could understand what I'd wrote... I'd feel a bit better when I'd wrote it out nice and neat, and that took me about three fr****g hours to do it over and over again but it looked like I could read it...*” (Line 710). Mary would “force” herself to go to work (Line 1199). Continuing to work was a “*mini achievement*” (Line 1216) and this made her feel proud and she avoided the feelings upset “*I didn't want to be down all the time*” (Line 1223). She was fighting to be normal as she felt ashamed of who she was becoming “*...I was trying to push myself all the time and nothing was happening...that's what brought the dark days; is when I felt exhausted from trying to continue to be normal..*” (Line 1022). To stop

fighting would confirm she was no longer good enough and she was not ready to face her fears *“just, the just fear of useless and worthless, and er [pauses] not being able to, to help with anything. You know not being able to clean up or cook or anything...”* (Line 1229).

False dawns. This theme is situated in the time point of finally getting a diagnosis of FMD and treatment. Five participants (Rita, Jude, Dan, Tina and Sundip) were diagnosed by Doctor Alty at the Neurology service and they were either referred by the GP or another doctor (type unknown). One participant (Zoe) was diagnosed by a private doctor. Two participants (Mary and Anne) were diagnosed by other NHS Consultant Neurologists. Those who were not diagnosed by Doctor Alty eventually transferred under their care. Overall participants did have a positive diagnosis experience. They all welcomed a diagnosis. They described feeling relieved, happier and hopeful. The prospect of treatment consolidated these feelings further. Participants talked about how being given a diagnosis did not stop the symptoms and they experienced the benefits of treatment to be short-term. All the participants had experienced a long wait to receive a diagnosis. This process took anything from ten months to sixteen years and thus, they were once again feeling disappointed, angry and frustrated.

Breaking the silence

Eventually, the five participants (Zoe, Jude, Mary, Sundip and Anne) who felt dismissed by their GPs and doctors at the hospital, finally encountered doctors that provided them with a more positive experience. Participants explained it only took one doctor to take notice and this then changed the course of their life. For

“...he was like there’s something not right here. And this is like eight / nine months down the line. And it’s like, ‘Right...I’m gonna do that referral, do this, that and the other.’ ...he’s been fab really... if we hadn’t have had that appointment with him that day we’d have still been the same position probably, without a diagnosis, without anything.” (Zoe, line 787).

Participants were able to describe what the doctors did that made it such a positive experience in comparison to previous doctors. They valued the doctors listening to

them. This active listening made the participants feel heard and believed. The doctors were interested in them and curious about the symptoms and this reassured participants they were finally being taken seriously. Furthermore, the doctors were committed to finding out what was wrong. This curiosity and perseverance broke the silence, released the anger and gave them hope

“he listened ... he believed or acted as he believed ya ...He actually asked about each individual symptom, ‘How does it affect you...instead of trying to address it as a full picture... if you looked at it now it’d be like, yeah, you wouldn’t have known where to start...” (Zoe, line 801).

“...she took a full history. She wa’ actually listening to what you were saying...she said, ‘You know what we’re just going to start again.’...so that gave you the reassurance um, the fact that she spent so long...” (Zoe, line 1354).

“he [. . .] [sighs] asked me so many questions about what was happening and everything...” (Sundip, line 1113).

“I felt very comfortable with her; she was very easy to talk to...She didn’t sort of rush me or anything...”(Sundip, line 1129).

“he made you feel comfortable... he used to talk and [. . .] it was nice and made you [. . .] feel as though [. . .] you know [. . .] it was interested what was matter with ya... Whereas when I went to [NAME] he wan’t interested in you at all...it made you feel better knowing that somebody was interested in what was the matter with ya. Rather than somebody who [. . .] just made you feel as though they didn’t care less...” (Anne, line 778).

“ohhh, she listened [. . .] ...that was the time the legs had stopped working; the arms had stopped working. Umm, and she listened to all of that whereas I just felt that was just br-brushed aside before.” (Mary, line 886)

A commonality that resonated with each participant throughout these extracts is they felt worthy of the doctors’ time. They encountered a warm relationship where two human beings attempted to relate to one another to figure out ‘the mystery’.

The act of being listened to significantly impacted on participants' wellbeing. Zoe felt relieved when she was finally believed. During a desolate and difficult time of still living with symptoms this experience provided her with hope and happiness.

"a big relief but I think it's like shock at the same time that somebody's actually, you know is trying to help...there was some happiness at the same time like, god, something's happening...happy tears...just a big shock of relief... you're just getting to breaking point and somebody, something just pulls you back up...it helps." (Line 1249).

Being listened to restored Mary's confidence in doctors. She felt validated and understood during a time of great uncertainty and distress *"...I think a doctor to be interested in why that would be happening after [. . .] it'd been brushed aside, I think that was a big thing. And I felt confident then that I was being listened to..." (Line 915).*

A bittersweet answer

Seven of the participants spoke about welcoming a diagnosis. It was a positive experience as they finally had an answer. Being given a diagnosis was a relief and they felt happy they knew what was wrong, although, they also felt disappointed as they felt that nothing actually changed as the symptoms were still there.

"I walked out of that consultation room with the biggest smile... I think you're just overwhelmed; like happiness...it was like the best thing that happened in ages, you know you've finally had that answer" (Zoe, line 1407)

"being told that you had something the matter with ya . . . and they knew what it was [. . .] felt better. But [. . .] it didn't really make any difference to me life [chuckles] I still had it." (Anne, line 960)

"Well, relief in a way because obviously there was something there actually could (.) diagnose me with (h) rather than things being up in the air...It was nice to know it was just that, rather than it being a major thing like MS or Parkinson's..." (Rita, line 384).

Nevertheless, being given a diagnosis created a ripple effect of small but significant changes for some of the participants. Zoe and Jude were able to see themselves through a different lens and this led to them being kinder to themselves. The diagnosis enabled them to externalise the condition and see it as something separate to them and thus they were no longer blamed themselves

“I know that I’ve got dystonia. Before it were like, ‘Why can’t I do it?’ I’m so frustrated...but now I know...I don’t blame myself as much now cause I know it’s not me...” (Jude, line 2372).

“I can swear and call it names and talk to it...you’ve got something; you’ve got that ‘it’... when you’re having a bad day, it’s like, you know ‘Damn you, FND,’... you have that [. . .] object or item or whatever to sort of put the blame under to sort of be angry with. Whereas without a diagnosis you don’t have that so you take it out on yourself... when you can put the blame onto something else, then you can think about how to overcome that something else um, how you’re gonna get there cause you’re not just blaming yourself all the time. I think that was probably a big turning point for me” (Zoe, line 1750).

Zoe and Rita felt the diagnosis provided them with ‘evidence’ to prove to others something was wrong. The diagnosis helped to restore their sense of self as they felt credible once again *“Look, I have got something up with me and I ain’t just taking the piss. I have got something wrong with me medically, medically, this is it, I’ve got it.”* (Jude, line 1022). In addition, a significant change for Jude was that the diagnosis restored her sanity and eradicated her fear she was losing her mind *“I’ve got a name for it now so i know that it’s not in my mind, it’s not all me... It is, it is actually a real, it wasn’t me going mad thinking I’m going crackers at 50-odd. ‘No, no, no...”* (Line 2269). For Zoe a diagnosis helped her to reconnect with life once again. She had hope of returning back to who she was and she became more motivated to re-engage with life *“you had hope that you were gonna return to who you wa’... It were still hard. You still felt, you know like that individual that wasn’t . . . contributing fully but, I don’t know, it gave me hope. You sort of, you feel a bit happier because you’ve, you’ve got a name.”* (Zoe, line 1742).

Six of these participants spoke about their experiences of treatment. A common feature within all their experiences was they felt a sense of hope at the beginning of treatment but the hope soon fell.

Jude, Sundip and Anne were all given botulinum toxin injections as part of their treatment. They felt treatment only provided benefits in the short-term and there was 'no cure' or long-term treatment plans. They were happy with the initial improvements, however, the botulinum toxin injections eventually stopped working and they were left with nothing and back to feeling disappointed. Jude noticed an improvement in the spasms, however she was disappointed because she was still unable to write *"She says some people get their writing back, just wanted, write again...Just write me name or whatever just so people can understand it... but I didn't get nought back..."* (Line 1459). Sundip's glimpse of returning back to her old life was rather short lived

"...for a week or so I could write...I was thinking, 'Yes! I can write!'... Although it wasn't in a line...but people could read it ... It felt really joyful. It felt good because I thought-felt right, I'm going in the right direction now. I'll be able to be self-sufficient again... But then it would go back to it...That solution wasn't permanent." (Line 925).

Rita, Zoe and Mary had different treatment plans. Zoe was given physiotherapy but she felt this was only helpful in the short-term as she was still experiencing the symptoms *"...it has helped loads...but I sort of see the importance of it but I don't really see it [. . .] how it helps with the bigger picture..."* (Line 1683). Zoe was disappointed that there were no further treatment options *"...I think it's a big question of, 'Well where do we go from here?' Because I do keep having these relapses, sort of big influx of symptoms..."* (Line 1695). Before the diagnosis of FMD Mary endured 10 years of an array of drugs. She hoped to be 'cured'. Even though treatment had started she reported the doctors were not sure what they were treating. 10 years of side effects and little change was a difficult experience. She was angry about being on this prolonged path of what seemed like false hope.

“...ten years of this drug’ll work; take this drug [. . .] it’ll be fine. It’s not fine. Umm, I now don’t take any drugs and I’m no different to what I was taking the drugs...the drugs have not been good. But to get drugs when they don’t know what they’re treating...it just felt like they didn’t really know and because they didn’t know [. . .] they just wanted to try everything. And in fairness...that was what I wanted. I just wanted to be cured... I wanted to go to work. I wanted to be me! So I would try anything...by the end it was [. . .] it was just getting [. . .] unbearable. Just stop, stop giving me things that don’t work, you know if you don’t know what it is you don’t know what you’re giving me...” (Line 678).

Living with ‘it’. This theme is situated in the here and now. Participants reported they are still losing control of their body. This experience was no longer confusing, but they still felt scared and worried. They now understand the condition was chronic and they felt frustrated as the loss of control would get in the way of living life. Some of the participants still did not feel better (Jude, Tina, Sundip, Anne and Dan) and appeared to still have a negative self-image, whereas others (Zoe, Mary and Rita) did feel better and they had a positive self-image. The difference between these two groups seemed to be that, one group still judged themselves in a negative way and this self-criticism meant they were still living with feelings of anger, shame and embarrassment (negative self-image). Whilst the other group judged themselves in a compassionate way and thus, they felt happier (positive self-image). The act of self-criticism was indicative of acceptance of self had not yet been reached and the act of compassion brought about acceptance of self.

The scary and unpredictable ‘it’

Seven of the participants still experienced a loss of control of their body *“it just twitches itself”* (Dan, line 188), *“I’m vigorously going”* (Sundip, line 136), *“me hands just going [moving] like that all the time”* (Tina, line 620). They still saw themselves as separate to their affected body part and the symptoms were still experienced to be an external force *“something going round in my body just doing silly things”* (Dan, line 2672). This external force appeared to be malevolent and they saw themselves as a victim to their body and to the force. Anne described the force as being something that is ‘out there’ and it is doing something malicious to her

"...feels as though I need some matchsticks to keep my eyes open [. . .] and they won't stop open...you're fighting all the time to open them...but you just can't do it..." (Line 170).

"it's a nuisance!...how it can just go like that... you think the easiest thing in the world is to open your eyes. Close your eyes, open them; but when they can't you feel as though somebody's glued them together...and you just can't do it" (Line 624).

Sundip externalised the force to 'it' and this malevolent force was something that was abusing her *"it's hurting me"* (Line 145). The participants described the loss of control of the body as an experience where the body appeared to have its own agenda, for example *"what are you, what are you doing to me"* (Dan, line 2668).

Participants were still scared by the loss of control of the body as the force was unpredictable and it could strike at any time. Tina feared the danger the force can put her in whilst doing everyday tasks within the home *"...if I go and pick kettle up, like I said, and it's [tremoring hand] moving all about and it's hot water...I'm just frightened it might end up burning me."* (Line 670). The fear of being in danger within the home also resonated with Mary *"I've smacked my head on the boiling kettle...hit myself in the face with remotes... I think is the, was, dangerous the scariest thing. Never knowing [. . .] what's gonna set me off or how bad it's going to be is, is scary. So to go out alone [. . .] is very rare..."* (Line 42). Anne also described a fear of going out of the house *"I mean I never go out on me own because I daren't because me eyes just go like that"* (Line 1012). Dan also feared being hit by the force in public and falling to the ground and being "stuck" without any help *"...it's the unknown...It's the panic...I've had them on the bus...I can feel it going all the way along my body... I've been so-o-o close. I mean just so close to just being gone [. . .] on the floor..."* (Line 2261). Mary also described the force to be unpredictable and the uncertainty of when it will strike is what she feared *"it's just an uncertainty and uncertainty of safety... It's scary being, it's scary being unpredictable...and not knowing myself sometimes when, when I'm going to be like that..."* (Line 539). The participants appeared to be living in threat mode awaiting to be attacked.

The force still impacted on the participants' ability to function and complete daily tasks. They were frustrated and angry at the force, the loss of control of the body and the way 'it' disrupted their life

"I can't do anything... it's same the next day; each day it's just the same. I do a little bit when my eyes come back and . . . when they don't I just sit and listen to the telly cause I can't watch it..." (Anne, line 608).

"it's sort of life-limiting...you know I-I'm forty-one! I should be able to brush my own teeth. I should be able to dress myself! Umm, and make myself a cup of tea. And on good days I can. Umm, and on bad days there's-there's nothing." (Mary, line 37).

"...if I ever met them in person I'd knock 'em out! ... they drive me mad..." (Dan, line 757).

"I think why is it doing, you know, pack it in. Just get frustrated. Just get annoyed." (Jude, line 1639).

I want 'it' gone

Five of the participants still spoke about themselves negatively and thus, this contributed and maintained a negative self-image. They still judged themselves in a negative way and this self-criticism made them feel angry, ashamed and embarrassed. Their new identities and the bodily limitations were still too painful to accept and they were left feeling demoralised by their circumstances. Three of these participants self-reported having currently mental health difficulties (Jude: depression and anxiety, Tina: low mood and Sundip: low mood).

These participants experienced feelings of shame which led to self-criticism and a belief that others will also see them in a negative way. They were their own internal bully and they were stuck in a vicious cycle of emotional abuse. The constant criticism reminded them of their shameful self and the criticism then continued. Anne's feelings of shame demonstrated how deep this self-hatred is *"...when your face goes to one side oh God, you feel as ugly as sin..."* (Line 632). The feeling of shame made her to feel embarrassed as she believed others would see her the way she saw herself *"I feel like a freak...that's why I don't like going out*

because I feel like a freak and I feel everybody's staring at me...I cover my face up with a handkerchief or something so they can't see it. It's very embarrassing [. . .] and I don't like it." (Line 146). Sundip also still felt ashamed of herself and worried about people judging her for being different as she was struggling to accept this difference *"...you go somewhere...and you know my leg, the spasms hurt like hell... and I feel so stupid there. 'Look at her. She's so well-dressed and everything. And just now she was fine...What's she doing now'..."* (Line 1544). These feelings of shame and embarrassment made the participants feel uncomfortable when out in public as they thought others might also see them in a negative way. Tina explains *"I'll try and get sort of into a corner...sort of out of way...so that, like they're not staring at me...I don't like 'em to stare...I just feel embarrassed."* (Line 804).

The negative perception of self meant they still saw their new identities as weaker. Sundip spoke about her difficulties in accepting she was a disabled person. She had always prized herself on being seen as strong to the world *"...when my husband died...I showed people that I'm quite strong... even sometimes they'd come and see me and go and afterwards I'd burst out crying..."* (Line 1012). However, with the condition it was more difficult to hide one's vulnerabilities from others

"... 'Oh my God! People are going to see this chair and think she's disabled,'...which I am, in a way...I wasn't coming to terms with it, but it helps me...I think slowly I'll just accept, you know that this is the way now...I can always hide it... I want to be normal. I don't want, I want to be the way I was... you just want to be well. You don't want to be ill. You don't want to be known to be ill...You-you want to be perfect." (Line 1471).

To be disabled was to be imperfect as she was not who she once was. Living with the condition meant she saw herself as incomplete and thus no acceptance of self. The notion of being disabled and not being as good as one used to be resonated with Jude *"...can't do things that I want to do; like a, a disability...I can do things but not as good as I used to be able to do...It is annoying..."* (Line 2266). In light of this she had to make adaptations around the home. For Jude being disabled also came with a weaker identity *"I feel old; feel like one of me customers. I think, 'God.' I hide 'em. No, I don't want people to see cause I feel embarrassed but I need 'em."* (Line

1622). These new identities were still experienced to be shameful and embarrassing and they perceived themselves as being different to their old selves and others. Within Sundip's and Jude's extracts there was an emphasis on the word "want". They both expressed a desire, almost a wishing to return to 'normal' and belong in the world. They wanted to accept themselves again and to be accepted by others. Their yearning for the old selves made it difficult to settle into and accept their new identities.

Dan also shared a similar experience of self-criticism and shame that contributed to a negative self-image. In comparison to his other health conditions Dan was still frustrated that there were no concrete answers with regards to the cause, treatment and future prognosis of the condition, "*...I can say, okay, at any one of those points [sighs] one of my other medical conditions could really affect my life. With this one, I have absolutely no idea if it's gonna disappear and go away. If it's gonna bombard me with more severe seizures or muscle movements ...*" (Line 2616). The absence of answers left him curious as to whether developing the condition was his fault. He felt guilty and ashamed by the prospect he may be to blame "*... I feel a let-down to my family, to my children. To myself. Umm, because really there's no [pauses] medical diagnosis... you know organic, it-it's most likely something that I'm doing...*" (Line 813). This self-criticism made him feel like a failure ("*a let-down*") as he perceived himself to be failing himself and his family. He was disappointed in himself as he perceived himself to not be successful in fulfilling his role. Dan perceived inability to fulfil his role as the 'male' and living in his new identity of a 'weak man' may have left him feeling emasculated. For example, after a symptom episode he described himself to be a "*a quivering wreck on the floor*" (Line, 2705). Living with the condition possibly prevented him from living up to his idea of what he should do and be in his role as a man. Similarly, to Sundip and Jude he also may have been still yearning for the return of his old self; but in a different way. He was not wishing the condition would go away rather he was focused on searching for answers. He found it difficult to accept his diagnosis "*I'm in 90% agreeance with the, what Dr [name] said but it's feels that little bit of nagging doubt thinking [. . .] is it possibly something else?*" (Line 2589) and he still wanted answers "*...never gonna give up tryin-to look for a consistent pattern...*".

This search for answers may have served two functions. Firstly, a satisfying answer on the cause could relieve him of the burden of guilt and the feelings of shame. Secondly, a satisfying answer on treatment or prospect of a treatment (e.g. cure) would mean his situation would improve and thus, the return of old self.

The participants symptoms (limited motor functioning) still made it difficult to live a meaningful life; although, this was not the case for Dan; although, this was not the case for Dan. The other participants still struggled to function. Everyday tasks still required great effort in comparison to the functioning of their old selves and they still felt angry, frustrated and distressed by the bodily limitations.

"...just functioning in the day. I feel down with it sometimes... I feel that I just want to go back in into bed, curl up and just stay there...I was much quicker before. It takes time for everything; cause everything is so slow... I would just jump in the shower and get ready and go to work...It was nothing. But now it's a task, it's been frustrating... But then I can't do anything about it." (Sundip, line 1573).

"...it's exhaustion...like it'll take somebody probably I don't know two minutes or whatever it takes me five... it's just frustrating and it just gets me angry sometimes...when I find it harder to do..." (Tina, line 681).

"...I couldn't even open that. Just stood there crying cause I wanted a cheese and beetroot sandwich and nearly threw jar out of window. I felt annoyed..." (Jude, line 1645).

They still appeared to be measuring themselves against their old selves and thus their goals for living have not been adapted. It did not feel okay to be struggling in this way and they still got angry with themselves *"...get really angry with me-self not being able to just do somat what's really simple."* (Tina, line 635). Furthermore, they still blamed themselves and saw themselves in an unfavorable way. Jude referred to herself as being a "slack arse" (Line 1345) when she struggled to do things. Tina was also uncompassionate towards herself "why I'm I so useless I can't sort of do these things?" (Line 1167). Their feelings of distress were also reinforced by the loss of engaging in meaningful activities. Anne's experiences of shame and embarrassment made it difficult for her to still engage with the things

she likes to do “...you don't have any life... we don't have any social life [. . .] we don't go on holidays anymore...” (Line 1032). Sundip's hand tremor made it difficult for her to sew and crochet and she had been unsuccessful in finding new hobbies “...it's not coordinating because it shakes. I prick myself. So I've given it up now... I had a lot of hobbies...I feel sad...because I enjoy doing them that does affect me...it was a good hobby. I've been doing it for so long...” (Line 371). The loss of activities and skills reinforced the feeling of desolation. They felt like they were failing as they were unable to do the things they used to do. Their restricted and deprived lifestyle and how they felt about themselves had left them feeling demoralised, in despair and low in self-esteem.

Even though life was a challenge living in a body with limited motor function, these participants with a negative self-image had learnt to practically cope as they had found ways of adapting to the body's needs. Jude had many adaptations within the house “...just bought things to do things differently [. . .] having to work around it sort of thing...” (Line 2097). Tina feared burning herself with a kettle, therefore, she had adapted the way she made a cup of tea “...put some water in me cup and I'll put it in microwave...” (Line 668). On one level there appeared to be some form of acceptance, although the loss of self and the shameful feelings towards the self had left them longing for the return of their old self. They had not yet come to accept with their new identities. Sundip's experienced moments when her hand did not tremor and she had a glimpse of her old self “...I could carry beautifully. See it's not all the time...it feels that I'm perfect and then it comes again.” (Line 1118). She still admired her old self as she perceived her quality of life as poor and to be unbearable “I really want to get rid of these spasms because the quality of my life is poor...” (Sundip, line 1284). Tina missed her independence and being to do things for herself, for example she “I wished I could do it me-self [. . .] like at Christmas. Me son and daughter helped make dinner and things.” (Line 551). She still felt overwhelmed and distressed by the losses and she just wanted her old self back “I wish, like I say, I could get rid of it” (Line 576).

Rebuilding of self

Three of the participants talked about now having a positive self-image. They used to be self-critical but they now judged themselves in a positive way and once again they were living with positive beliefs about the self. They accepted their new identities and they were no longer grieving the loss of their old selves.

These participants were kinder towards themselves and their limitations and thus they were now living compassionately. They no longer judged themselves or criticised themselves for their short comings

“you just live with it and then you adapt and then it just becomes part of your life and you feel okay about it because you know what you can do with it and what you can’t do with it” (Rita, line 51).

“I expect a bad day... you are living with an illness... You are gonna have days where you feel worse than others...that’s just part and parcel of being poorly...you don’t like feeling poorly...but you don’t mind them as much now...it’s just [. . .] part of the life now; but then I just enjoy my good days more [. . .] cause I appreciate them more” (Zoe, line 2014).

Their ability to show compassion towards themselves enabled them to assimilate the condition to be part of who they were. They accepted their new self without perceiving it to be a weaker or shameful identity

“Now I feel as though, Right, okay, it’s a tremor and it’s part of me and it’s not working fine but so what?” (Rita, line 1041)

“I just think it’s part of me now...I could probably live like this...I think I might feel a bit weird if I’m not [. . .] who I am now...It’d be nice not to... but I’m also happy being me.” (Mary, line 1411).

Instead they embraced a self that coexisted with the condition *“I still see myself as a person with tremor...”* (Rita, line 1473). Zoe reflected on her resilience and appreciated her experiences of hardship as they had contributed to who she was today *“I’m a lot stronger person... it’s made me the person I am today”* (Line 440). The participants also accepted their differences as opposed to being

ashamed of it and thus ashamed of themselves *"It's almost like I am different to everyone else but not that different...it's good to be more unique..."* (Rita, line 1478), *"...I am still me [. . .] just a [. . .] different shape...I am a little bit different. I do do the odd [. . .] strange [. . .] movement..."* (Mary, line 483).

Their ability to show compassion towards themselves had restored their sense of self and improved their wellbeing. They had completed a whole process as the self had evolved and once again they valued themselves. Mary's restoration of self was evident in the return of her feelings of confidence and self-worth

"So in that sense it wasn't a [pauses] a big thing but it was more of a, 'Well actually I can't control myself in these situations.' So I wasn't, I wasn't a confident person I was [. . .] before...it took a long time to [. . .] feel secure again in myself and with other people [. . .] that I am still worthy of being me. And I am still me." (Line 628).

Rita noted a return of confidence *"feeling confident in having something...just feeling like it's okay to have this rather than feeling as though: "This is really bad."* (Line 1333). This confidence meant she was no longer ashamed of herself and embarrassed around others. Having a diagnosis was also important in the process. This information empowered her to confidently talk to others about what was happening

"after I developed the tremor I really did go within myself, I didn't want to meet other people because I was really quite embarrassed about it, quite nervous about what people would think about the tremor if it showed up... now it's getting better...I would happily meet people now...I feel more open to talking about it now than what I did when, you know, it developed and I didn't even know what was going on myself..." (Line 292).

Rita and Zoe felt proud of themselves and their achievements. To feel proud indicated a restoration of self-esteem as they felt good about themselves

"I seem to have got through a very rough period in my time, I feel as though I'm quite proud of myself as well and I just feel as though I'm quite happy at the

fact as well that I've just accepted myself a bit more now than what I did last year."
(Rita, line 1315).

"...I'm happy now for the first time in a long, long time. I got myself to where I want to be, and I'm proud of myself as well, probably, cause I've got to where I am now on my own. And I wouldn't have done that before. And I wouldn't have been in the career I'm doing now. I wouldn't have seen and done some of the stuff I've done...it'd be brill not to have an illness but [. . .] this is life and I really, I enjoy life. I enjoy life." (Zoe, line 2146).

Their positive self-image had enabled them to recalibrate their sense of self and their life. They were now pursuing hobbies that were appropriate for a body with limited motor function.

"...incorporate other things into my life now, so I do a lot of pilates and a lot yoga as well, so it's more gentler forms of exercise, um, so, yeah, hopefully I'm still keeping fit that way...just trying to change and adapt that way really." (Rita, line 247).

"I choose to fight. I want to live! I've found a new hobby... I couldn't climb, I couldn't abseil! I couldn't do those dangerous things...I found a new hobby... it was a, a chance encounter with photography [. . .] that made me want to get out, I suppose; get out more, take pictures, see things" (Mary, line 71)

Furthermore, the participants' goals for their lives had changed to be more in line of living with a body with limited motor function. Mary's shift in goals enabled her to experience a sense of achievement *"...the little things excite me the most; because it's fine not to be able to do the big things on, on bad days. But doing the little things, they're the ones that count...it's more of an achievement. It's more of a [. . .] yeah, this really is a good day."* A shift in her goals had changed how she perceived herself *"I feel more capable"* (Line 1380) as opposed to previously feeling useless. Zoe had also shifted in how she appraised her life and her goal was to appreciate the small things *"...before I never thought that way and why can't I just do that big step now...You sort of appreciate what you do have and like the little*

*things that you never noticed before...you know being able to spend a day pain free.
Being able to go a week and not be laid up for a few hours each week.” (Line 460).*

Discussion

This chapter will first present an overview of the findings and discuss these in relation to the literature on FND, and other neurological and medically unexplained conditions. The findings will be reviewed in light of psychological theory. The strengths and limitations of this study will then be considered. The clinical implications from the findings will be presented and a discussion on future research will follow. Finally, a conclusion will be provided.

Research question

The study aimed to explore *“What are the experiences of people living with functional movement disorders (FMD)?”*. The additional research aims were:

To understand the nature of the impact of FMD on an individual’s life.

To gain insight into how individuals make sense of, or understand, their experiences.

Main findings

The data analysis of the eight interviews produced three superordinate themes and fourteen subordinate themes. The themes reflected significant time points within the participants’ story and this provided insight into their experiences of living with FMD across time. The sudden onset of symptoms was a distressing experience. Participants reported having no self-agency over their affected body part. Over time the loss of motor functioning resulted in many losses (e.g. of physical ability, positive affect, identity) and a poor QoL. Some participants experienced people around them as not believing something was wrong and without a diagnosis trying to explain what was wrong was a frustrating experience. During an already difficult time, participants experienced further distress when attempting to get a diagnosis. Some participants reported unhelpful interactions with healthcare professionals’ and other participants struggled with the long wait to get a diagnosis. Some of the participants who had a significantly delayed diagnosis struggled to live their old lives. The absence of a diagnosis and understanding of what was happening

resulted in a sense of fighting to get through the day. Those participants who had unhelpful interactions with professionals eventually encountered more helpful interactions. Participants experienced relief and hope when they finally received a diagnosis, however, participants felt a diagnosis did not change anything and they perceived treatment to be unsuccessful. All participants described continuing symptoms. They still experienced a lack of self-agency over the affected body part. Some participants were not feeling better and appeared to have not yet accepted living with the condition, whereas others felt better and appeared to have accepted living with the condition.

Each theme will now be summarised and discussed with reference to how it addresses the research aims and how the findings of this study fit in with the literature in chapter one. This section will close by considering how the findings contribute to the current medical and psychological literature.

Unexpected and progressive losses captured the time period of life during onset of symptoms and encapsulated the losses participants experienced. The onset of physical symptoms was very sudden and in two cases occurred weeks after a fall or injury. The loss of control of the body was unexpected but this loss then progressed in severity. The loss of self appeared to develop gradually but over time the loss of control of the body and self progressively got worse. The losses of control of the body, self-image and credibility progressed over time and were associated with emotional distress, often compounded by a period of uncertainty whilst trying to get a diagnosis. For many, the diagnostic process took a number of years. Participants made sense of their experiences of FMD to be life altering, in that, living with a body with limited motor functioning restricted the things they could do. Furthermore, they understood themselves to be 'something lesser', in comparison with their previous self and developed a negative self-image. A summary of this theme will be presented and how it answers the research aims.

Losing control of the body: participants experienced strange symptoms that had arisen out of the blue and consequently they described a sudden loss of control of their affected body part. They experienced the symptoms to be an external force, in that, the affected body part was experienced as being something separate to them and acted independently, almost according to its own volition.

The loss of control was a complete and absolute absence of control. It appeared participants may have been experiencing an 'all or nothing' phenomena (i.e. there is no middle ground between control and no control). Their perception of control of the affected body part was now that they had absolutely no control. Their accounts described how they felt powerless and helpless to control their affected body part, not reduced control but a complete loss of control. Patients with FMD have been described as experiencing motor symptoms as involuntary (Stenner & Haggard, 2016) and research has shown they lack self-agency (Voon et al., 2010).

When participants experienced involuntary movements they externalised the affected body part to 'it' and they no longer identified with that body part, almost as if they had lost it to the external force. A significant impact of losing control of the body was the extreme feelings of fear and confusion. They could not understand or control what was happening to them and this precipitated the worry, confusion and fear. Furthermore, living without a diagnosis intensified the worry and they were anxious about the fate of their future selves. A study involving people with NES found participants described a loss of control due to the seizures and the seizures were also seen to be separate to their conceptualisation of self (Wyatt et al., 2014). Thus, it would appear when living with an FND people experience themselves to be separate from the symptoms and the body part affected.

A novel finding of this research for the FMD literature is the experience of an external force and the sense of separateness from the body part affected. To my knowledge the experience of an external force has not been reported in other neurological disorders and this is evident from the literature on PD and MS. The sense of complete separateness from the body part affected is also unusual and possibly a characteristic feature of FMD; it is rarely reported in neurological disorders aside from those associated with dissociation and alien limb phenomena.

Losing the old me: living with a body with limited motor functioning impacted on their ability to do things, and thus, live a meaningful life. Participants struggled to manage at home and work and to engage in recreational activities. Qualitative studies on PD and MS have found similar findings regarding the loss of

functioning and independence (Soleimani et al., 2016; de Ceuninck van Capelle et al., 2016). A meta-synthesis of qualitative research on CFS found the symptoms affected peoples' physical, social, educational, occupational and economic functioning and this resulted in multiple losses (e.g. roles, relationships) (Anderson et al., 2012) and experiences of isolation (Dickson et al., 2007). Qualitative studies on NES found that participants would avoid going out, had reduced motivation to see friends and family, social isolation and reported an inability to work (Karterud et al., 2015; Rawlings & Reuber, 2016; Wyatt et al., 2014). The findings from this current study are similar to the findings in the PD, MS, CFS and NES literature; in that, when living with these condition participants experience external signs of change that lead to an experience of loss (e.g. roles or relationships).

The current study found the experience of significant losses affected participants QoL and this is also the case for people with PD (Dauwerse et al., 2014) and MS (Barker et al., 2014). An Australian report was commissioned to explore both carer's and patient's experiences of FND in Australia (Gill, 2019). This report was published whilst the discussion was being written. A survey (mixed methods) was used to collect the data. The qualitative element was free text to answer questions and the data was not analysed using qualitative analysis. 170 participants took part. Participants reported their QoL to be poor due to social isolation (no longer engaging in social and leisure activities), difficulties in maintaining relationships, an inability to work or study, loss of independence to manage self-care tasks and basic domestic activities. In addition, quantitative research on FMD has shown people have an impaired QoL (Anderson et al., 2007). The findings of this current study provide a deeper insight into the impact on QoL when living with an FMD from the subjective experience of the patient. In comparison to quantitative studies, this qualitative study has been able to provide detailed findings as to why the QoL may be lower in FMD compared to other movement disorders such as PD (Anderson et al., 2007). This understanding of QoL could be useful to inform the development of interventions (either psychological or MDT) that focus on the factors affecting ones QoL. The findings of this study demonstrate the value of qualitative methodology as participants were not constrained in how

they shared their experiences, for instance, a questionnaire with set response to choose from will limit how much one can share.

In this study a consequence of living in a body with limited or, at times, no motor functioning meant participants struggled to retain their old lives due to the multiple losses. The sense they made of this was they had lost who they were as they did not feel able to be the person they once were. Participants made sense of their new identities to be 'somewhat weaker'. They perceived these new identities to be shameful and embarrassing. They no longer lived with positive beliefs about their self. Instead they were self-critical and they felt angry and frustrated with the new identities. Furthermore, they blamed themselves for the symptoms and the loss of function. This self-blame may possibly be a novel finding for FMD as it has not been found in the previous evidence base for FMD, PD, MS, CFS or NES. They saw themselves in an unfavourable way as they were no longer living in line with their values, for example, being able to work and 'contribute' to society and the financial income of their home.

Participants appeared to have an all or nothing cognitive bias. They were either good or not good enough and they compared themselves with their previous self and others. Participants felt desolate and they mourned the loss of their old self. Qualitative research on PD, MS and CFS have also found these conditions can impact on a person's sense of self and result in a loss of identity (Anderson et al., 2012; Barker et al., 2014; Irvine et al., 2009;). In PD and MS, the loss of identity was associated with changing roles within the home or workplace and a loss of productivity in society (de Ceuninck van Capelle et al., 2015; Habermann, 1996; Irvine et al., 2009). The loss of identity in CFS was associated with the loss of confidence and self-esteem when valued roles are lost (Anderson et al., 2012). Within the qualitative research on NES the themes did not depict a loss of identity rather the focus was on external losses, for example no longer able to work.

The current study's finding on loss of identity has provided a new understanding of the experiences of living with FMD- in particular it has highlighted the experiences of shame and embarrassment that comes with these new identities, the inability to live in lines with one's values and the burden of self-

blame as being responsible for the condition. All these factors contributed to and maintained negative affect. This finding in the current study broadens our understanding of FMD. In comparison to NES, FMD affects identity to the extent that people feel they lose the 'old me'. NES is an episodic condition (people are well in between in seizures) and presents in a different way to FMD. The symptoms of FMD tend to always be there but fluctuate in severity. This may explain the loss of identity when living with an FMD. There is some similarity between the two conditions, for example, the unpredictability of seizures occurring or sudden worsening of FMD symptoms.

The extreme feelings of shame and embarrassment led to some participants avoiding others and isolating themselves. They no longer went out as they felt shame in not being able to control their body and they feared being negatively judged by others. Participants believed others would judge them in the same way they judged themselves. A qualitative study found people with MS also attempted to avoid stigma by not using mobility aids; such aids were perceived as a symbol of disability and thus, stigmatising (Dennison et al., 2011). This experience of shame and fear of being judged for being different was not a theme present in the NES literature.

Losing my credibility: three of the participants found it difficult to explain to others what was happening to them because they did not have a diagnosis and therefore, they struggled to explain something that did not yet have a name for and they did not understand it themselves. Participants experienced others as not believing that something was wrong and trying to explain to others was a frustrating experience. This perception of others had a significant impact on their emotional wellbeing; the perceived doubt of others induced self-doubt, they feared they were losing their minds (in that there was nothing wrong and they were imagining the symptoms) and as a response to not being believed they felt suspicious and anxious around others. The experiences of distrusting either themselves or others appeared to be an understandable response in light of their circumstances (e.g. no diagnosis and others doubting their experiences). This experience of losing one's mind is also a finding that is not present in the medically unexplained and neurological literature. The significance of this experience was yet

another loss. The loss of self as being a credible and trustworthy person. Furthermore, participants felt alone with their distress and became estranged from their relationships. The disengagement from relationships resulted in participants isolating themselves because they either struggled to trust others or they wanted to avoid these difficult conversations. This study lacked detailed information on participants experience of interpersonal relationships. They made sense of their experiences of others in terms of perceiving others to make negative judgements, and thus, being around others was too difficult as they no longer felt secure in their relationships. A qualitative study found people with MS experienced awkward attitudes (e.g. misunderstanding their symptoms or inciting ignorance about multiple sclerosis without realising) towards their illness from others (de Ceuninck van Capelle et al., 2016). Furthermore, qualitative research on NES found participants described others as seeing their condition as illegitimate (Karterud et al., 2015). This negative experience of others threatened participants' social identity in terms of being credible (Karterud et al., 2015) and their QoL as they socially withdrew (Karterud et al., 2016). The experience of perceiving others as not believing something is wrong, the feelings of suspicion and anxiety around others and the fear of losing one's mind are all contributions to the FMD literature. The only experience that did not resonate with people's experiences of living with NES was the fear of losing one's mind. These experiences may be reflective of the historical and current understanding of FND within society. The cause of the condition is not clear and thus, society may struggle to understand such conditions.

The subordinate themes of *dismissed and silenced* and *waiting in fear and feeling frustrated and angry* demonstrated how participants had different experiences when seeking a diagnosis, although, for all participants it did take some time. The length of time varied from 10 months to over 10 years. Getting a diagnosis was a difficult and lengthy process. A common theme in the NES and CFS literature was participants reporting difficult experiences of getting a diagnosis (Anderson et al., 2012; Rawlings & Reuber, 2016). This theme was not present in the neurological conditions (PD and MS) literature. In this study participants fell into two groups with regards to diagnosis experience. One group were distressed as they experienced the doctors as not believing them or dismissing them (i.e.

saying 'nothing was wrong') and the other group were distressed by the long wait for consultation and test results. The latter group were directly seen by Dr Alty's service and thus they had a different experience of services and interactions with healthcare professionals.

Dismissed and silenced: participants described being dismissed and not listened to and they perceived the doctors to not believe something was wrong. The impact of this experience made participants feel very angry, frustrated, disappointed and upset as they felt they were getting nowhere and left living with the unknown. These experiences of diagnostic delay were associated with living in a prolonged state of emotional distress and feeling alone with the problem.

This finding of unsatisfying experiences supports previous quantitative research where other patients with FMD reported inconsistent patterns of care, dissatisfaction and iatrogenic harm (Crimlisk et al., 2000). People with other medically unexplained conditions describe similar experiences: the Australian report found that participants with FND experienced negative attitudes from health care professionals, such as being rude, condescending, dismissive and stating they did not believe the symptoms were real (Gill, 2019). A systematic synthesis review of qualitative studies found patients with NES sought validation of their experiences from professionals but were often ignored, not believed, not taken seriously and their voice was not heard and this resulted in feelings of anger and disengagement from treatment (Rawlings & Reuber, 2016). Participants with NES described their experiences with medical professionals as a period of active struggle (Wyatt et al., 2014). Furthermore, being doubted by the medical community contributed to feelings of isolation and distress (Thompson et al., 2009). These feelings of being alone 'with the problem' and distress were also a common experience for the participants in this current study.

Qualitative research on participants with CFS found that unhelpful experiences (e.g. limited knowledge of the condition and stigmatising attitudes) with medical professionals led to delayed and prevention of a diagnosis (Anderson et al., 2012). Another qualitative study on CFS found delegitimising experiences can leave patients in a prolonged period of distress and negatively impact on the therapeutic expectation of doctor-patient relationships (Dickson et al., 2007).

A novel finding of the current study is that not being believed by doctors resulted in some of the participants trying to make sense of the condition by considering that they were losing their mind - in that the absence of a label and validation from others must mean they are imagining the symptoms. This was an upsetting and disturbing prospect. The notion of 'losing their mind' was in reference to their experiences with doctors and family and friends (discussed earlier). It is possible their other experiences of suddenly losing control of their body, experiencing symptoms as an external force and the unpredictability of the symptoms also contributed to the experience of 'losing one's mind'.

Waiting in fear and feeling frustrated and angry: participants were seen by doctors and underwent testing, but they felt distressed by the long wait in completing the tests and waiting for the results to get a diagnosis. The impact of this experience was again living in a prolonged state of emotional distress and uncertainty. Participants felt scared, anxious, confused and frustrated. They worried and feared as to what the diagnosis might be, for instance, they worried it might be something serious like PD. Waiting for a long period of time was also a common experience for people with NES, who report feeling frustrated and described their experiences as being left in 'limbo' or 'dumped' (Rawlings & Reuber, 2016).

A commonality between both two groups (*dismissed and silenced and waiting in fear and feeling frustrated and angry*) was feeling frustrated and angry by what they perceived to be doctors lack of knowledge and confusion with regards to the symptoms. Participants made sense of the doctors' roles as taking a 'not knowing' position and this left them feeling alone as they perceived themselves to be a medical mystery. It has been suggested that doctors may perceive this client group as being too complex, and thus, this may explain why patients with FMD receive inconsistent patterns of care (Crimlisk et al., 2000). The finding of this study indicated that from the patient's perspective some doctors struggled to understand the symptoms they presented with.

Struggle and surrender: a significant experience for some of the participants who had a delayed diagnosis was the struggle to live their old lives. In the absence of a diagnosis and understanding of what was happening to them they may have

felt that they almost had no choice but to fight to get through the day as others (family, friends, medical professionals) had not accepted something was wrong. They resisted change and were actively fighting to restore their previous identity. If they had won the fight, then their previous self would have returned, and their distress would have subsided; therefore, this may be why they persevered with the fight. A qualitative study found people with CFS also experienced a lack of illness acknowledgement and this led to them to also fight to retain previous levels of functioning and roles (Edwards et al., 2007). In this study, the fight became too much and eventually they surrendered and relinquished their old identities. The participants who received a diagnosis more quickly did not go through this process of fighting and thus, a timely diagnosis may enable patients to quickly transition and either adjust to their situation or develop new identities.

False Dawns captured the experience of the process of receiving a diagnosis. The theme encapsulated participants positive diagnosis experiences. A summary of this theme will be presented and how it answers the research aims.

Breaking the silence: the group of participants that reported unsatisfactory experiences with doctors eventually found doctors who listened and believed them. Two of the participants were diagnosed by Doctor Alty and three were diagnosed by other doctors (service unknown). A compassionate approach is crucial in developing a trusting patient-physician relationship when working with patients with FND (Jankovic, 2011) and this was evident in the findings of this study. The participants valued the doctor's skills of actively listening and being curious about their symptoms. These skills reassured participants they were being taken seriously and thus, the beginnings of a trusting relationship. The importance of being listened to for these participants, supports Clark's (2006) viewpoint that physicians need to go beyond looking for symptoms and listen to the patient's life stories when working with FND. In addition, Clark suggested once a diagnosis has been made patients would benefit if the delivery of the diagnosis is non-judgemental, empathetic and validating of their distress, as opposed to being blamed for behaving in this way and treated as illegitimate patients that are malingering. In this current study, the impact of being believed and being given a space to talk provided participants with some happiness and relief, as well as hope

and support during a desolate time. These findings advocate the importance of a warm therapeutic relationship. A validating approach could potentially avoid iatrogenic harm as the negative experiences with healthcare professionals (*Dismissed and silenced*) led to diagnostic delay and living in a prolonged state of emotional distress.

It is important to note that this pivotal stage of finding a doctor is the end point of a long and distressing journey. Participants experiences of a doctor that knows about the condition and manages their care in a constructive way gave them a different experience in comparison to other doctors. The way these doctors and services work is an important approach to adopt and promote. In addition, the three participants who were not in the theme '*dismissed and silenced*' and '*struggle and surrender*' appear to have been directly referred to Doctor Alty. They were not exposed to the additional emotional distress that the other participants experienced within these themes. This further promotes the value of working in a positive diagnostic framework and the importance of the therapeutic relationship; as such approaches have the potential to avoid subjecting the patients to further emotional distress.

A bittersweet answer: the impact of being given a diagnosis restored participants' feelings of hope and they predominantly experienced a sense of relief from finally having an answer and knowing it was not something 'more serious' like PD or MS. Furthermore, there was a feeling of happiness at knowing what was wrong. People with NES also have found a diagnosis be a validating experience (Rawlings & Reuber, 2016). Qualitative studies on NES also found similar findings as participants were relieved it was nothing more serious (Rawlings & Reuber, 2016).

Two participants in this study experienced significant improvements in their wellbeing once the diagnosis was confirmed. Firstly, the diagnostic label enabled them to externalise the condition and see it as something separate to them, for example "*I don't blame myself as much now cause I know it's not me...*" (Jude, line 2372). This ability to externalise enabled them to stop blaming themselves and this contributed to the reduction of distress. A qualitative study on NES found similar findings. The experience of receiving a diagnosis enabled participants to externalise

the condition and this reduced self-blame. (Thompson et al., 2009). Secondly, the two participants felt they now had the evidence to prove to others something was wrong. A systematic synthesis review of NES qualitative studies found similar findings as people thought a diagnosis legitimatised their experiences (Rawlings & Reuber, 2016). A qualitative study on NES found being given a diagnosis enabled people to explain to others what was wrong and thus granted legitimacy and reduced the self-doubt that had arisen from being disbelieved (Wyatt et al., 2014). Another qualitative study on NES found being believed restored participants' self-image of being credible (Karterud et al., 2015). These two participants no longer feared that they were losing their minds and this was a finding that was not present in the NES literature.

Even though gaining a diagnosis was initially a positive experience the sense participants made of this experience was nothing changed as the symptoms remained. Once again they felt disappointed. A systematic synthesis review of NES qualitative studies also found some people experienced a diagnosis to be 'meaningless' and they were disappointed (Rawlings & Reuber, 2016). In this current study commencement of treatment brought about hope for change and a return of their old selves. The participants sense of hope soon fell as they felt the success of treatment was not sustainable in the long-term and once again, they experienced feelings of disappointment and anger.

Living with 'it' captured the time period of here and now. The participants still experienced a loss of control of their body. Furthermore, some participants did not feel better and they still had a negative self-image whereas others felt better and they had a positive self-image.

The scary and unpredictable 'it': participants understood the condition to be a malevolent external force that controlled their affected body part. They still saw themselves as separate to the symptoms and a victim to their body. Participants were no longer confused but they were still worried and lived in fear of 'the force' as they experienced 'it' to be unpredictable and dangerous. Consequently, participants were scared to go out on their own as they feared being in a precarious situation and completing daily tasks within the home was a struggle. The

disruption to their daily life caused participants to feel angry and frustrated. Living in an unpredictable body was also evident in people's experiences of living with MS. Research with people with MS also indicated that they no longer felt able to trust or depend on their body to act as reliably or expected (Mozo-Dutton et al., 2012).

A significant experience in this main theme was the process of self-image. The experience of living with the condition and the impact on identity differed for participants. Some still had a negative self-image whereas others now had a positive self-image. The difference between these two groups was the process they were going through. One group still judged themselves in a negative way (negative self-image) whilst the other judged themselves in a compassionate way, and thus, they felt happier (positive self-image).

I want 'it' gone: this group still judged themselves in a critical way and thus, they still lived with a negative self-image. They were still ashamed and embarrassed of their new identities as they still experienced them to be weaker in comparison to their old selves. Furthermore, they still thought others would judge them in a negative way and see them the way they see themselves. This led to participants avoiding others and feeling uncomfortable when out in public. Rawlings and Reuber (2016) systematic synthesis review of NES qualitative studies found people with NES experienced feelings of shame and embarrassment about their seizure and this made them think they were different from others. This group of participants were still measuring themselves against their old selves and thus they had not experienced a recalibration of life. They had not yet reached a stage of developing new goals and new values that were accepting of a body with limited motor functioning. Instead, they were still stuck in a process of self-blame and self-criticism which maintained their feelings of distress. Participants still experienced the condition to be a barrier to living a meaningful life and they still felt angry, frustrated and distressed. These participants had found practical ways to adapt to living with the condition, however, they perceived living with adaptations to signify disability. Being different was difficult to accept as it meant not being as good as they used to be and thus, a few of the participants felt a need to hide their adapted equipment because of embarrassment. The findings of this study suggest

participants in this group appear to have not yet completed a whole process and they are still stuck, feeling demoralised by their circumstances and longing for the return of their old self. This group appeared to be struggling to accept the condition. They were aware the symptoms will not go, but there was still a yearning, a “wanting” that the symptoms will disappear.

Rebuilding of self: this group no longer judged themselves in a critical way. Instead they were kinder to themselves and thus, self-compassion brought about the emergence of a positive self-image. It appeared they had completed a whole process as they were no longer mourning the loss of old self and they had acceptance the new self. Acceptance of the self meant living with the symptoms and understanding the symptoms to now be a part of them. Participants had assimilated the FMD symptoms to be part of their identity. The acceptance of a new self made them feel good about themselves and they valued themselves once again. This enabled them to recalibrate their life as they were no longer distressed by their impaired functioning and they were no longer yearning for the return of their old self. Instead they began developing new goals that were mindful of their body’s limited motor functioning and once again living in line with their values. The re-establishment and acceptance of their identity appeared to be key to their experience of positive affect as “a well-functioning identity enables one to experience feelings of personal meaning and well-being and to find satisfying and fulfilling engagements in one’s social context.” (Kroger, 2017, p.2). A qualitative study on NES found similar findings. A small number of participants no longer experienced their seizures to be shameful or embarrassing and NES became a valid and integrated aspect of self (Wyatt et al., 2014).

Novel contributions to the evidence base of FMD

There have been many qualitative investigations of the illness experience of NES but there is limited qualitative research on FMD. This is a missed opportunity because the qualitative research on NES has provided an important insight into the impact of this conditions on the experience of diagnosis, activities of daily living, physical and psychological functioning, adjustment and stigma. Nonetheless, (to my

knowledge) two previous qualitative studies on FMD have been helpful in outlining some important features of life with FMD.

Epstein et al. (2016) explored the value of qualitative psychiatric interviews as part of the diagnostic process to enhance the understanding of psychological features of FMD. The themes reflected the patient's understanding of their illness and the impairments with emotional processing; 'minimization of emotional impact of trauma', 'symbolic conversion of psychological stressors into a specific movement disorder', 'emotional states converted into physical symptoms and expressed in somatic language', 'secondary gains from symptoms' and 'avoidance of or inability to recognise emotional states' (for example, participants avoided feelings of stress or low mood or did not recognising feelings of stress. The aim of the study was to demonstrate the value of exploratory psychiatric interview; therefore, this may explain why the themes appear to resemble diagnostic criteria and thus, reflect an objective perspective (psychiatrist view). Whereas the theme names in this current study appear to reflect a more subjective perspective (participants view). For example, the theme name 'unexpected and progressive loss'. It could be argued that the findings from this study have produced some themes that are more reflective of the patient's subjective experiences of living with an FMD. The two studies had two different aims, and thus, two different set of findings.

Nielsen, Buszewicz, Edwards, & Stevenson (2019) identified that patients struggled to understand their diagnosis and they were unhappy with psychological explanations being cited as the cause. Nielsen et al. (2019) aimed to explore why patients may have these views and how their experiences and beliefs impacted on their relationships with healthcare professionals. They interviewed ten patients who had different motor symptoms (tremor, gait disturbance, mixed movement disorder and limb weakness). Six themes were found using inductive thematic analysis.

The theme 'the burden of living with FMD' described how participants struggled to complete activities of daily living and had restricted mobility. Their experiences of coping with the symptoms, not understanding what wrong, unknown prognosis and unhelpful interactions with healthcare professionals

contributed to their feelings of distress. The inability to function led to the experiences of social isolation and loneliness. Participants described that FMD impacted on their relationships, as others struggled to relate to their experiences of living with the condition. This theme in Nielsen et al. (2019) study shares many similarities with theme one in the current study, although, the current study understood participants experiences from the perspective of loss and discovered how prominent the loss of identity was to their wellbeing.

In Nielsen et al. (2019) study the theme 'nobody knew what was wrong' captured participants perception of healthcare professionals. Some participants did not accept a diagnosis based on excluding other diseases (negative investigations). In addition, the experience of a long wait to get a diagnosis and the many tests contributed to a loss of confidence in doctors. In this current study participants also perceived medical staff as taking a not knowing position and they endured a long wait for a diagnosis (theme one).

The theme 'dissatisfaction with psychological explanations' in the Nielsen et al. (2019) study found most of the participants did not subscribe to this viewpoint. Some participants reported experiencing psychological problems or trauma but they did not think this was the cause. This current study did not produce any themes on this topic, however, two of the participants (Dan and Tina) did think the cause of their symptoms may have been psychological as their symptoms presented during a period of stressful events, whereas, Zoe did not believe the condition was psychological in nature. The differences between these findings maybe because the participants in each study had different experiences of services. In the Nielsen et al., (2019) study most of the participants had been given psychological explanations as the cause, whereas in this current study this did not appear to be the case. In addition, in this current study participants did not choose to talk about their understanding of the aetiology and this was not something I actively attempted to explore during the interview.

The theme 'patients feel abandoned' in Nielsen et al. (2019) study described participants negative experiences with healthcare professionals. Participants reported experiencing conflict with staff and poor treatment. This current study also found that participants had negative experiences (not being believed) with

professionals (theme one). In the Nielsen et al. (2019) study the theme 'iatrogenic harm' described how participants felt inappropriate treatment was given and this made their problem worse. This finding was also present in this current study. Mary felt she inappropriately received drugs in the past prior to her FND diagnosis and Zoe felt it was inappropriate that she was put on a ward and given drugs to treat her 'psychological problems'.

The theme 'powerless' in Nielsen et al. (2019) study described how participants felt stuck because they did not know what was wrong and this prevented them from helping themselves. This experience of powerless was also exacerbated by their feelings of abandonment by healthcare professionals. This theme was not captured in this current study, although some of the participants did feel abandoned by professionals ('*dismissed and silenced*'). This theme may have not been present in this study because all the participants were recruited from Doctor Alty's service, therefore, they were in a service where their condition was being understood as well as it could be. In contrast, the sample in Nielsen et al., (2019) study came from services that had a more traditional view of the aetiology.

Neither of the studies by Nielsen et al. (2019) and Epstein et al. (2016) appeared to have explored participants experiences across pre- and post-diagnosis phases. Furthermore, the research aims of these two studies differed from the aims of this current study and thus, to my knowledge the current study is the first study to explore people's experiences of living with an FMD using IPA and across the pre and post diagnosis phases.

The standalone contributions of this current study that are not present in Nielsen et al. (2019), Gill (2019) or Epstein et al. (2016) are:

- the conceptualisation of identity.
- the external force (perceiving themselves to be separate to the symptoms and the affected body part).
- the experience of self-blame.
- the extreme experience of shame and embarrassment.
- the fear of losing one's mind.
- the belief others will judge them negatively.

- the importance of working within a positive diagnostic framework.
- the processes (compassion versus criticism and shame) involved as to whether a person is able to accept or not accept living with the condition.

The findings from this study have provided a detailed understanding of the lived experience of FMD and such insight has the potential to inform clinical practice for both medical staff, psychologists and psychotherapists.

Psychological literature

This section will present psychology theory to make sense of the participants experiences.

Leventhal's common-sense model. The participants in this study experienced a sudden health threat. The CSM may further our insight into understanding their responses to this health threat and how they coped. The CSM describes the individual's cognitive and emotional responses to a health threat (Petrie & Weinman, 2006). Individuals understand their condition based on five cognitive dimensions: identity (symptoms and labels), causes, time line (permanent or temporary), consequences (emotional and/or physical impact) and cure-control (Leventhal, Phillips, & Burns, 2016). An individual's cognitive representations inform whether coping responses are adaptive or not (Leventhal et al., 2016). One's sense of self is derived from the innate neuro-biological representations of the 'normal body', however, the onset of symptoms activates a deviation from the 'normal self' (Leventhal et al., 2016). Theme one captured this experience of deviating from the 'normal self' during onset of symptoms.

The participants experiences in theme one and two can be mapped onto the proposed five cognitive dimensions. In theme one the delayed diagnosis may have prevented the participants from representing their illness as part of their identity. This inability to identify with a label may have created the identity conflict (ill self versus normal self). Having no explanation (for some this led to blaming themselves) or understanding of prognosis resulted in experiences of negative affect. The condition impacted on participants in terms of reduced physical ability, emotional distress and reduced QoL (e.g. affected their, family, work, finances,

lifestyle). Participants were aware there was no 'cure' and they did not feel in control of the illness experience, furthermore, once a diagnosis was received they realised the symptoms cannot be controlled by treatment (theme two) and this led to feelings of disappointment. It is evident the participants in theme one and two may have held negative illness appraisals and this affected how they coped with the illness, which then affected their QoL. In addition, the way participants coped with their emotional responses to illness affected their QoL; negative illness appraisals led to negative affect and/or negative affect led to negative illness appraisals. A systematic review and meta-analysis of the CSM showed negative illness representations are associated with higher rates of depression, anxiety and stress (Brooke & Lusher, 2012). In addition, individuals with CFS perceived their illness to be serious, they had no control and thought there was little possibility of cure and reported greater mental health difficulties (Heijmans, 1998).

The lack of self-agency appears to be a common theme in conditions that are medically unexplained. Ludwig et al. (2015) found that patients with FMD and NES reported a low level of personal control over symptoms and limited understanding of their symptoms. The findings of this study (theme one) provides further support for these quantitative findings. The participants experienced a lack of self-agency over their body. It could be possible that people with FND may have a perceived lower threshold for control and this may be impacting on their ability to function within their normal daily life, for example, *"just, the just fear of useless and worthless... not being able to, to help with anything. You know not being able to clean up or cook or anything..."* (Mary, line 1229).

The dual process model of coping with bereavement. The participants appear to be going through a grieving process as they were mourning the loss of their old self. The dual process model of coping with bereavement (Stroebe & Schut, 1999) can be used to further understand their experiences. The model identifies two components; loss-orientation and restoration-orientation, and a regulatory coping process of oscillation. Loss-orientation is where the individual is processing some part of the loss. They are yearning for the deceased. Negative affect is predominant. In theme one all the participants experienced negative affect as a consequence of yearning for their old selves and lifestyle. Restoration-

orientation is where the person adapts to the bereavement, for example, they focus on what needs to be dealt with (e.g. loneliness) and how it is dealt with (e.g. by avoiding solitariness). The changes one may have to adjust to could be mastering new skills and/or developing a new identity. The individual will still be dealing with the grief as well as adjusting to changes. The participants with a positive self-image experienced a change when they recalibrated their lives and established new goals and interests. The group of participants with a negative self-image were practically adapting to living with body with limited motor functioning. During this phase people may develop a new identity. The participants with a negative self-image were still grieving and had not yet accepted their new identities. For example, Sundip and Jude expressed a “wanting”, almost a wishing of the return of their old self. This group of participants appeared to be still attached to their loss of old self. The model suggest that people can ruminate on the loss and thus, they may be experiencing a complicated grief process (e.g. loss orientation syndrome). The participants prolonged grief may explain their continued experience of negative affect as well as why it may be taking them longer to reach acceptance. Over time, three of the participants developed a new identity that coexisted with the condition. They had reached a place of contentment and acceptance with who they were.

Individuals will oscillate between loss and restoration. Whilst trying to live their life people either confront or avoid the loss. The participants who were fighting to get through the day (*‘struggle and surrender’*) may have been trying to distract themselves by seeking relief and focusing on something else other than the emotional pain of the losses. The model considers this distraction to be a form of adaptive coping as the person takes time off from grieving and dealing with either component. The participants experience of fighting may have been their way of taking time off from grieving. The participants with a negative self-image appear to have been oscillating between loss and restoration, whereas for the positive self-image group the process of loss orientation no longer dominated. The model is not a stage process model. It is expected the group with a positive self-image will still oscillate between the two components and experience episodes of upset at any point in their life. This is evident in the following extracts “... *the really simple*

things of making a cup of tea or brushing my teeth are really difficult...it's those little things that you miss the most being able to do..." (Mary, line 27-31) and *"It'd be nice not to be poorly..."* (Zoe, line 2076). These participants still missed their functioning bodies. The model can account for gender differences within the process of bereavement. Stroebe and Schut reviewed research and found that men are more likely to use restoration-orientation activities to cope with loss.

The dual-process model of assimilative and accommodative coping. During the onset of symptoms, a significant experience for some of the participants was the sense of fighting to get through the day. They had not adjusted their standards in view of living with a body with limited motor functioning (*'struggle and surrender'*). The process of pushing the body to keep up with their lifestyle resulted in both physical and emotional distress and thus, this was not an adaptive coping strategy. Within the present day some participants (two of which were in the *'struggle and surrender'* theme) were able to adjust to living with a chronic illness (*'Rebuilding of self'*). They developed new goals that were mindful of their body's limited motor functioning. The dual-process model of assimilative and accommodative coping (Brandtstädter & Rothermund, 2002) can be applied to further understand the participants responses to living with a chronic health condition.

The model provides a framework for understanding how one negotiates attaining goals while adjusting to changes that may affect goal attainability (Brandtstädter & Rothermund, 2002). The model comprises of two processes to explain adjustment to development gains and losses across the lifespan. The two processes are assimilation (e.g. circumstances are adjusted to keep goals) and accommodation (e.g. goals are adapted to be achievable). It has been proposed that adapting to a critical life events such as chronic illness may require varying degrees of assimilative persistence or accommodative flexibility (Boerner & Jopp, 2007). The participants source of distress in the *'struggle and surrender'* theme may have arisen from not being able to adjust their circumstances in order to live in line with their goals (assimilation) as well as not adapting their goals (accommodation). The process of accommodative flexibility is evident in the theme *'Rebuilding of self'*. These participants developed new goals that were mindful and

accepting of their body's limited functioning. The accommodative mode is more useful in accepting constraints or permanent losses in life (Boerner & Jopp, 2007).

Social identity theory. The sudden onset of symptoms resulted in participants losing their sense of self. They were no longer able to do the things they used to do, and thus, they were unable to fulfil their social roles. Social identity theory may provide further insight into the participants experiences of loss of self. A person's sense of self is embedded in belonging to a group and their identity is derived from group membership (Tajfel & Turner 1979). Before the onset of symptoms participants derived their social identity from multiple groups, for example Rita and Jude's group memberships were based within the family, work, recreational activities, relationships/friends and health (the healthy person). Their roles within these social systems provided them with a status within society, for example, 'the worker', a person who contributes to society. The role of working and contributing to society and the household were valued roles for Zoe and Rita.

The theory proposes there are two types of groups (Tajfel & Turner 1979); in-group (the group we belong in and want to be a part of) and out-group (the group we do not belong to and do not want to be a part of). Before symptom onset participants belonged to their preferable in-groups and had multiple social identities. The core cognitive components to social identity are: *social categorisation* (perception of belonging to group), *social identification* (identity and self-esteem is embedded within group identification) and *social comparisons* (comparing self to out-group improves and maintains self-esteem).

Before illness participants had *social categories* they belonged in. When they became ill they were no longer able to *socially identify* as belonging to their previous in-groups. Their group membership (social identity) had been lost. This may explain why the loss of self was such a distressing experience. They no longer understood who or what they were. Furthermore, some of the participants begun to question their own worth and the purpose of their existence as they were unable to identify and associate with their previous in-groups. Before illness the participants derived their self-worth and self-esteem from being in preferred in-groups (*social comparisons*). For example, part of Rita's self-esteem was obtained

from her worker role “...making a difference to patients as well as bringing in some money for the house...”. When these participants lost their social roles they appeared to have also lost their self-esteem and self-worth as these were embedded within belonging to their in-group. Furthermore, five of the participants previously worked in healthcare or caring roles therefore not only did they lose these roles they also became the ones that needed ‘care’ (a new in-group). This role reversal was something that Rita acknowledged as being difficult “*just a big change...now all of a sudden I’m a patient*” (Line 190). Consequently, participants developed new group memberships, new in-groups (for example, ill person, no longer a worker) and they saw these as undesirable in-groups to be associated with and thus, the resentment, anger, frustration, shame and embarrassment and upset. The loss of social identity is also present in the neurological condition PD. A systematic review identified that identity loss can be managed by being able to maintain or develop a new social identity (Soundy et al., 2014).

Erikson’s psychosocial theory on identity development. The study has provided findings that evidence the participants experiences across time. For some, the time period between the onset of symptoms and receiving a diagnosis was nearly a decade or more. Furthermore, when onset of symptoms developed participants experienced an unpredictable change that disrupted the course of their lifespan. Erikson’s psychosocial theory maybe be useful in understanding the participants experiences of identity change and development. Erikson’s (1963, 1968) proposes a person’s identity develops over a series of eight stages across the lifespan (as cited in Bee & Boyd, 2003). During each stage the individual will experience a conflict and it will need to be resolved in order to develop a strong sense of self. The stages relevant to the findings of this study are intimacy versus isolation (18-30 years old), generativity versus stagnation (30-65 years old) and integrity versus despair (65 years old and older).

During onset of symptoms participants were within different life stages. Zoe had just entered the intimacy versus isolation stage (forming intimate relationships). The outcome of this conflict will either be successful relationships or isolation and loneliness. Living in a body with limited motor functioning was affecting Zoe’s ability to successfully complete the task of intimacy. She reported

not being able to “*go out and do things with friends...*” (Line 385). The body was a barrier to fostering caring relationships and thus, Zoe felt isolated and sad. Rita, Jude and Dan were in the generativity versus stagnation stage. The important event during this stage is work and parenthood. There is a need to be productive and contribute to society. Success leads to feeling useful and a sense of accomplishment and failure may cause a sense of stagnation and separation from the world. Both Jude and Rita struggled with the loss of meaningful roles within the workplace. Living in a body with limited motor functioning prevented them from being productive and contributing to society at the organisational level. They experienced a sense of stagnation and separation from the world as they no longer felt useful and productive and thus, possible why they felt desolate. Anne was currently in the integrity versus despair stage. The important event during this stage is reflection on one’s life. The individual establishes whether they have had a successful life and achieved a sense of fulfilment. Anne was retired and avoided both recreational and social activities. Living with FMD meant to live with regret “*...you don’t have any life...*” (Line, 1032). Anne’s stage of life would usually be linked to old age (integrity versus despair) and her expressions of regret suggest a difficulty in resolving this conflict satisfactorily.

The integrative cognitive model. The study identified that it is difficult and stressful to live with an FMD. Potential stressors were; losing their sense of self, the inability to do things, the intense emotions experienced in response to the symptoms, the internal thoughts and perceptions about self and others, the experience of uncertainty, unhelpful interactions with healthcare professionals during the diagnosis process, and trying to retain their levels of previous functioning. This adversity was present for all participants at the onset of symptoms, however, for some participants things improved after diagnosis whereas for others things remained the same. Even though the ICM model is specific to NES it may provide some insight into the lived experience of stressors when living with an FMD and its aetiology.

The model proposes a psychological explanation for functional symptoms - that are produced by “the automatic activation of a mental representation of seizures (the “seizure scaffold”) in the context of a high level inhibitory processing

dysfunction” (Brown & Reuber, 2016, p.2). While in accordance to the model, it is possible that the participants experience of chronic stress and arousal may have led to and maintained their functional motor symptoms (e.g. participants may have formed a ‘motor/movement scaffold’). Unfortunately, the application of our findings to the model is limited. Firstly, the interviews did not explore the participants understanding of aetiology. The collection of this data might have provided further information to map onto the model and further our understanding of aetiology. Secondly, data was not collected on their life experiences prior to the onset of symptoms, such information may have provided insight into the concept of mental representations.

Strengths and limitations of the research

At the time of developing the research proposal the study was a novel research project as there was no qualitative research on people’s experiences of living with FMD. Subsequently, over the three years since this study had started there have been two qualitative papers and a mixed methods study. This is the first study to explore people’s experiences of living with FMD across the whole pre- and post-diagnosis phases using IPA. The overall strength of this study is the originality of the research and the novel findings that contribute to the literature.

Sample. A strength of the study was that recruitment fulfilled the maximum sample size and eight participants were recruited. This provided a big enough sample to make inferences about people’s overall experiences of living with FMD; although, unlike quantitative approaches a limitation of the study is that the small sample size means the findings do lack transferability to a wider population. Consequently, the findings might only apply more strongly to people with more similar characteristics than it does to those who have different characteristics. For example, different demographics or recruiter. The approach of IPA has the ethos of “sacrificing breadth for depth” (Smith & Osborn, 2007, p. 56), therefore, a strength of the study is the rich data obtained from this idiographic stance. Another strength of this study was the varied age range. Living with FMD affected the participants

experiences of the 'life challenges' (e.g. Erickson's lifespan stages) they were facing, therefore, the findings provide an insight into living with FMD across the lifespan.

The sample was predominantly white British, except for two participants who were British Indian. The slight diversity of ethnicity was a strength of the study, although it was not wide enough to make a strong inference that the experience of living with FMD is similar across the two cultures. The findings suggest there may be similarities between these two cultures. The sample was also predominantly female except for one male. A high proportion of females is a strength of the study as the findings indicate there appear to be similarities between females' experiences of living with FMD. In contrast, a limitation of the sample size was the under representation of males. I noticed the male's account of his experiences felt different to the female's accounts. His use of feelings language and discussing a variety of direct experiences was less detailed. I was left with a sense of there may be more to his experiences and I do not think I have been able to bring this out, particularly in theme three. I do wonder whether he may have differing experiences of living with FMD in the here and now, in comparison to the females. I was able to make some hypotheses about his experiences based on what I knew but the hard data (e.g. direct quotes) to support this was absent. A strength of the study is the finding there may be a gender difference with regards to accepting the diagnosis of FMD; the female participants accepted the diagnosis but he still questioned the diagnosis. A limitation of qualitative methodology is the way people communicate their experiences, therefore, future research would benefit from taking this into consideration. In addition, researching the effects of the expectations we have of ourselves as gendered individuals when going through a condition such as FMD could be interesting.

A strength of the study was the clinical homogeneity of the sample. They were a group of people experiencing a new phenomenon and they were all recruited from the same specialist service. They all had hyperkinetic forms of FMD (rather than hypokinetic manifestations such as weakness and paralysis). Some may argue the sample is not homogenous enough as participants had *different* types of hyperkinetic motor symptoms for example tremor compared to dystonia. The degree of similarity across experiences of other conditions, for example, NES

and CFS indicates that a sample with a specific diagnosis is not significant for homogeneity. Furthermore, the study was interested in the social and psychological experiences more broadly rather than just the experience of specific symptoms. In addition, there currently is not a clear understanding of the aetiology of FMD, therefore this allowed a varied homogeneous sample. If the aetiology of functional tremor differed to functional dystonia then the study would have only focused on one group to ensure homogeneity, as ones' experiences of a condition may be different if the aetiology was biological rather than psychological.

The sample was a mixture of chronic and relatively newly diagnosed patients. A possible limitation is that two of those with a chronic presentation (eight and sixteen years between symptom onset and diagnosis) struggled to remember their experiences of onset of symptoms and the diagnosis process. This did impact upon the richness of their accounts, although, other participants with chronic presentations did not have any issues recalling their experiences of onset and the diagnosis process.

Recruitment. All the participants were recruited via an NHS neurology clinic. The field supervisor of the project, Doctor Alty recruited all participants into the study. A strength of the study was that I could be confident the sample all had a diagnosis of FMD by a neurologist who specialises in movement disorders and FMD and thus, the sample was homogenous. Therefore, the study was exploring the experiences of living with FMD. Nevertheless, having only one recruiter did have some limitations that may have impacted on analysis. I know from working with my recruiter they are a pioneer in promoting the importance of working within a positive diagnosis framework within the NHS. If the sample had been recruited from different consultant neurologists with different ways of working and viewpoints then I wonder whether the themes for the time period of diagnosis time and here and now may have been different.

In addition, a further limitation of recruitment strategy two (Consultant Neurologist identified outpatients from clinical caseload) was selection bias. The recruiter identified participants by considering who would be suitable for the research. Even though they were given the recruitment criteria it is difficult to

ascertain whether their subjective experiences with patients influenced their decision on who was selected. It could be argued the sample is rather narrow as most participants came from recruitment strand two (n=6). A strength of recruitment strand one (participants approached during routine neurology or inpatient admission, n=2) was that everyone eligible was asked consecutively. Therefore, there is more confidence that the study had access to the wider potential sample without the interference of selection bias and thus, this strategy broadened the sample. A general issue with both recruitment stands is self-selecting bias. All participants chose to take part in the research. They were motivated and keen to take part and this inevitably will have an impact on the data produced. I wonder whether there may be more to understand about the experience of living with an FMD through those who do not wish to take part in research as we only know about the experiences of those willing to come forward.

Interview and data collection. To explore participants' experiences the interview schedule was semi-structured but with a story telling sequence. This was a key strength of the study as it has provided a set of findings that illustrates an understanding of people's experiences across time and the lifespan. The interview schedule started with broader questions and moved towards more specific questions. This funnelling technique (Smith et al., 2009) supported those who struggled to talk about their experiences to warm up to the interview process.

A strength of the interview process was using semi-structured interviews. This method of data collection allows for a flexible dialogue using open and expansive questions (Smith et al., 2009) and such questions are intended to guide not dictate the interview (Smith & Osborn, 2007). The use of semi-structured interview approach encouraged rapport and empathy and it provided flexibility in the data captured which enabled exploration of novel areas and the production of richer data (Smith & Osborn, 2007). A strength of this study is the richness and detailed themes developed. A consequence of this approach is the researcher has less control, interviews take longer and thus, data is harder to analyse (Smith and Osborn (2007). I think a consequence of less control may explain why the study was unsuccessful in gathering data on the participants understanding of the aetiology of FMD.

A surprise during the data collection method was the length of the interviews. Smith et al. (2009) recommend a good IPA interview is around 90 minutes. Nearly all the interviews in this study lasted longer than this. It appears participants may have valued and appreciated having a space to be heard and listened to, therefore, a strength of this study is giving this clinical group a voice. Another strength of the interviews is that they were conducted by a trainee clinical psychologist. My skills as a psychologist to focus, manage and facilitate peoples thinking about difficult things may have contributed to the richness of the data accounts. Furthermore, my position as a non-expert in the field of FND may also be another strength of the study. I came from a position where I was less biased and less influenced by any prior knowledge, therefore, I was open to their stories and I did not make assumptions about what they may mean when discussing their experiences.

Analysis. The analysis was based on IPA analysis guidelines by Smith et al. (2009) and these are guidelines a researcher has a degree of flexibility with regards to implementation. The guidelines advise to complete the first three stages and then identify the individual themes for that transcript before moving onto the next transcript. Instead I completed the first three stages for all the transcripts and then I returned to identify the individual themes for each transcript. I think a strength of this approach is that it provided me with a strong sense of each transcript, although a potential disadvantage is that I may have risked carrying over understandings from one interview into the next. I was aware I had been immersed in the data and I intentionally took a break between each transcript. The function of the break was to *bracket* my own preconceptions and attempt to keep any ideas and assumptions from interfering with the other accounts. The risk of carrying over understanding across the data set may also be an issue when adhering to the guidelines, as IPA researchers are always in a process of immersion and *bracketing off*. Therefore, quality assurance checks (e.g. grounding in examples or owning one's own perspective) are important in assessing whether both have been achieved. The results section was quality checked by my four supervisors and two peers. They all reported the findings resonated with them, therefore, it would appear the altered method may not have had a critical effect on the analysis. Once

the individual themes had been completed for all the participants I decided to take a break from data analysis before moving onto the group analysis. I had been immersed within the data for some time and this break enabled me to approach the data set from a different and hopeful less biased perspective. During the analysis process I came across a qualitative study exploring peoples experiences of living with FMD. I decided not to have a look at the findings of this study as there was potential the findings from this paper could interfere with my interpretation of my data. A strength of this was limiting the risk of data contamination and approaching the data with preconceived bias for themes.

Quality control. To evaluate the quality of the research I used Elliott, Fischer and Rennie's (1999) guidelines for good qualitative research (see table 3). In the method section I devised a table to show each criterion for the evaluation and evidenced how I applied the criteria to the study. I attempted to achieve good standards and the table has been provided for the reader to judge whether this is the case. The biggest challenge was owning one's perspective, for example, consciously remembering to use the journal and keep memos. Furthermore, keeping a reflexive dairy and attending a peer support group for IPA researchers supported me to notice that in the early stages of analysis I was interpreting the data in a negative way, for example, others supported me to notice the experiences of resilience and bravery within the accounts.

In the method section I discussed what I expected to find. I expected people to struggle with functioning and being able to do things but I did not conceptualise this as being associated to identity and the loss of self. I expected people would find ways of coping and adapting to the condition. I presumed this would be an indication of 'acceptance'; however, this was not the case, as some people practically adapted but still had not reached acceptance. I expected some people would reach acceptance but looking back at my notes I never defined or broke down what 'acceptance' meant or looked like. I was surprised by how people experienced their symptoms to be something separate to them. I did not expect people to experience such extreme feelings of shame, embarrassment, self-hatred and self-blame. I also did not expect people to have had positive growth

experiences. Owning my perspective has provided a strong quality assurance check as it demonstrates I have not just found what I expected to find.

Clinical implications and recommendations

The findings of this study provide clinical implications and recommendations for medicine, psychology, third sector organisations and patients.

Medical community. The study found many participants perceived negative experiences with healthcare professionals. Furthermore, they reported it took a long time to receive a diagnosis, and thus, from the participants perspective there was a diagnostic delay. These experiences had a detrimental impact on participants psychological wellbeing. For instance, the participants who perceived the doctors as not believing and dismissive felt angry, disappointed and alone during a desolate time. Furthermore, the absence of a diagnosis resulted in some participants blaming themselves and/or fearing they were losing their mind. Further training on the importance of a timely diagnosis and the therapeutic relationship during the consultation process and delivering the diagnosis should be considered to improve patients' experiences of healthcare but also reduce psychological distress. Stone (2009) proposes patients with an FND are not dissimilar from other patients with 'pathological defined disease' in terms of distress; and thus, investigations should be done quickly and a clear explanation of what is wrong as opposed to what is not wrong. The findings of this study support Stone's viewpoint as the participants experiences of living with FMD are similar to peoples lived experiences of PD and MS. Furthermore, Stone, Carson and Hallett (2016) identified there are a number of components to ensure effective communication of a diagnosis. Two of their key components that are supported by this current study are taking the patient seriously and diagnosing the 'problem' with a label can be therapeutic. In addition, the Australian report on people's experiences of FND found that lack of knowledge in professionals led to a delayed diagnosis and treatment (Gill, 2019). Furthermore, 92% of patients reported that training and education of FND in healthcare professionals was urgently needed.

In this study participants experienced positive affect when doctors worked within a positive diagnosis framework and part of this involved achieving a warm therapeutic relationship. The importance of this experience with healthcare professionals should not be underestimated as it coincided with a time when participants were feeling distressed and desolate as a consequence of all their losses. The study captured how complex and distressing the participants diagnosis experiences were with regards to length of time it took to get diagnosed, going back and forth between services and not being believed.

A stark finding was the extreme feelings of anger and frustration experienced by participants. These strong emotions and their experiences of mistrust may require clinicians to engage patients in a different way compared to other clinical groups. They may need to prioritise and work harder to build a therapeutic alliance and trust. Pioneering neurologists who are working in a positive diagnosis framework and already delivering training may want to consider incorporating a section on people's experiences of living with the condition. This could be co-facilitated with a clinical psychologist to consider the psychological impact and/or a patient with FND. This 'expert by lived experience' role (person with a FND) could provide a first-hand account that professionals can listen to, a story that may otherwise be lost to time constraints of clinical appointments. This training could be useful for all members of the MDT.

A novel finding of this research is the externalisation of symptoms and the sense of separateness from the body part affected. This finding has not been found in previous of FMD research, suggesting it may be a unique clinical feature of FMD. Clinicians may benefit from listening out for such experiences when taking a patient's history as a supportive clinical feature. Furthermore, the findings indicated that people with FMD may have a fear of 'losing their mind' and acknowledging this concern and reassuring them that this is not the case could reduce their feelings of negative affect. The participants experienced extreme psychological distress in response to living with FMD, therefore, they may benefit from being referred for psychological therapies as well as physical therapies.

Psychology. Research interest in developing psychological interventions for this clinical population has predominantly focused on the application of CBT in NES (Goldstein et al., 2010; LaFrance et al., 2010; Speckens, 1995). The neurology community have recognised the value of CBT alongside pharmacological treatment and physical therapy (Stone, 2009) but clinical trials of CBT interventions have not been widely studied in FMD (Ricciardi & Edwards, 2014). A Cochrane review found there was not much reliable evidence to support the use of CBT in the treatment of NES (Martlew et al., 2014).

The present study's findings could support psychologists and psychotherapists to consider alternative approaches to CBT. A key finding in this study was the extreme feelings of shame, self-blame and self-criticism that led to and maintained their feelings of distress. The psychological model compassion focused therapy (CFT) was developed for people with high levels of shame and self-criticism (Gilbert, 2010). CFT aims to support clients to develop self-compassion and it could be a useful approach when working with FMD. The model's ethos of developing compassion towards the self may support the process of acceptance. Accepting the self as a person living with a chronic condition and thus accepting their new identity and reducing psychological distress.

The findings of this study demonstrated living with FMD means to live with a chronic illness. The distress experienced by participants was also due to not being able to live in line with one's values, and thus, a loss of identity. The success of medical treatment from the participants' perspective was short-term, therefore, patients may benefit from interventions that focus on improving their quality of life and developing a more meaningful life whilst living with a chronic condition. A psychological model that may support clinicians with this is ACT. Unlike CBT, ACT does not focus on reducing symptoms instead it is interested in changing the client's relationships with their symptoms and their feelings. ACT aims to "to create a rich, full, and meaningful life, while accepting the pain that life inevitably brings" (Harris, 2009). The principles of ACT are represented in the psychological flexibility model. This model comprises of six core processes: contact with the present moment, acceptance, diffusion, self-as-context, values and committed action

(Harris, 2009). ACT focuses on these core processes to enable people with chronic illness to experience understandable and tricky psychological experiences that are caused by the situation they are in (e.g. feelings of frustration, worry or anger) and at the same time to focus on doing things that make their life better (Yu & McCracken, 2016).

This current study found that participants experienced a loss of identity and sense of who they were when living in the context of illness. ACT may offer some therapeutic possibilities in this area, particularly by focusing on self-as-context process. In this model the sense of self is conceptualised as self-as-content versus self-as-context, with the latter seen as a more helpful stance. The self-as-content “involves identifying with the descriptions and evaluations of one’s thoughts and feelings. Simply put, I am who I think I am” (Yu & McCracken, 2016, p.12). The self-as-context requires “taking an observer perspective which is separate from thoughts and thinking and the ideas we have about who we are” (Graham et al., 2016, p.48). For example, in this current study it was evident that the participants conceptualisation of identity was infused with their psychological experiences of illness. When the symptoms presented they often were no longer able to be the person they were and thus, they saw themselves (identity) to be defined through their illness experiences (theme one). Furthermore, some of the participants were still not feeling better (theme three). This is important because the more one is focused on unhelpful descriptions and evaluations of self (e.g. “I am useless”) then the more difficult it might be to adapt to living with a chronic illness. Graham et al. (2017, p.11) propose “where a person with FMD experiences disabling symptoms, with no control over symptoms, then negative thoughts, illness beliefs, and unwanted emotions might simply reflect this context”. Focusing on the process of self-as-context in therapy may increase one’s psychological flexibility and improve their psychological well-being when living with an FMD. Therapist can use techniques or exercises to tap into the ‘contextual self’, for example, self-compassion and decentering exercises (Yu & McCracken, 2016). Self compassion requires non-judgmental kindness towards self and separating self from evaluations (Yu & McCracken, 2016). Decentering requires ‘stepping back’ from

thoughts and feelings or 'observing' these in a detached manner (Yu & McCracken, 2016).

The findings demonstrated participants experienced an incongruence between who they are and who they wanted to be (old self) and this caused them distress. The ACT model could be useful in supporting patients to consider how to close this 'reality-gap' that brings them feelings of distress (Harris, 2012). A systemic review of eighteen studies (six RCTs, four used pre-post designs and six case studies) found that the application of ACT is not a well-established intervention when working with chronic disease/long-term conditions; although, the application of ACT to seizure-control in epilepsy, psychological flexibility and possible disease self-managements is promising (Graham, Gouick, Krahe & Gillanders, 2016).

It appears that a challenge of living with an FMD is the experience of perceiving others to be making negative judgements and this contributed to their experiences of distress. Patients may benefit from a CBT approach working on perspective taking. It is important to note people may have experienced an unhelpful attitude or situation with others and thus, they could be generalising and expecting others to behave the same. Alternatively, the CFT approach of working on their internal feelings of shame and embarrassment may have a secondary impact on improving their perception of others, for example, if they are compassionate to themselves they may perceive others to be less threatening. Third wave CBT approaches of CFT and ACT could have promising results on increasing the quality of life. A case study has shown ACT to have promising outcomes when working with FMD. The participant showed improvements on psychometric scores for psychological flexibility, functioning and mood (Graham et al., 2017). The ACT techniques applied were: relational framing, defusion and mindfulness exercises. The authors propose third-wave CBT approaches may be useful to improve functioning as opposed to controlling or attempting to eradicate symptoms. The unknown aetiology of functional disorders makes symptom elimination a challenge.

Working psychologically with FMD may not be too dissimilar than working with other presentations that psychologist and psychotherapist may work with in the field of mental health or health psychology. In addition, clinicians may benefit from using the theories on bereavement models of loss, social identity theory, Erikson's psychosocial theory on identity development, the dual-process model of assimilative and accommodative coping and the CSM to guide their understanding and thinking when formulating and developing interventions. In addition, some participants were already using externalisation techniques and this reduced their experience of distress, therefore, a narrative approach to working with FMD could be useful.

Healthcare professionals in general. These findings have captured the essence of participants distress and experiences. Clinicians may experience an emotive reaction when reading these findings, for example, the multiple losses, and hatred of self have been stark findings. If these findings can elicit an emotional resonance with clinicians this may enhance their ability in perspective taking; and thus, their capacity to develop and maintain empathy and compassion which are fundamental skills to build a therapeutic relationship. Furthermore, these findings could be used as a clinical aid to provide a contextual understanding of living with FMD. In addition, using this study as a clinical aid may support clinicians to see beyond the physical symptoms and hold in mind the distress that comes with living with this condition and thus, working with people who have FMD is about considering both the physical and psychological impact. The findings demonstrated that some people can adapt to living with a chronic illness, in that, they can recalibrate their life and learn to accept their new self that has been born out of the context of illness. In comparison, some people still struggled to let go of what life was like before illness. They had not yet accepted their new identities and they were not content with their situation. It is important for services to consider that people will vary in how long it takes them to adapt and accept living with a chronic illness. Therefore, services would benefit from supporting patients with this process.

Patients. Another insightful finding was participants experiences of loneliness and isolation. There is a strong online presence of support groups (i.e.

Facebook group) but the face to face groups are limited. Within the region of Yorkshire where the research was carried out, I was only able to find one face-to-face support group and it was for people who experienced epilepsy and NES. NHS and third sector services may want to consider developing more local support groups that can be accessed more easily by patients. Neurology departments could provide them as part of the care pathway. Furthermore, these services could empower the patients to take ownership of these group with regards to facilitating and thinking about how such a group can be used. The development of support groups could function to promote social inclusion within what appears to be an isolated population. Furthermore, a group such as this could function where members learn from each other in how to manage and live with the condition. A key finding was the insight into how some of the participants felt better and they had a positive self-image whereas some of the participants did not feel better and appeared to still have a negative self-image. Third sector services and the NHS may benefit from developing a peer support scheme. This scheme could consist of mentors who are in a place of acceptance to support others in a variety of ways, for instance, during the consolation and diagnosis process or those who are struggling to adapt to living with the condition.

Future research

Future research has been identified on the basis of this study's findings.

The sample was predominantly white British, except for two participants who were British Indian. Unfortunately, the diversity of the sample was not wide enough to make a strong inference that the experiences of living with FMD is similar across the two cultures, although the findings suggested similarities between these two cultures. This study did not consider the impact of living with FMD from a systemic perspective. It would be interesting to see whether culture has an impact on living with the condition, in particular trying to understand the experiences of shame and embarrassment and loss of roles from a cultural perspective.

The sample was predominantly female. There may possibly be a gender difference within how males live with the condition, particularly in the here and now. An IPA study on males' experiences of living with condition would be a useful contribution to the evidence base. This wider pool of data on males' experiences would enable us to see whether there are some gender differences.

All the participants were recruited from the same Consultant Neurologist. Only having one recruiter may have impacted on the analysis. This recruiter is known to work within a positive diagnosis framework, therefore, if the sample had been recruited from different consultant neurologists, with different ways of working and viewpoints then it is possible the themes for the time period of 'diagnosis time' and 'here and now' may have been different. Future research may want to consider using more than one recruiter to see whether there would be any differences in the accounts.

The study did not attempt to explicitly explore people's experiences of relationships with others as this was not core to the research question. The findings did provide a limited and superficial insight into the impact of the condition on their relationship with others. The experience of living with FMD may impact on the quality of these relationships. A qualitative study could explore the impact of FMD on their relationships with others. The study could investigate the narrative of these relationships over time (for example, life before symptom onset, during symptom onset, diagnosis and treatment time and the here and now). This research may inform how this client group could be supported from a systematic perspective, especially as the MS evidence base is moving towards a systemic perspective. A meta-synthesis of MS found that the family is an important factor in identity reconstruction (Barker et al., 2014). It could be interesting to explore friends and families experiences of living with a person with a FMD. This information may support our understanding of why people with FMD fear negative judgement from others as well as provide some insight into both parties interpersonal experiences of living with a FMD. The Australian report on patients and carers experiences of FND found that FND had a significant impact on carers QoL as it impacted on their mental health, physical health (e.g. manually handling a wheelchair) and their ability to work (Gill, 2019). To my knowledge neither

quantitative or qualitative research has previously been completed on carers experiences, therefore, this appears to be a novel and valuable area of research.

Focus groups can be used to collect data in IPA research. It would be interesting to use a focus group to explore people's opinions of living with a FMD. This could be analysed using IPA or thematic analysis. A benefit of focus groups is that it enables one to explore the 'attitudes' and 'opinions' from a large group of people on one topic (Smith et al., 2009). I wonder whether bringing together a group of people who have a shared experience may enable access to a different set of experiences that may not otherwise present in a one to one interview. For example, during the interviews of this current study participants would sometimes say they "felt silly" when discussing their experiences. Being with others who may have similar experiences could provide a more validating environment and encourage the sharing of more detailed and reflective accounts. In addition, the group conversation is a back and forth process where people build upon each other's viewpoints and thus, this brainstorming may provide a higher level of thinking that produces a different set of results.

If the clinical recommendations are taken on by the workforce then there is potential for novel areas of research. Working in third wave CBT approaches could in the first instance be evidence through a case study, with the aim of slowly building the evidence base to demonstrate the need for RCT using third wave CBT approaches. Research could also look at the impact of support groups on people's psychological wellbeing. This could be a mixed method design. The qualitative component could explore people's experiences of the group and the quantitative component would consist of psychometric measures to explore change in participants psychological wellbeing. These could be administered at the start, middle and end of group.

Conclusion

This study explored people's experiences of living with FMD. Three themes emerged from the analysis. 'Unexpected and progressive loss' captured the participants experiences of multiple losses. They were distressed because they

lacked control over their body and living in body with limited motor functioning prevented them from functioning in everyday life. The barriers to living a meaningful life was experienced by participants as a loss of self. Some participants experienced others as not believing something was wrong and without a diagnosis trying to explain what was wrong was a frustrating experience. During this time they were trying to get a diagnosis but either unhelpful experiences with healthcare professionals or waiting a long time for a diagnosis led to further distress. 'False Dawns' captured participants positive experiences of receiving a diagnosis. Some of the participants who had a significantly delayed diagnosis struggled to live their old lives. The absence of a diagnosis and understanding of what was happening resulted in them fighting to get through the day. Participants welcomed the diagnosis and this resulted in positive affect. The therapeutic relationship between the doctor and patient during the diagnosis process also contributed to this positive affect. Unfortunately, participants felt that having a diagnosis did not change anything and they perceived treatment options to be unsuccessful and once again they experienced negative affect. 'Living with 'it'' captured how participants still experienced a loss of control of the body and the condition was still experienced as being separate to them. Some participants were not feeling better and still had a negative self-image and thus, it appeared they had not yet accepted living with the condition. Whereas others were feeling better and had a more positive self-image and thus, they appeared to have accepted living with the condition.

The findings from this study are consistent with qualitative research on neurological disorders (PD and MS) and medically unexplained conditions (CFS and NES). Furthermore, some of the findings from this study are consistent with the one of the qualitative studies (Epstein et al.,2019) and the mixed methods study (Gill, 2019) In addition, this study has also provided novel findings to the evidence on FMD.

The standalone novel contributions of this current study to the evidence base of FMD are:

Theme one: the conceptualisation of identity and the experience of shame and embarrassment associated with the new illness identities, the experience of perceiving themselves to be separate to the condition (external force), blaming themselves for being ill (before the diagnosis), the fear of losing one's mind (imagining the symptoms) and the belief others will judge them negatively.

Theme two: a timely and compassionate diagnosis may prevent people from thinking they are losing their mind. The participants who received a more timely diagnosis (within a year) did not go through this process of fighting the symptoms; therefore, a timely diagnosis may enable some patients to quickly transition and adjust to their new identities. The experience of a delayed diagnosis was a difficult and distressing experience for participants. Even though, gaining a diagnosis was a positive experience the sense participants made of this experience was nothing changed as the symptoms remained. The implications of working within a positive diagnostic framework resulted in positive affect during a distressing and desolate time.

Theme three: participants still experienced the symptoms to be something that was separate to them. The processes (compassion versus criticism and shame) involved as to whether a person can accept or not accept living with the condition are illustrated.

The findings have informed key clinical recommendations. The delivery of an early and accurate diagnosis and working within a positive diagnostic framework can have a significant impact on patient's wellbeing and reduce their distress during a difficult time. Services that worked in this approach offered patients a different experience compared to other services. Patients highly valued the experience of a genuine and warm therapeutic relationship and doctors that took their concerns seriously and acted accordingly (e.g. investigating the symptoms). It is imperative that services like these should continue and develop, as well other services adopting this way of practice, as FND are one of the most common presentation a neurologist will see. The findings indicate that working psychologically with this clinical group may not be too dissimilar to other presentations (e.g. mental health and chronic illness). Psychologist and

psychotherapist may benefit from using third wave CBT approaches (ACT and CFT). The findings demonstrated that some patients can adapt to living with a chronic illness, whereas for others this process takes longer. It is important for services to acknowledge that patients will vary in how long it takes them to adapt and accept living with FMD. Therefore, services would benefit from supporting patients with this process (e.g. psychological therapies). This clinical populations experiences of loneliness undoubtedly contributed to their distress, therefore, the NHS and third sector organisations should consider setting up more local support groups. The evidence base for FMD is still within its infancy and this study has highlighted areas of further research.

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List of Abbreviations

Abbreviations

FND: Functional Neurological Disorders
FMD: Functional Movement Disorders
PD: Parkinson's Disease
MS: Multiple Sclerosis
CFS: Chronic Fatigue Syndrome
NES: Non-epileptic seizures
QoL: Quality of Life
CBT: Cognitive Behavioural Therapy
RCT: Randomised Control Trial
ACT: Acceptance and Commitment Therapy
GT: Grounded Theory
IPA: Interpretative Phenomenological
Analysis
DA: Discourse Analysis
MDT: Multi-disciplinary team
CFT: Compassion Focused Therapy

Appendix A

Delivering a diagnosis of FND

Consultation Process	What you do
<i>General Approach</i>	<ul style="list-style-type: none">*Open questions: What are your main symptoms?*What are you concerned about?*Ask questions for clarification.*Neurological examination: “May I examine you to assess those symptoms further?” instead of “let’s have a quick look at that?”
<i>Discussing the diagnosis</i>	<ul style="list-style-type: none">*A positive affirmative diagnosis: say what it is “your symptoms and signs are consistent with a neurological condition called functional tremor”.*Reassure them this is a condition I am familiar with.* Explain briefly what this means “There is no physical abnormality of the brain or nerves, but the wrong messages are being sent, so the muscles are not functioning properly”.* Address their concerns directly: “I have done several tests today to rule out other conditions such as (substitute) and all these tests are normal. You do not have (substitute)”.*Address their expectations: “there is no need to do a scan”.*Signpost to more information.
<i>Clinic letter</i>	<ul style="list-style-type: none">*Brief explanation about pathophysiology: “The brain and nerves do not have a physical disease, but the brain sends the wrong signals to the hand”.*Give an example of improvement with distraction: “the brain signals are normal at times, especially when distracted, for example your tremor disappeared when you used the other hand”.*Be positive but realistic about prognosis.
<i>Reassure the patient</i>	<ul style="list-style-type: none">*I am not going to discharge you, I will keep you under my care while you are being treated.* Treatment: MDT approach of neurophysiotherapy and neuropsychology.*To re-train the brain and body to enable the correct signals to the muscles.*Explain they will be copied into the clinic letter and this will be their record of all the information as there is a lot to take in.

Adapted from Dr Alty’s training slides (Personal Correspondence)

Appendix B

Research invitation letter

Recruitment strand 1

Dr Jane Alty
Department of Neurology
F Floor
Martin Wing
Leeds General Infirmary
Great George Street
Leeds
LS1 3EX

[Patient Name and Address]

[Date]

Dear [patient name]

A new study is about to begin in our department looking at people's experiences of living with motor type Functional Neurological Disorders (mFNDs). I would like to invite you to take part in this study. You will be asked to take part in a one-off interview, lasting around one hour and 30 minutes. The interview will be face to face and will involve us talking about your experiences of mFND. The interview will be written up into a document (transcribed) and will not have any identifiable information about you.

There is little discussion of people's experiences of living with mFNDs in the medical literature. This means there are few resources to help medical professionals understand what it's like for their patients who live with an mFND. Your input could result in a better understanding of what it means for people who live with an mFND, and we hope this will inform healthcare practices and improve patient care.

I have enclosed an information sheet that explains the research and what will be involved if you wish to take part. There is no obligation for you to take part if you do not wish to. Your decision to take part or not, will not affect your medical care.

The researcher of this study is Mandip Dosanjh and she is a psychologist, at the University of Leeds. As you have shown interest in the research taking part in the department, Mandip Dosanjh will request your name and telephone number from the NHS neurology administrator, and give you a call soon after this appointment to discuss taking part in the study. During this call you can ask any questions that you may have.

Alternatively, if you are interested in taking part or would simply like to know more, then you can directly contact Mandip Dosanjh on email ummd@leeds.ac.uk or phone **07391 942713**. Her full contact details are on the information sheet. You can also contact Dr Alty's secretary to register your interest by phone **0113 3928118**. Dr Alty's secretary will then pass your details onto Mandip and who will then contact you.

Thank you for taking the time to read this.

Yours sincerely

Dr Jane Alty
Consultant Neurologist

RE: Recruitment strand 2

Dr Jane Alty
Department of Neurology
F Floor
Martin Wing
Leeds General Infirmary
Great George Street
Leeds
LS1 3EX

[Patient Name and Address]

[Date]

Dear [patient name]

A new study is about to begin in our department looking at people's experiences of living with motor type Functional Neurological Disorders (mFNDs). I would like to invite you to take part in this study. You will be asked to take part in a one-off interview, lasting around one hour and 30 minutes. The interview will be face to face and will involve us talking about your experiences of mFND. The interview will be written up into a document (transcribed) and will not have any identifiable information about you.

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The researcher of this study is Mandip Dosanjh and she is a psychologist, at the University of Leeds. If you are interested in taking part or would simply like to know more, then please contact Mandip Dosanjh on email ummd@leeds.ac.uk or phone **07391 942713**. Her full contact details are on the information sheet. You can also contact Dr Alty's secretary to register your interest by phone **0113 3928118**. Dr Alty's secretary will then pass your details onto Mandip and who will then contact you.

Thank you for taking the time to read this.

Yours sincerely

Dr Jane Alty
Consultant Neurologist

Appendix C

Participant information sheet

Project title: “What are the experiences of people living with functional neurological disorders (motor sub-type)?”

My name is Mandip and I am training to be a clinical psychologist at the University of Leeds. I would like to invite you to take part in a study on motor type Functional Neurological Disorders (mFNDs). Please take your time to read this information sheet. It will help you to understand why the project is being done and what it will involve, this will support your decision as to whether you take part in the study.

What is the purpose of the study?

There is little discussion of people’s experiences of living with a mFND (for example, functional weakness, functional tremor, functional dystonia and functional ticks) in the medical literature. This means there are few resources to help medical professionals understand what it’s like for their patients who live with a mFND. Your input could result in a better understanding of what it means for people who live with a mFND, and we hope this will inform healthcare practices and improve patient care.

Why have I been chosen?

Your consultant neurologist has sent you this letter because you have a mFND and they think you might be interested in taking part in this study. We aim to recruit around 6-10 people for this study.

Am I suitable for the study?

You can take part in this study if you’re aged 18+ years old, have a diagnosis of mFND (for example, functional weakness, functional tremor, functional dystonia and functional ticks), and have the capacity to consent.

Do I have to take part?

Taking part is voluntary and it is your decision whether you decide to take part or not. There is no time limit to make the decision; however, recruitment will close once recruitment numbers have been reached. If you come to the interview, you can change your mind and stop, at any time. If you like you can choose to have your data removed from the study even after you have completed the interview. If you wish to withdraw from the study, you can do so within a week of your interview, without any consequences to you. After this, the data would have been anonymised and sent to the transcription service, so it would be too late to get the data back. Withdrawing from the study will not affect your NHS medical care in any way.

What will it involve?

You will be invited to take part in a one-off interview. I will contact you to arrange a time and venue for the interview and you can ask me any questions about the study. On the day of the interview we will have a conversation to make sure you understand what taking part in the study involves and then you will be asked to sign a consent form to show that you agree to take part in the study.

We will then do the interview, which will involve us exploring your experiences of mFND. For example, we might talk about what your day to day life is like. I will then complete a short questionnaire with you and collect general information about you, such as demographic information (for example, age, gender), information about your health (for example, any physical health problems) and support networks. This information will be used to support the data analysis.

The interview will last around one hour and 30 minutes and it will be recorded using an dictaphone. The interview will either take place at the University of Leeds or the Neurology department at Leeds General Infirmary. If these venues are not suitable, we can consider an alternative venue. Other locations such as your home might be a possibility.

What will happen to the information I give?

Your audio data file will be transcribed so it can be analysed. The transcript will be anonymous and will not have any identifiable information about you. A professional transcription service will be used and they will sign a confidentiality agreement. Some of your anonymised quotations may appear in the report. To support data analysis the transcripts will be made available to the research team and peers on the course. All third parties are bound by professional's codes of confidentiality. Your personal details will not be passed onto any third parties.

Any paper notes will not personally identify you and will be locked away when not in use. All electronic files will be held on a secure server on the University of Leeds computer network and password protected. The only document that will have identifiable information about you is the consent form. The paper copy will be scanned and converted into an electronic document and then held on the secure university server, the paper copy will then be securely destroyed. Your contact details will be kept until the project has been completed; they will be held on the secure university server as an electronic document. After the project is complete, all research documentation will be given to the research department at the University of Leeds. All documents will be kept for three years and then securely destroyed.

What will happen to the results of the study?

The findings from this study will be written up as a thesis, which is an internal report that is written for a university qualification. The study may also be submitted to medical journals or presented at conferences. The report will be available in the University of Leeds Library

in 2019 and White Rose Etheses Online which holds electronic doctoral level theses. In any written work or presentation your identity will be anonymised, we will remove any names or events that could identify you. I can provide you with a short summary report of the study, if you would like this.

What are the possible benefits of taking part?

There are no guaranteed or immediate benefits of taking part in this study. However, some people may find talking about their experiences useful and interesting. For some, this can be a valuable experience, especially if they have not had any other opportunities to talk to others. Your participation could provide some important insight into mFNDs, which then could increase others' understanding of mFNDs and possibly inform healthcare practices.

What are the possible disadvantages of taking part?

You will need to give up some of your time to attend the interview. We do not think there will be any major risks or disadvantages experienced as a result of taking part in this study; however, there is a possibility that talking about your experiences could make you aware of the distress you might feel about living with mFND. In this event, you will be given the opportunity to take breaks or stop the interview at any time. You can also choose to not answer some of the questions.

Confidentiality

A limit to confidentiality; if the researcher is concerned that there is a risk to you or others, she may need to share this information with third parties and whenever possible you will be consulted first.

What next?

Your clinical team has told you about the study that is happening in the department. As you have shown interest in the study, the researcher of the study, Mandip Dosanjh will give you a call to discuss taking part in the study. Mandip Dosanjh will request your name and telephone number from the NHS neurology administrator. Mandip will be in private and confidential room when making the call. During this call you can ask any questions that you may have. Alternatively, you can also directly contact Mandip Dosanjh by either email or telephone to discuss taking part.

Once you have decided to take part in the study, I will then contact you, and we can arrange a time for the interview and you can ask me any questions that you may have. After the interview has taken place, you will be offered the choice of a **£20 love to shop voucher or £20 in cash** to compensate you for your time and any travel expenses.**How to make a complaint about the study**

If you have any concerns then please do contact the supervisors of this project; their details can be found below.

Transparency Information

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 3 years after the study has finished, until 2022.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The University of Leeds will collect information about you for this research study from either you or the neurology service that you attend. This information will include your name and contact details and your type of diagnosis, which is regarded as a special category of information. We will use this information for the sole purpose of the research study.

You can find out more about how we use your information, by visiting http://www.leeds.ac.uk/secretariat/data_protection.html

Contact details

If you have any other queries please contact Mandip Dosanjh.

Mandip Dosanjh (Researcher)

Email ummd@leeds.ac.uk / Tel: **07391 942713**

Supervisors of the project

Dr Christopher Graham (University Academic Fellow in Behavioural Medicine)

Email c.d.graham@leeds.ac.uk / Tel: 0113 34 33910

Dr Carol Martin (Clinical psychologist)

Email c.martin@leeds.ac.uk / Tel: 0113 34 30812

Thank you for taking the time to read this information.

Appendix D

Interview schedule guide

Introductions

- Thank them for taking part.
- Outline research aims and ask if they have any questions about the study.
- Explain confidentiality.
- Complete consent form.

Setting the scene questions

10. Can you tell me what interested you to take part in the study?

Topic Area: Life before mFND

11. What was life like before you had the condition mFND?

Prompts

- What were your relationships, work, interest/hobbies like?
- What was your day to day life like?
- How did you see yourself back then?
- How did you feel about yourself back then?
- How do you think others saw you back then?
- How did you see your future back then?

Topic Area: Getting the diagnosis

1. Can you please tell me about your story from the beginning?

1a. What did you **first notice**?

Prompts

- What were your symptoms like at this time?
- What was it like having these symptoms?
- What was going on at the time?
- What sense did you make of the symptom/symptoms?
- What did you do about it?
- How did you see yourself?
- How did you feel about yourself?
- What do you think others thought about you?

1b. When you started to have these symptoms what was going through your mind at time?

- What were your thoughts? How did you feel?
- What were you thinking about those symptoms?

- What was going on at the time in work, relationships, activities, life generally?
- How did the people in your life respond/understand/react to what you were going through?
- Good days and bad days; Did anything help? Did anything not help?

2. Tell me about **getting the diagnosis?**

(Choose an event; 'Can you tell me about...' e.g. getting tests and test results appointments with Doctors/Nurses).

Prompts

- What was that like, how did you feel, what did you think?
- When you were given a diagnosis what were you thinking and feeling?
- What were your symptoms like at this time? (What did you notice?)
- How have your experiences been with healthcare professionals?
- How have your good experiences differed from your more difficult experiences?
- How did the people in your life respond to you/understand the diagnosis?
- Good days and bad days; Did anything help? Did anything not help?

3. Can you tell me whether you received any treatment?

Prompts

- What did you think to your treatment?
- What were your symptoms like at this time? (What did you notice?)
- How did you feel about yourself?
- How did you see yourself?
- What did others think about the treatment?

Topic Area: Life after the diagnosis

4. Then what happened, what was life like **once you had received the diagnosis**, so the first 6 months?

Prompts

- How did you feel / think about the diagnosis?
- Did you notice any changes in your life?
- Work, relationships, activities, life generally?
- How did the people in your life respond/understand/react to what you were going through?
- What were your symptoms like at this time? (What did you notice?)
- Good days and bad days; Did anything help? Did anything not help?

5. So, what is life like **living with a mFND?**

Prompts- Negotiate a recent 'typical day'

- What is your day to day life like with this condition?
- What are your symptoms like now? How do you feel about your symptoms?
- Good days and bad days; what kind of things help you get through the day? What sort of things are helpful and not helpful and why?
- What's it like to go work, home, hobbies/interest, socialise, exercise, relationships, etc?
- How would you describe yourself now?
- How do you see yourself now?
- How do you feel about yourself now?
- How do you think others see you now?

6. What does having mFND mean to you?

Prompt; how do you feel about mFND?

7. What advice would you give someone who has been diagnosed?

Closing

Is there anything else that you think might be helpful for me to know?

What was the interview like?

Has anything surprised you?

General Prompts

- How do you think you have changed?
- How do you feel about yourself now/then?
- What do you think has been the biggest difference?
- How would you describe yourself now?
- How do you think other people see you now/then?
- How do you see yourself in the future?
- Change; self, life in general, lifestyle, relationships, work, education, independence
- Have you noticed any changes in your relationships since having the condition? What are your relationships like now?
- Has there been any difficult changes? If so, what has been the hardest change?
- Have you experienced any positive changes?

General prompts and probes: Can you tell me a bit more about that? Could you elaborate on that? Have I got that right? (summarising), how did you make sense of that? What were you thinking? How did you feel? What was important about that experience? What do you mean by? What happened next?

Appendix E Demographic information and other information

1. Age:.....
2. Gender:.....
3. Ethnicity:.....

4. Are you in employment?
Yes
No
If so, what is your job
.....
.....

If no, what are the reasons for this
.....
.....

5. When did you receive the diagnosis of functional neurological disorder (motor subtype)?
.....
.....

6. How long did it take to get the diagnosis?
.....
.....

7. Do you have any other physical health problems?

Yes Please state condition
No

8. Do you have a history of mental health problems?

Yes Please state condition
No

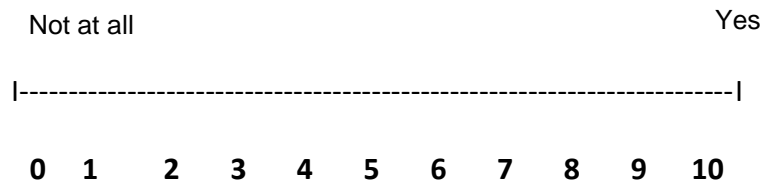
9. Are you currently experiencing any mental health problems?

Yes Please state condition
No

10. What is your marital status?

- Married
- In a relationship
- Single

11. Do you feel like you have a good network of social support from friends?



12. What are your current living circumstances?

- Live alone
- Live with family
- Live with partner
- Live with wife/husband

13. Do you access any of these services?

- Functional Neurological Disorder Charites
- Functional Neurological Disorder support group
- Other (Please state, e.g. blogging site)
-
-

Appendix F Informed consent form

Research Title: “What are the experiences of people living with functional neurological disorders (motor sub-type)?”

Lead Researcher: Mandip Dosanjh (Psychologist in Clinical Training)

Thank you for agreeing to take part in this study.

If you agree with the statement please tick the corresponding box.

I confirm that I have read and understand the information sheet for the above study.

I have been given the opportunity to ask questions about the study and the answers have been satisfactory.

I understand that my participation is voluntary and I agree to take part in the above study.

I am free to withdraw from attending the interview at any time and if I attend the interview I can withdraw my data one week after the interview. I am aware that I do not need to give an explanation if I wish to withdraw from the study and there will be no negative consequences.

I understand that the interview will be digitally recorded and then transcribed by a third party and they will adhere to a confidentiality policy. Also, the transcripts will be anonymous and my identity will be protected. I will remain anonymous in any future reports, publications or presentations.

I agree to my direct quotes being used for the purpose of the research and I understand that I will remain anonymous.

I understand that the electronic data collected will be securely stored on a university server and password protected. Hard data will be securely stored in a locked cabinet. I am aware of what will happen to my data after the study is complete.

I understand that members of the research team and peers will look at the anonymised transcript. I give my permission for these individuals to have access to my data.

I understand that if the researcher is concerned that there is a risk to myself or others, she may need to share this information with third parties. I understand that whenever possible I will be consulted first.

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from

Leeds university, from regulatory authorities or from the NHS Trust,
where it is relevant to my taking part in this research. I give permission
for these individuals to have access to my records.

I would like a brief summary of the report. I am happy to provide my address and I
understand that it is my responsibility to notify the researcher should I move
address.

Please provide your address for the report to be sent to

.....
.....
.....
.....

Participant's Name (Printed): _____

Participant's signature: _____

Date: _____

Researcher's Name (Printed): _____

Researcher's signature: _____

Date: _____

(To be signed and dated in presence of participant)

Appendix G Debrief sheet

Research Title: “What are the experiences of people living with functional neurological disorders (motor sub-type)?”

Thank you for participating as a research participant in the present study. If in the event you experience any distress from participation in this study, then we encourage you to seek support. There are a number of useful resources that may be of support:

If you are distressed and would like to contact someone outside of this study you can contact:

1. Your **GP**
2. **The Samaritans** (Leeds Service):

Local telephone: 0113 245 6789 (local call charges apply)

National telephone: 116 123 (this number is free to call)

Email Samaritans: jo@samaritans.org

Address: Samaritans Leeds, 93 Clarendon Road, Leeds, West Yorkshire, LS2 9LY

You might find Functional Neurological Disorders charities a useful resource

1. FND Hope: <https://fndhope.org/>, you can contact them using the ‘general contact form’ only available on their website
2. FND Action: <http://www.fndaction.org.uk/>, contact@fndaction.org.uk

How to make a complaint about the study

You can contact the supervisors of this project

Dr Christopher Graham (University Academic Fellow in Behavioural Medicine)

Email: c.d.graham@leeds.ac.uk / Tel: 0113 34 33910

Working days: Monday, Tuesday, Thursday, Friday

Dr Carol Martin (Clinical psychologist)

Email: c.martin@leeds.ac.uk / Tel: 0113 3430812

Working days: Wednesday, Thursday, Friday

Appendix H NHS approval letter



Miss Mandip Dosanjh
Clinical Psychology, Level 10,
Worsley Building, University of Leeds,
Clarendon Way,
LS2 9NL



Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

21 August 2018

Dear Miss Dosanjh

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: "What are the experiences of people living with functional neurological disorders (motor sub-type)? An Interpretative Phenomenological Analysis study."
IRAS project ID: 237944
Protocol number: Version 1
REC reference: 18/YH/0244
Sponsor: University of Leeds

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

Appendix I

Step by step guide to IPA (Smith, Flowers & Larkin 2009)

Stage	Process
1. Read and re-reading	Read and reread the transcript a number of times and become familiar with the account. Immerse self with data.
2. Initial noting	Examine semantic content and language use on an explanatory level. Note anything of interest or significance. Aim to produce a comprehensive and detailed set of notes on the data. Commentary will involve descriptive comments that is close to the participants explicit meaning and interpretative comments indicating the researchers understanding of how and why the participants has these concerns.
3. Developing emergent themes	A analytic shift to working with the initial notes and not the transcript. Analyse exploratory comments to identify emerging themes. To identify themes, a concise statement is needed to capture what is important in the various comments.
4. Searching for connections across emergent themes	Map how the themes may fit together. Develop 'super-ordinate' themes by clustering similar themes together. Also, extract oppositional relationships between emergent themes and identify contextual and functional elements within analysis. Produce a graphic representation of the emergent themes (e.g. table).
5. Moving to the next case	Repeat the process above with the other transcripts.
6. Looking for patterns across cases	Look for patterns across cases, by laying out each table of themes for each participant on a large surface. Then produce a table of themes for the group, illustrating how themes are nested within super-ordinate themes for each participant.

Appendix J Transcript extract of coding and interpretation

P1

1030

1031 P: umm ... [sighs] having everything on your

1032 plate and there's nothing much you can do. You just

1033 felt just sad that you just wanted to cry all the

1034 time, you know there wasn't ... it didn't matter

1035 how much you cried or how much you tried to

1036 forget it or you tried to change it or you tried to

1037 laugh at it, it didn't change. There was just,

1038 [sighs] I think you just start to give up. You just

1039 start to shut down and nothing's enjoyable

1040 anymore. Everything's just an effort and something

1041 else you have to do. And even my horses that were

1042 such a passion I became not interested anymore.

1043 Umm, just wanted to like sleep all the time in an

1044 effort to avoid ... thinking about it. Just to have

1045 a break. You just, I don't know ... I think you

1046 just, your whole life just becomes encompassed in

1047 trying to get away and not have, be in the situation

1048 anymore

Everything in your plate + nothing you can do

Sad

Can cry, but forget, laugh but nothing changes!

Start to give up

Shut down

No enjoyment, ongoing effort

No interest in horses

Want to sleep

Avoid anything = a break

Life about coping situation

Depressed

Everything better

Not interested in seeing is out!

What on plate?!

Very sad / awful

Nothing she does can change situation!

Helpless / Powerless

Feeling overwhelmed (big)

So give up! as no control of her life + turning things around.

Losing the use!

Like "start to shut down" -> trying to bring self to body

Very great since life keeps, feeling so gentle like able body + mind???

Loss of interests, horses, no passion, no identity, "not common!"

Learned to deal with strong life

Awful! Feeling so much, but difficult to see with a sleep!

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family

staying part

stuck in

alone

no one to talk to

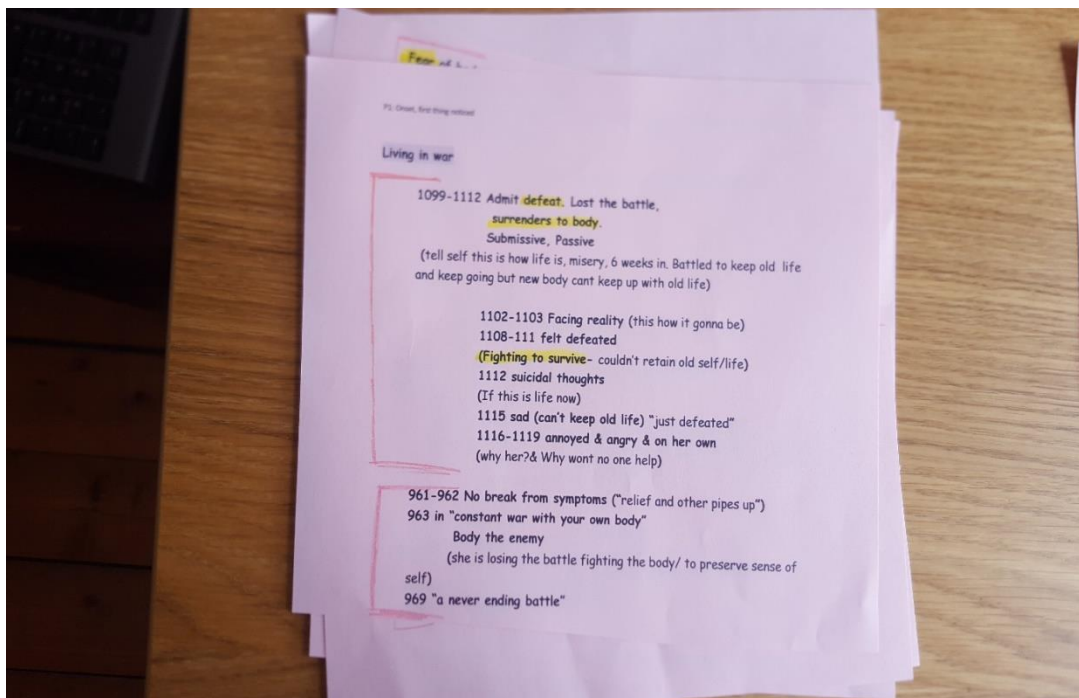
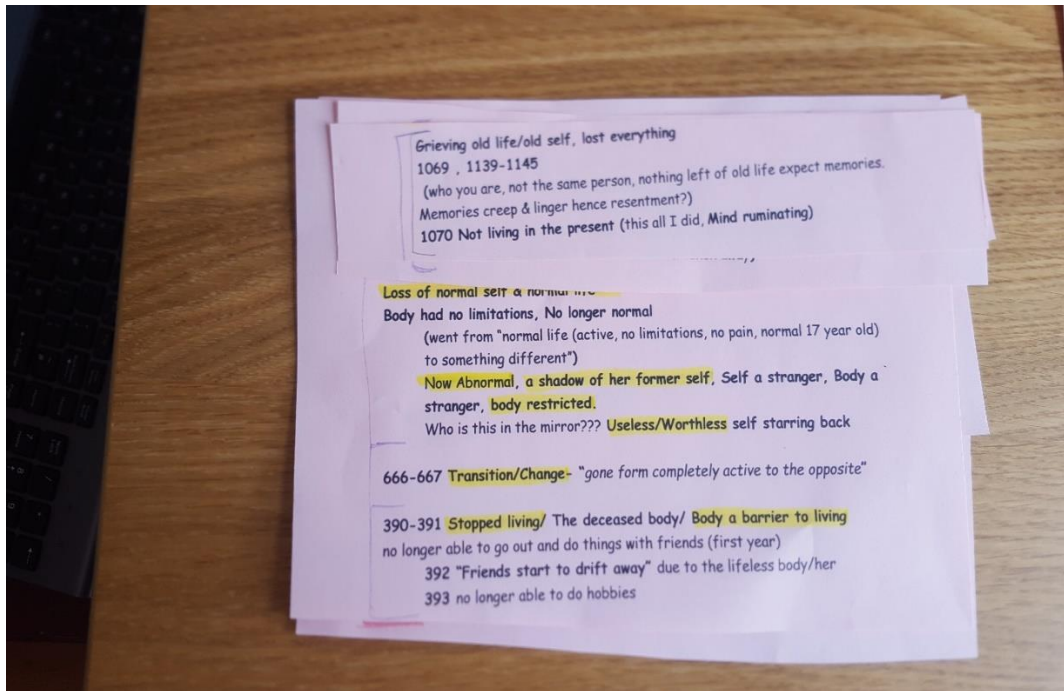
through door

questioning existence

division of others

you're

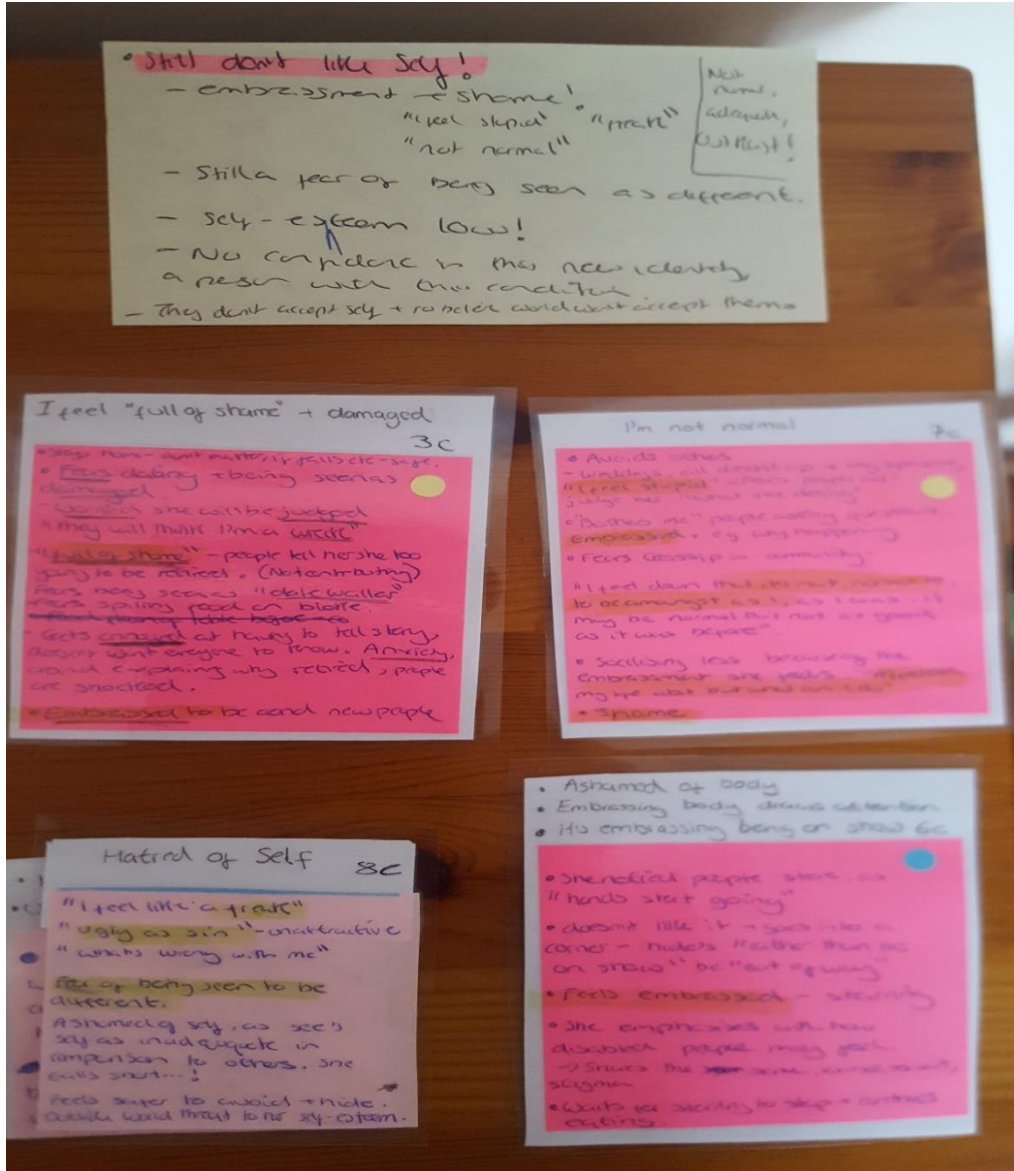
Appendix K Emerging themes



Appendix L Individual theme board



Appendix M The process of group analysis



Appendix N

Reflexive interview schedule

1) Why did you become interested in the condition functional neurological disorders?

- Since starting the interviews has your interests changed in anyway?

2) Why did you choose to recruit the participants the way that you did?

- What has gone well with recruitment?
- What has been difficulty about recruitment?
- Has there been any surprises about recruitment?

4) Tell me about each of your interviews?

- How were you feeling (before, during, after)?
- Can you tell me what was memorable about it?
- how did you feel about this interview?
- how did you feel about the interviewee?
- What did you learn from this interviewee?
- Did anything surprise you?
- Did you experience any difficulties during the interview?
 - how did you respond?
 - what was this like for you?
 - how did you feel about this?

-Can you summarise your experience of the conversation; including the bits that were not recorded and is there anything that you would like to share about your gut feelings?

8) Can you tell me what you thought about the condition and what you expected to hear from participants?

- how this has been in practice?
- have you been hearing differences in the accounts from your predictions? If so, can you put into words what you have discovered?

9) How have you found the experience of being a researcher interviewer, as your profession is a trainee clinical psychologist? any challenges, the difference and how have you managed these?

10) Can you tell me something about your process as an interviewer; and the skills or stances that you have developed as you become more experienced with research interviewing?

11) Have you had to do the interviews in different locations?

- have there been any challenges?

- have there been any benefits?

- how have you felt about the locations? Any preferences?

12) Before you start the IPA analysis, do you feel that you have gained any new understanding from the interviews?

- do you feel anything has changed in your understanding?

- what do you think has contributed to your change in understandings?

13) What are your thoughts and feelings with regards to the research process so far?

Analysis- Part 2 of interview (to be done after analysis)

14) how have you found doing the IPA on the interview data?

- Do you think it's a valid way of interpreting the data from the interviews and peoples reported experiences?

15) So, take a moment to consider the whole research process – Has conducting the research enabled you to learn anything about yourself?

- Do you think you been changed by this experience?