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FUNCTIONAL NEUROLOGICAL DISORDER: EXPLORATION INTO DIAGNOSIS, BELIEFS AND EXPERIENCES.

Section A: Investigating the role of illness beliefs in FND: How might this inform how we discuss the diagnosis with patients?

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Section B: Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.

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Summary of Major Research Project

Section A

This is a systematic review exploring the role of illness beliefs in Functional Neurological Diagnosis and how this may impact how the diagnosis is discussed. A narrative synthesis of 14 quantitative studies investigating illness beliefs in this patient group identified themes in relation to differences in FND relative to the general population, to other organic neurological disorders and differences depending on the nature of symptoms. Illness beliefs may be related to the diagnosis itself and the fact that there is an overreliance on psychological explanations which do not fit patients' experiences of symptoms. Interventions that focus on psychoeducation may help to improve patients' beliefs about their illness and their prognosis.

Section B

Increasing evidence points to patients' experiences of receiving a diagnosis of Functional Neurological Disorder (FND) as harmful. This study sought to explore what it is about receiving a diagnosis of FND that might be different to that of another similar neurological diagnosis, such as Multiple Sclerosis. Five FND participants and three MS participants were interviewed about their experiences of diagnosis and themes were developed using a Multiperspectival-Interpretive Phenomenological design. Similarities were observed initially, but divergence in experiences indicated the different impact of diagnosis on the two groups and how FND patients are left feeling blamed and stigmatised.

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Section A

A systematic review investigating the role of illness beliefs in FND: How might this inform how we discuss the diagnosis with patients?

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Abstract

Background: Functional Neurological Disorder (FND) is a condition characterised by neurological symptoms without the congruent pathology. It is a more prevalent diagnosis to fall under medically unexplained symptoms (MUS). The label itself can be experienced as stigmatising, which in turn can impact patient's engagement with services, treatments, and prognosis. Illness beliefs play an important role in how people relate to their diagnosis and how they manage. This has been explored in MUS, but less so in FND. This review aimed to summarise the research into illness beliefs in FND. **Method:** A systematic literature search was conducted, and 14 studies were selected that contained a quantitative measure of illness beliefs. These studies were assessed using quality appraisal tools and summarised using narrative synthesis. **Results:** Themes that emerged from the data included the efficacy of interventions on changing illness beliefs in this group, differences in illness beliefs between FND patients and the general population, differences between FND and organic neurological conditions, and differences depending on the nature of FND symptoms. **Discussion:** Differences were observed in patients with FND and this may relate to the diagnosis itself and the associated stigma. Interventions with a psychoeducation component may be able to target illness beliefs and in turn improve prognosis.

Introduction

Illness beliefs

Illness beliefs are an important phenomenon in health and are being recognised as a mediating factor in how people respond to a variety of conditions, as well as their longer-term prognosis (Petrie, et al. 2007). They reflect our cognitive representations of illness and conceptualise what it means to be healthy and what it means to be sick (Ogden, 1996). When illness occurs, these cognitive representations are accessed to make sense of the condition and whether it is manageable or threatening (Sawyer et al., 2019). Illness beliefs form a key part of models for health that predict consequential behaviours such as medication adherence, and psychological outcomes, such as quality of life (Dempster et al., 2015).

One such model is the Common Sense Model of illness behaviour (Leventhal, 1980), which stipulates that people go through three stages in response to a health threat: interpretation of the problem, coping, and appraisal of how successful coping is. Illness beliefs are an important part of this process and comprise of five main domains: identity, cause, timeline, consequences, and controllability (Leventhal et al., 2016). People's beliefs about how their illness is defined, what the perceived cause is, how long it will last, the potential impact and whether anything can be done about it, influence how they respond and their subsequent coping. Many studies have already highlighted the importance of patient's illness beliefs in primary care settings, within a range of health conditions. With evidence that they impact consultation satisfaction, future healthcare use (Frostholm et al., 2005) and treatment adherence (Falmer et al., 2006), as well as physical wellbeing (Treharne et al., 2005), and quality of life (French et al., 2005; Fowler & Bass, 2006). Illness beliefs can indicate how patients might react to investigations and to reassurance offered in consultation (Donkin et al., 2006).

Illness beliefs may also account for variance in causal attributions for symptoms experienced. Studies investigating causal attribution found that people with a history of mental health difficulties tend to use more psychological attributions, but where complaints were somatic without mental health comorbidities, then there was a reliance on organic attributions (Rief & Broadbent, 2007). Attributions are important because they are part of the cognitive constructs that inform the individual's understanding of their illness and how they experience symptoms. Taillefer et al. (2002) found that patients with chronic fatigue syndrome, who endorsed more physiological causes, also reported worse physical pain. It is possible that the lack of awareness of emotional processes may result in increased misattribution of physical symptoms or increased attentional processes. This is also evidenced in studies of alexithymia and impaired interoception (Demartini et al., 2014; Pick et al., 2020), where patients who struggle to characterise internal bodily states as emotions tend to report more physical causes and concerns. This is particularly relevant to functional/somatic conditions or illnesses which remain 'medically unexplained' where causes are not well defined, and the variance of causal attribution can greatly impact patient's engagement with health care and longer-term health outcomes.

Illness beliefs in functional/somatic illness

Medically Unexplained Symptoms (MUS) is a term given by clinicians that covers an increasing number of symptoms a patient experiences that do not appear to have a known cause. That is, patients' subjective experiences of symptoms that cannot be explained by physical pathology. Therefore, they are categorised under the term MUS despite the varied nature of the symptoms and experiences. The term itself is controversial and often a barrier to successful treatment as it refers to the patient's illness as not what it is, but rather what it is not (Creed et al., 2010).

Behind this label is a history of constructing psychological explanations for suffering (Kirmayer et al., 2004). Other terms in history have also been used to categorise symptoms that do not appear organic in origin, such as somatisation syndrome, functional neurological disorder, conversion disorder, and hysteria: which was a term favoured for centuries. The changing terms do not remove the ambiguity. The term MUS raises questions about what constitutes a medical explanation of symptoms. MUS implies that symptoms are either organic or not, which then is usually inferred to mean that the cause is psychological, when both can be true. Does this mean that medicine has nothing to offer the patient? Similarly, to the mind/body debate and the nature vs. nurture argument, this dualistic approach to health is becoming outdated. Psychological conditions such as depression are now understood to also be caused by chemical imbalance and alterations in neuronal function in the brain (Pitsillou et al., 2020). The environment can give rise to certain susceptibilities that may be genetically wired, and it is now understood that illness is determined by a combination of biological, psychological, and social factors (Creed et al., 2010).

MUS is not a specific disorder, but rather a medical predicament (Kirmayer et al., 2004), with approximately 50% of all new presentations to clinic, having at least one medically unexplained symptom (Nimnuan et al., 2001). Symptoms can be linked to many bodily systems and most specialities have their own MUS syndromes (Brown, 2007). Diagnosis of MUS is one of exclusion rather than inclusion, which is one of the major problems that contribute to over reliance of psychological explanations of symptoms. This is problematic because it assumes that MUS are exclusively psychological in origin, which cannot be inferred from the exclusion of organic disease alone. Diagnosis is further complicated by patients who may have an existing medical condition, but with symptoms that aren't typical of that condition or where disability exceeds that of which might be expected (Brown, 2007). This raises questions about the subjective nature of judgements made concerning expected

disability with a given illness. Other issues with judgements relate to the overlap between MUS and physical symptoms that are part of a broader psychiatric condition (Brown, 2007). Therefore, there is the potential to misdiagnose MUS if psychological symptoms, such as panic or depression, are not severe enough to meet formal diagnostic criteria (Brown, 2007).

As stated, there is an over reliance on psychological explanations where medical explanations fail. However, psychophysiological and sociophysiological factors may also account for symptomology in MUS (Kirmayer et al., 2004). The Biopsychosocial model already recognises the interaction of biological, psychological, and social factors in the cause and maintenance of illness and so may address the challenge of reconciling patient and doctor's perspectives in MUS (Guthrie, 2008). Cultural views are often neglected in medical explanations of illness and may be important to the individual and how they understand their symptoms. By exploring people's social and cultural worlds and linking this to physiological explanations of illness, we may succeed in capturing some of the nuance that is relevant to the individual. This emphasises the role of the person's environment and the relevant context that removes responsibility from the individual, which is often a consequence of purely psychological explanations (Robson & Lian, 2017).

The relevance of psycho-social and systemic factors has also been highlighted in studies of MUS and in shaping illness beliefs. Daniels et al. (2021) demonstrated that there was an increase in MUS presentations at A&E relating to experiences of shortness of breath during the COVID19 pandemic. Whilst the role of health anxiety cannot be ruled out, the context at the time may have influenced perceptions for people who had specific illness beliefs about their susceptibility and ability to cope with symptoms. Furthermore, evidence has shown that patients who had believed their illness to be due to lifestyle factors, were 40% less likely to receive a diagnosis of MUS (Nimnuan et al., 2001). Those with a diagnosis of MUS may be more likely to attribute their illness to physical causes.

Functional Neurological Disorder

One branch of MUS that is becoming more widely recognised is Functional Neurological Disorder (FND), which presents a growing dilemma for healthcare services. It is the umbrella term for functional neurological symptoms, which can relate to impairments of motor, sensory or cognitive functioning (Hallett et al., 2022). Much like other MUS conditions, it was considered to be psychological in origin, however, more recently there is growing acknowledgment that there is an interaction of psychological, perceptual, cognitive and biological processes at play.

Theories are now focusing more on 'how', rather than 'why' FND occurs, focusing more on understanding the pathophysiology (Demartini et al., 2014). Current models are now attempting to synthesis psychological, biological, and cognitive processes to understand how the body produces functional symptoms (Lowe & Gerloff, 2018). In this there is a role for beliefs and understanding how emotions are processed, particularly in relation to internal representations/predictions of sensory experiences and interoception. The Somatosensory Amplification Model (Barsky & Wyshak, 1990) suggests that there is an interoceptive hypervigilance in FND, whereby normal bodily sensations are misattributed to reflect illness or pain. Other models, such as the Integrative Cognitive Model (Brown & Reuber, 2016) emphasise the role of predictive processes in sensory awareness. This model refers to a hierarchical structure of output linking prior beliefs/experiences, cognitive processes and nervous system function in the perception of sensations. Within this system, information about the internal and external environment is combined with prior beliefs and stored representations to generate a hypothesis about a sensation which then forms part of the conscious awareness. Part of this process involves making a prediction about the sensation experienced based on the information collated at the different levels of this top-down process and from this there is always a prediction error. One of the goals of this hierarchical process

is to minimise prediction errors, i.e., the experience of unexpected sensations, and to use sensory information to make fewer prediction errors in the future.

In FND it is hypothesised that this prediction error is likely to be larger than in healthy controls due to abnormal interoception. Previous studies have highlighted the role of interoception in MUS (Flasinki et al., 2020), with suggestions that there are multiple levels at which it can falter and lead to the experience of physical symptoms, including the initial noticing of interoceptive signals and interoceptive accuracy, and then at later stages relating to the appraisal of interoceptive signals and response. There is also the notion that interoception interacts with prior beliefs to construct misrepresentations of physical symptoms (Lowe et al., 2008).

Whilst most models of FND describe the interaction of perceptual and cognitive processes, there is limited reference to what links them. The mechanisms through which psychological, social and biological factors interact to manifest functional symptoms is still yet to be understood in terms of the physiological embodiment of what are very real symptoms for these patients. This might be better understood from the perspective of illness beliefs, which, historically, have been ignored (Nimnuan et al., 2001). Illness beliefs reflect perceived vulnerability and coping and are therefore predictive of subjective complaints and how these are managed. Illness beliefs about the need for an external stimuli or cause may mean that in the absence of this, patients have a more internal focus and therefore perceive sensations as more intense.

Review rationale and aims

There is a breadth of research investigating illness beliefs in MUS more generally (McAndrew, et al., 2019), however, FND is now more widely recognised and represents an illness which is becoming more prevalent, impacts quality of life and is reflective of a

combination of psychological and physiological mechanisms. Despite this awareness, there is substantial stigma, which is perpetuated by patients' interactions with services. The result of stigma is that patients withdraw from services and do not receive appropriate treatment and difficulties are compounded (Foley et al., 2022; MacDuffie et al., 2020). Patients with FND are frequently interacting with services that invalidate their experience and blame them for their suffering (Nielsen et al., 2020), which has a significant impact on their illness beliefs (Wright, 2015) and can lead to poorer health outcomes (Sharpe et al., 2010).

To improve patient care, a balanced approach is required that addresses not just the symptoms, but also patient's beliefs about their illness and their specific needs (Creed et al., 2010). Understanding their illness beliefs may serve to bridge the gap between perception and experience, and help to understand their needs, which may facilitate treatment and recovery. Knowledge of people's illness beliefs involves understanding the subjective meaning they attribute to their experience of illness, which also presents an opportunity for validation, something which is often missing in this group. A more nuanced understanding of FND would take into account social and cultural factors at play which shape people's illness beliefs and have a role in their subjective experience of symptoms and ill health.

The aim of this review is to summarise the current research investigating illness beliefs in FND, to address this gap. In doing so, it is hoped we can gain a better understanding of this group's experiences and needs. This review may also provide a summary of evidence that will highlight future directions in how to support patients with FND so that both doctors and patients are satisfied.

Method

This systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) including the PRISMA checklist (Appendix A) (Page et al., 2021),

and is based on the methodology described by Grant and Booth (2009). Included studies conducted a quantitative analysis of illness beliefs, even if this was not the primary measure, and included a sample of people aged 16 years and over with a confirmed diagnosis of FND. Only studies published since 2010 were included as there has been a substantial drive in FND research during this timeframe (Perez et al., 2021) and this should also limit studies to the most relevant. Studies included information about the relationship between illness beliefs and the experience of having FND, that utilised a quantitative psychometric measure of illness beliefs. The rationale for the psychometric measure criterion is that narratives around illness beliefs can produce a breadth of responses that vary in both quantity and quality (Petrie et al. 2007). Full inclusion and exclusion criteria are detailed in Table 1.

Table 1

Inclusion/Exclusion Criteria

	Inclusion	**Exclusion**
Type of study	Quantitative studies that include a psychometrically-sound measure of illness beliefs, based on a theoretical model, in an FND population	Qualitative studies Review articles
Participants	Participants with a diagnosis of FND Participants over the age of 16 years	Participants without a diagnosis of FND Participants under the age of 16years
Origin	Studies from any country that are available in English	Studies not available in English
Publication years	Studies published since 2010	Studies published before 2010

Search Strategy

An extensive search was conducted using three databases: Web of Science, PsycInfo and Medline. FND is a heterogenous label, and there are various subtypes that were included in the search terms. These are listed in Table 2.

The search terms were used in conjunction with Boolean operators 'AND', 'AND/OR' and truncation was used to instruct the database to search for all forms of the words, e.g., Functional neuro* OR Functional motor* AND Illness perception*.

Table 2

Key word search terms

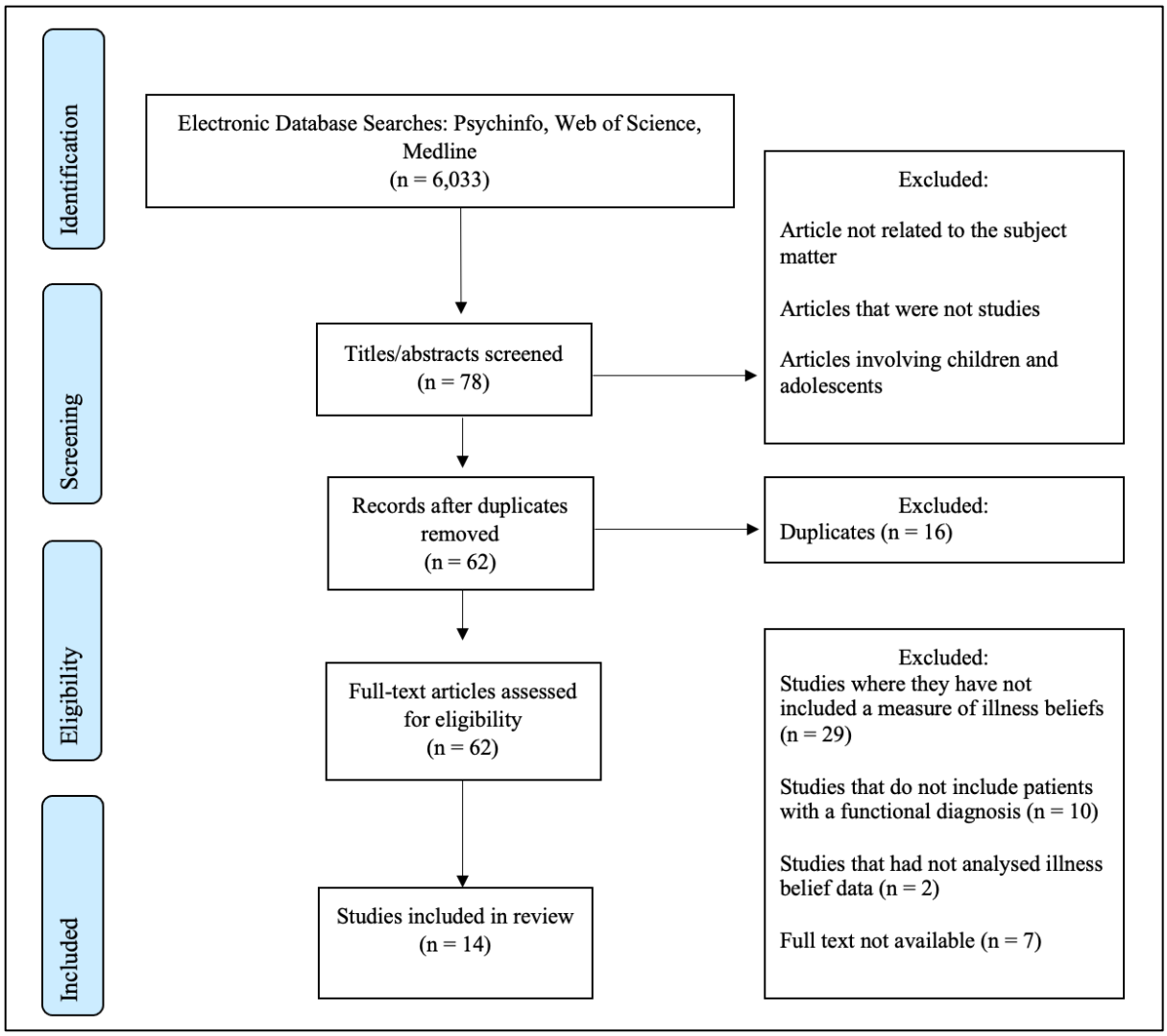
FND	Illness beliefs
FND	Illness perception*
Functional neuro*	Illness cognition*
Functional motor*	Illness representation*
Functional movement*	Illness belief*
Functional seizure*	
Non-epileptic seizure*	

Study selection and analysis

The search process and studies eliminated at each stage is detailed in Figure 1. Duplicates were removed and the study abstracts were assessed according to the inclusion/exclusion criteria. The full text publications were then reviewed and eligibility was reassessed. This process was completed independently by the main researcher. Reference lists of selected publications were also reviewed for any additional studies. This process produced 14 studies that met the full eligibility criteria and could be included in this review. Due to the breadth of studies included, they were analysed using 'narrative synthesis' (Popay et al., 2006). Narrative synthesis is particularly useful when statistical synthesis, such as a meta-analysis, is not possible (Campbell et al., 2018). As such, this review will aim to synthesise the findings and explore relationships in the data.

Figure 1

PRISMA Flowchart of search strategy



Quality Assessment

Following the selection process, each study was appraised using the quality appraisal tools from the National Heart, Lung, and Blood Institute (NIH, 2014) (Appendix B). Three tools were used: the tool for or Before-After (Pre-Post) Studies with No Control; the tool for Observational Cohort and Cross-Sectional Studies; and Quality Assessment of Case-Control Studies. Each one provided an overall rating of either Poor, Fair, or Good. Evaluation of the studies using these quality appraisals tools can be found in Appendix C.

Table 3

Summary of study characteristics

Study	Citation, Title & location	Design	Sample	Illness Beliefs Measure	Main findings
1	Baslet et al. (2022) *Sustained improvement with mindfulness-based therapy for psychogenic nonepileptic seizures* USA	Pre-post study design investigating the impact of a 12 week MBT treatment protocol on seizures and illness beliefs. Data were collected at 4 time points: T0 = diagnostic admission or first outpatient encounter T1= First follow-up after initial diagnosis T3 = End of MBT treatment T4 = 3–6-month follow-up	26 patients with video-EEG documented PNES – 14 attended follow-up at T4 Mean age = 46.6 Female = 88.5%	BIPQ Plus a 3-item questionnaire which included a question about illness attribution.	BIPQ scores post intervention were lower than at T0 and T1. The differences were significant, suggesting that illness perceptions improved following the MBT intervention. Illness attribution: There was a significant decrease in the perception of patients who attributed FND to purely physical causes between T0 and T3. There was a significant increase in patients who attributed causes to psychological factors between T0 and T3. Limitations included: - Convenience sampling - Small sample - Lack of control intervention - Attrition
2	Butler et al. (2021) *International online survey of 1048 individuals with*	Cross-sectional study investigating prevalence and patient's own experiences and perceptions.	1048 respondents to an online survey who answered yes to the question 'Have you been diagnosed with functional neurological	BIPQ Plus two free text questions on perceived causes.	Most respondents believed that FND has multiple causes, constituting both physical (65%) and psychological factors (60%) such as stress and trauma.

	functional neurological disorder UK		disorder by a medical professional?' Average age = 42.5 years Female = 86% 50.1% of respondents had more than 10 symptoms.		Most believed FND has a severe impact on their life and that symptoms would continue for a long time. Majority perceived little personal control over their symptoms and felt that treatment would not help. Most reported having many symptoms and high levels of concerns. Understanding of symptoms was mixed, but most felt that they had a significant emotional impact. Limitations: - Selection and response bias - Diagnosis was not clinically verified. - Heterogeneous sample
3	Chen et al. (2018) *Change in illness perception is associated with short-term seizure burden outcome following video-EEG confirmation of psychogenic nonepileptic seizures.* USA	Pre-post study investigating differences in seizure burden and illness perceptions following confirmation/explanation of functional seizures, compared to epilepsy. Data was collected at 3 time points: enrolment, 3 month follow up, and 6 months follow up.	72 patients diagnosed with PNES. Patients with PNES were split into two groups based on their score on whether they attributed their diagnosis to physical causes (n = 32; mean age = 50.9; gender = 75% male) or psychological causes (n= 40; mean age = 44.4; gender = 62.5% male).	BIPQ Five-point Symptom Attribution Scale (SA)	After PNES diagnosis, both the physical and psychological groups endorsed the same proportions of new mental health interventions, such as therapy and psychotropic medication. There was a greater proportion in both groups that endorsed psychotropic medication. The physical group was significantly more likely to have modified their symptom attribution towards psychological causes at the 3-month follow-up. They also perceived the impact on life to be less severe. At 6 months postdiagnosis, the physical group continued to be significantly more likely to have modified their symptom attribution psychological

			26 patients diagnosed with epileptic seizures (mean age = 51.7; gender = 80.8% male).		causes and consequences remained significantly less severe. The scores from all other items of the BIPQ did not demonstrate significant differences. Within the physical group, the change in attribution and consequence was positively correlated to improvement in seizure burden. Both the psychological group and the group with epilepsy showed no significant correlations between the extent of change in illness perception and improvement in seizure burden. Limitations: - Sample not representative - High attrition rate
4	Cope et al. (2017) *Evaluation of a pilot innovative cognitive-behavioral therapy-based psychoeducation group treatment for functional non-epileptic attacks.* UK	Pre-post study investigating the impact of 3 CBT-based psychoeducation group sessions on seizure frequency, illness beliefs and mood.	25 Patients diagnosed with Functional Non-Epileptic Attacks (FNEA). 64% aged between 26 and 45. Female = 84%	BIPQ	There were significant pre- to post-treatment differences on BIPQ items concerning beliefs about how long the illness will continue, the level of concerns, and understanding of illness. Effect sizes ranged from small to medium. Patients demonstrated increased acceptance and understanding of their FNEA illness at post-treatment. 40% of patients were reportedly seizure free at the end of the treatment group.

					Limitation: - No follow up data - Small sample - No control intervention - No comparison group - Attrition
5	Ludwig et al. (2015) *Differences in illness perceptions between patients with non-epileptic seizures and functional limb weakness* UK	Case control study. Comparison of illness perceptions.	Patients recruited through Neurology departments with the following diagnoses: functional weakness (n = 102), neurological disease causing limb weakness (n = 43), epilepsy (n = 34) or non-epileptic seizures (n = 40). Mean age/Female: FW = 39.1/79.4% NES = 37/62.5% ES = 33.2/79.4% NW = 39.2/82.6%	IPQ-R	Significant differences in perceptions between NES and FW in the following domains: - Greater endorsement of six psychological causes. - Agree with stress as a cause of illness. - Condition has great effect on patient and family. - Condition will have long duration. Both the functional groups tended to reject psychological explanations; FW patients rejected them more strongly. Both groups agreed the conditions had major consequences on their lives, but FW patients reported a lower effect on themselves and families. NES patients considered treatments to be more effective than FW patients. No differences between the functional groups in terms of perception of the duration (Timeline), control (Personal control) understanding of their condition (Illness Coherence) or the emotional impact (Emotional representation).

					Patients with Epilepsy estimated the degree of personal control as significantly lower than patients with NDLW. No other differences were found between Epilepsy and NDLW. Limitations: - Differences in symptoms severity and length of illness existed between functional groups. - Attrition
6	Rosales et al. (2020) *Cognitive-emotion processing in psychogenic nonepileptic seizures* USA	Cross-sectional study investigating cognitive-emotion processing of patients with functional seizures compared to normative data. And the association with illness beliefs.	143 adult patients with video electroencephalogram (v-EEG) confirmed PNES. Mean age = 29 Female = 83%	BIPQ	Patients with functional seizures were found to have a higher degree of cognitive-emotion processing deficits compared to the general population. Patients with more negative illness beliefs were more likely to have difficulties with emotional processing. Limitations: - No control group. Differences may be related to having a chronic illness.
7	Sarudiansky et al. (2020) *Report on a psychoeducational intervention for psychogenic non-epileptic seizures in Argentina*	Longitudinal pre-post study investigating the impact of a 3-session psychoeducation group in patients with functional seizures on seizure frequency, illness beliefs and mood.	12 patients with VEEG confirmed PNES . Mean age = 30.75 Female = 83.3%	BIPQ	Significant differences were found between pre and post intervention measures. Negative illness beliefs reduced post intervention. A large percentage of patients reported having a better understanding of their PNES and its causes (91.7%)

	Argentina				There wasn't a change in causal attributions, but most patients already attributed seizures to psychological causes. There was an overall reduction in seizure frequency after the intervention. Limitations: - Attrition - Small sample - No control intervention or group - No follow up measure
8	Sharpe et al. (2010) *Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict 1-year outcome* UK	Cohort study investigating patients' characteristics that predict poor health outcomes at 1 year post diagnosis.	716 Patients seen in a neurology clinic whose symptoms were deemed 'not at all' or only 'somewhat explained' by organic disease. Mean age = 46 Males = 32%	Two categories from the IPQ: Beliefs about recovery and cause.	Patients' beliefs in expectation of non-recovery and non-attribution of symptoms to psychological factors were strong independent predictors of poorer health outcomes. Limitations: - Attrition - Treatment was not accounted for - No control - Heterogeneous sample
9	Shipston-Sharman et al. (2022) *Prognosis in functional and recognised pathophysiological neurological*	Prospective cohort study investigating the differences in patients with FND and patients with an organic neurological illness and predictors of physical health outcomes at 3 and 12 months.	716 (63% of original sample) Patients attending neurology clinics and identified as having symptoms 'Not at all/Somewhat' caused by organic disease (functional).	IPQ	There was no significant differences between groups in perceived health outcomes at 12 months, with both reporting the same or worse symptoms. Negative expectation of recovery was significantly associated with same or worse physical outcomes in both groups.

	disorders-a shared basis UK		Mode age = 36-45 Female: n= 490 1865 patients (71%of original sample) identified as having symptoms 'Largely/Completely' caused by an 'organic' disease.		A lack of psychological attribution to the cause of symptoms was a predictor of same or worse physical outcomes in the functional group. FND patient has worse scores on measures of mood and these differences persisted. Limitations: - Attrition - Heterogenous groups
10	Stone et al. (2010) *The symptom of functional weakness: a controlled study of 107 patients* UK	Case control study investigating characteristics of patients with functional weakness, with a comparison to patients with weakness explained by organic disease.	107 Patients with functional weakness as referred by a neurologist. Mean age = 39.1 Female = 79% 46 patients with weakness explained by organic disease. Mean age = 39.3 Female = 83%	IPQ	Similarities were found across all domains except two: patients with functional weakness were less likely to believe that their illness was permanent and that their illness was a mystery. Functional patients were less likely to believe that stress was a cause and overall less likely to attribute to their symptoms to psychological causes,. 45% of patient with functional weakness believed their illness was due to an undiscovered physical cause. Limitations: - Attrition - Small sample
11	Tolchin et al. (2018)	Prospective cohort study investigating the adherence to psychiatric follow up in	123 patients diagnosed with documented PNES via video–	BIPQ	Lower score on the BIPQ was associated with non-adherence with psychiatric follow up at 17 months.

	Long-term adherence with psychiatric treatment among patients with psychogenic nonepileptic seizures USA	patients with functional seizures, 17 months after diagnosis.	electroencephalography (EEG) capture of typical seizure event. Mean age = 38 Female = 85%		Higher BIPQ score, signifying greater concern about one's illness, was associated with decreased odds of drop- out. Limitations: - Attrition - No comparison group - Treatments not accounted for
12	Whitehead et al. (2015) *Differences in relatives' and patients' illness perceptions in functional neurological symptom disorders compared with neurological diseases* UK	Case control matched pairs design comparing illness beliefs of patient and their relatives in patients with functional weakness and functional seizures, compared to patients with organic seizures and organic limb weakness.	112 Patients with FNSD (functional limb weakness and psychogenic non-epileptic seizures) and 60 patients with ND causing limb weakness and epilepsy, and their relatives.	IPQ-R Coherence and identity subscales excluded.	Relatives of patients with FNSD were significantly more likely to endorse psychological causes such as "stress" compared to patients. This difference was not found among patients with ND. Relatives of FNSD patients as a group still disagreed with psychological causation overall. There were four subscales which differed in the same direction for both FNSD and ND patients. Relatives of both FNSD and ND patients reported that the condition caused a greater emotional impact compared to patients. There was a trend towards both sets of relatives believing in a worse outlook (timeline) and greater negative consequences, but this was only significant for FNSD pairs. There was also a trend towards both FNSD and ND relatives believing patients had less control over symptoms compared to patients. There no differences between patients and relatives regardless of disorder for perceptions of treatment control and cyclical nature of the symptoms.

					Limitations: - Attrition
13	Williams et al. (2018) *Changes in emotion processing following brief augmented psychodynamic interpersonal therapy for functional neurological symptoms.* UK	Pre and post study investigating whether a psychodynamic intervention (BAPIT) would improve emotional processing in FND patients and whether this would be associated with changes in illness beliefs and other patient outcomes. Therapy duration was tailored to the patient's need, with a max of 20 sessions	44 Patients with Functional Neurological symptoms recruited consecutively from referrals to Neurology Psychotherapy Services. Mean age = 41.5 Female = 77.3%	BIPQ	There was an overall improvement in illness understanding post intervention. Findings did not show an association between emotional processing and illness beliefs, suggesting that better emotional processing did not improve patients understanding of their illness. Limitations: - Attrition - Lack of control group or comparison intervention - Lack of pre-treatment monitoring - No follow up data - Small sample
14	Wiseman et al., (2016) *A multicenter evaluation of a brief manualized psychoeducation intervention for psychogenic nonepileptic seizures*	Pre-post study investigating the impact of a psychoeducation intervention made up of four 1 hour sessions, on patients understanding of their illness, in patients with functional seizures.	19 Patients diagnosed with PNES, not necessarily through VEEG.	BIPQ Additional questions about symptom attribution	Improvement in illness perceptions post intervention, as well as other measure and seizure frequency. significant improvements in the understanding of the disorder There was an increase in the number of patients who attributed the cause to psychological factors from 26% to 42%, post treatment.

delivered by health professionals with limited experience in psychological treatment UK		Post treatment, none of the participants attributed their seizures to purely physical causes, compared to 13% prior. Limitations: - Attrition - Only low risk and less complex patients were chosen indicating selection bias - No control group or control intervention - Small sample - No follow up data

Results

Study characteristics

The selected studies are presented in Table 3. Of the 14 studies, nine were conducted in the UK, four in the USA, and one in Argentina. Six used a pre-post study design, three were case control studies, three were cohort studies, and two were cross-sectional studies.

Six of these studies investigated the impact of an intervention on illness beliefs; one using CBT (study 4), one using MBT (study 1), one using a psychodynamic intervention (study 13), two using a psychoeducation group (study 7 and 14), and one following diagnosis as a therapeutic tool (study 3).

Three studies investigated the differences in illness beliefs between groups. One study compared illness beliefs of patients with functional weakness and weakness explained by organic disease, as well as between functional seizures and epileptic seizures (study 5). Another study compared patients with functional weakness and weakness explained by organic disease (study 10). One study investigated the differences in functional (weakness and seizures) patient's illness beliefs compared to their relatives and did the same for patients with organic disease and their relatives (study 12).

One study investigated the prevalence of illness beliefs in patients with FND (study 2). Two studies investigated the association between emotional processing and illness beliefs (study 6 and 13) in patients with functional seizures. Two studies investigated whether illness beliefs were predictive of physical health outcomes, one in a cohort of FND patients (study 8) and the other in FND patients and patients with organic disease (study 9). A final study investigated the association between illness beliefs and adherence to psychiatric treatment follow up in patients with functional seizures (study 11).

Quality Assessment

Strengths

Of the 14 studies, four received an overall quality rating of 'Good', and eight received a rating of 'Fair' (Appendix C). This was based on guidance provided and does not follow specific rules but is based on judgement made about the potential for bias when answering each question. Each study used either the Brief Illness Perceptions Questionnaire (BIPQ; Broadbent et al., 2006) or the Illness Perceptions Questionnaire (IPQ; Weinman et al., 1996) (IPQ-R; Moss-Morris et al., 2002) as a measure of illness beliefs. Demographic information was available for all but two studies, with the majority showing similar rates of gender split with higher rates of female, and age range, which is also reflective of the population prevalence. Most studies investigated a specific subtype of FND, such as functional seizures or functional weakness, thus making their sample more homogeneous and generalisable. And all studies, but one, recruited patients though health services following a diagnosis made by professionals. For the studies investigating an intervention, all provided a manualised and consistent approach across participants, except one (study 13).

Illness beliefs are influenced by socio-cultural factors, and most studies included a comprehensive list of demographic information of their sample, including socio-economic status, Adverse Childhood Events, marriage status, and ethnicity.

Weaknesses

Four of the studies accounted for their small sample size and therefore increased risk of a type II error. None of the studies reported power calculations and therefore it was not possible to determine whether the samples were large enough to have confidence in the results. Blinding was not always possible due to the studies being observational, however,

studies that involved a comparison could have adopted blinding, but did not, increasing the risk of bias.

Of the six studies that investigated an intervention, none recruited a control. Some included a comparable treatment group, such as patients with weakness or seizures as a result of organic disease. However, none made comparisons to treatment-as-usual, meaning that it is difficult to conclude whether the changes in illness beliefs were due to the intervention, or to other factors such as being 'held' by a team or receiving medical attention.

Whilst most studies attempted to recruit a sample that was representative, one study (study 3) used a sample of veterans that were majority male, which is not reflective of the typical demographics in an FND population, again reducing generalisability. One study (study 2) also recruited participants based on whether they self-reported a diagnosis of FND, increasing the possibility that they may not in fact be representative of the sample required, and could be malingering or having another undiagnosed condition. This study also recruited through an online survey disseminated by FND charities, meaning that those recruited will have reflected a sample that is engaged in these organisations, but also those that are online. This sampling bias is also relevant for all studies that collect cross-sectional illness belief data, without an intervention. People that are more likely to engage in these studies are perhaps more motivated and possibly less symptomatic. For the studies that have investigated a psychological intervention, this may reflect a sample of patients who are more likely to endorse psychological causes for their illness, as well as beliefs about controllability and longevity, hence their willingness to participate.

The cross-sectional studies only took one measure of illness beliefs at one time point. Illness beliefs could fluctuate depending on symptom severity, particularly in a sample of patients with functional seizures who experience episodic symptoms. Differences in illness beliefs

may also be dependent on how long-ago patients first experienced symptoms and time between first symptom and diagnosis. Therefore, it is not possible to determine whether illness beliefs are a result of diagnosis or perhaps linked to experiences of diagnosis and trajectory of their illness.

Illness belief measures used in these studies were self-report questionnaires, introducing the possibility of response bias. Particularly, in FND, patients may be more likely to steer away from responses that indicate psychological causes or responses that are suggestive of stress and mental illness. This is because of the associated stigma in FND and the fact that many patients interact with professionals who tend to overemphasise psychological causes and mechanisms. (MacDuffie et al., 2020)

Finally, of the studies investigating the impact of an intervention, they all lacked follow-up data, which would indicate whether changes in illness beliefs were maintained over time. All studies experienced high rates of attrition from initial recruitment through to data collection and most did not analyse drop-out data. Therefore, it is possible that those who dropped out may have different illness beliefs that are not reflected in the studies.

Preliminary synthesis

Illness Beliefs in FND

All the studies highlighted more negative illness beliefs in FND as indicated by higher scores on the BIPQ and IPQ, relative to the wider population and to patients with organic disease. They also demonstrated more negative beliefs about consequences, timeline and controllability. Patients with FND were also more likely to reject psychological causes for their condition.

Other studies investigated the association between illness beliefs and physical health outcomes. Both study 8 and 9 found that illness beliefs were a strong predictor of poorer

health outcomes. In particular, negative beliefs about recovery and not acknowledging psychological causes were strong predictors of poor health outcomes.

Finally, studies 6 and 11 focus on the link between illness perceptions in patients with functional seizures and emotional processing and adherence to psychiatric follow up respectively. Study 6 suggests that negative illness beliefs were associated with reduced emotional processing, which is more commonly seen in FND patients compared to the general public. And study 11 found that patients were less likely to engage in psychiatric follow-up appointments if they had more negative illness beliefs.

Impact of interventions

Significant positive changes to illness beliefs were seen following interventions including MBT, CBT and a psychodynamic intervention. A common theme throughout was the impact of psychoeducation. This was further supported by studies whose intervention was purely psychoeducation (study 7 and 14).

Many studies found that patients also modified their illness attributions to endorse more psychological causes following an intervention, which in turn appeared to have an impact on how severe they believed the consequences of their illness to be.

This change was also correlated with better physical health outcomes. Patients with functional seizures reported less seizure burden (study 3) and less seizures overall, with study 4 reporting that 40% of patients were seizure free by the end of the intervention.

One possible explanation offered for the positive effects of interventions is that patients had a better understanding of their condition and its causes, as reported by study 7. Study 13 also investigated whether emotional processing was a variable in this change process and found that this had improved, but the changes were not found to be significantly correlated.

Differences between functional and organic disease

Many of the studies incorporated patients with organic neurological disease to make a comparison and to conclude whether illness beliefs were more negative in those with a functional condition, or whether simply having a 'neurological' condition, whether it is functional or organic, means that people are more likely to have negative illness beliefs.

Study 10 found that differences between patients with functional weakness and patients with weakness due to organic disease on illness beliefs related to timeline, understanding and cause. They found that functional patients were less likely to believe their illness was permanent and more likely to believe that their illness was a mystery. They also differed on beliefs about attribution, with the functional patients being less likely to agree with psychological causes.

Interesting study 3 found differences in patients with functional seizures and patients with epilepsy, but only if the functional patients attributed their seizures to physical causes. For the functional patients who endorsed psychological causes, there was no differences in illness beliefs or symptom burden compared to patients with epilepsy. This highlights that beliefs about causation may be the most influential factor in overall perceptions of disease and physical outcomes. This is further supported by study 9 which investigated the impact of illness beliefs on health outcomes in patients with FND and patients with organic disease and found that negative expectations were a significant predictor of poor outcomes in both groups, but that a lack of psychological attribution was only a significant predictor of poor outcomes in the functional group.

These differences in patients with functional symptoms and patients with symptoms due to organic disease were also noted in relatives of these groups, as evidenced in study 12. They found that relatives of patients with functional seizures were unlikely to endorse

psychological causes, but still more likely than the patients themselves. However, no other differences were found between relatives of patients with functional seizures and relatives of patients with organic disease.

Differences between motor symptoms and seizure

Only study 5 investigated the differences in illness beliefs between patients with functional weakness and patients with functional seizures, though a number of studies did recruit a sample with only one subtype. Study 5 found that there were significant differences in illness beliefs depending on the subtype of FND. Patients with functional weakness were more likely to reject psychological causes for their symptoms, compared to patients with functional seizures. They also reported fewer consequences of their illness for themselves and their relatives, and were less likely to think that treatment would be effective. They did not differ on any other domains of illness beliefs, such as timeline, personal control, understanding, and perceived emotional impact.

Discussion

Main Themes

This review included 14 studies that investigated illness beliefs in FND patients either as a primary objective or as an additional outcome measure. From these studies it is evident that illness beliefs in FND may be different to the wider population and tend to be more negative which can influence prognosis. This is supported by evidence of other MUS studies of illness beliefs (McAndrews et al., 2019), though it is difficult to determine whether these differences in illness beliefs predate diagnosis or whether it is the ambiguous diagnosis itself that causes illness beliefs to be more negative. Studies on the role of illness beliefs in hypochondriasis show differences that may not be a consequence of the illness itself, with this population believing that being healthy means being symptom-free (Rief & Broadbent, 2007). Therefore,

their threshold for perceiving illness is lower. This may also be true in patients with MUS, who are hypothesised to have high expectations of experiencing bodily pain or discomfort. These expectations can lead to a priming effect for subsequent sensations (Rief & Broadbent, 2007).

Differences in illness beliefs were also highlighted in this review between patients with motor symptoms and patients with seizures, further evidencing that FND is a heterogeneous group. As highlighted by the studies investigating this difference, it is possible that this reflects differences in severity, but also reflects the episodic nature of functional seizures as opposed to motor symptoms that may be constant. Patients with functional seizures were more likely to endorse psychological causes. This may also be because of the acknowledgment of psychological mechanisms in organic seizures, such as in epilepsy, in which stress may be a trigger (McKee & Privitera, 2017)

Furthermore, some studies included in this review demonstrated that illness beliefs can be altered by interventions, though it may not be the specific intervention that is most important, but rather the psychoeducation element that makes a difference. Evidence in studies of MUS has shown mixed results, particularly in relation to CBT, though this may be due to the wide variety of conditions placed within this label. A review by Jones & de C Williams (2019) investigating the impact of CBT found limited benefits in reducing healthcare use in people with MUS. Other studies looking at specific conditions demonstrated the efficacy of interventions, such as CBT in CFS (Malouff et al., 2008) and psychoeducation in fibromyalgia (Luciano et al., 2011).

Finally, this review found that illness beliefs, particularly relating to causation, are relevant to patients' other beliefs about timeline and consequences etc. and can predict physical outcomes. This supports evidence relating to illness beliefs in MUS generally, except with

regards to causal beliefs. A review by McAndrews et al. (2019) found that attribution of illness was not a significant predictor of physical outcomes from the synthesis of 23 studies. This highlights a uniqueness of FND compared to MUS generally.

Clinical Implications

This review demonstrates the importance of illness beliefs in patients with MUS. Healthcare services should be aware of the impact of this diagnostic limbo on patient's illness beliefs and be more curious about this to facilitate engagement in treatment and management techniques. Services could include psychoeducation at the point of diagnosis to support understanding and facilitate more positive illness beliefs around this condition. Efforts to reduce the stigma surrounding FND may also impact patients' illness beliefs. This would involve improving knowledge of health care professionals and increasing awareness of the combined pathology of psychological and physical mechanisms in FND so that patients are not having to adopt a defensive stance against psychological causes, which are often pushed by services. By attending to patients' illness beliefs this may support a more positive doctor-patient relationship (Dowrick et al., 2004) which can in turn impact how patients engage with services and can motivate adherence and support them to overcome conflicting illness beliefs (Yardley et al., 2001).

Research Implications

Future research could aim to address some of the study limitations highlighted previously, such as not having a control group or control intervention. More robust studies might also include longitudinal follow-up data to assess illness beliefs over time and to determine whether interventions have long-term efficacy. Future studies would also benefit from separating patients with functional weakness and patients with functional seizures given the apparent differences highlighted in this review. Including qualitative measures of illness

beliefs might also provide further insight into patient's beliefs that may not be better represented by structured and brief questionnaires. Finally, this review indicated mixed findings about the association between illness beliefs and emotional processing. Further investigation into the role of alexithymia and interception and how these correspond to people's illness beliefs may prove to be beneficial, particularly when developing future interventions.

Limitations of this review

As mentioned, this systematic review is not an exhaustive analysis of all the studies relating to illness beliefs in FND. The studies included also have their own limitations and so the conclusions drawn in this review are tentative. The reviewed studies all include a quantitative measure of illness beliefs, which is open to bias, but also may fail to capture the nuance of patients' beliefs. Finally, the methodology utilised in this review may itself be a limitation, as narrative synthesis is subject to bias in that the data are interpreted by the researcher. Links between data and the narrative synthesis may not be clear (Campbell et al., 2018).

Conclusions

This review aimed to synthesis studies investigating illness beliefs in FND. This was to better understand the role illness beliefs may play in FND, which is an increasingly prevalent condition, where patients' beliefs may be of significance due to the ambiguity and stigma around the diagnosis. The review highlighted the differences that exist in illness beliefs of patients with FND compared to other organic disorders and the general population. It also demonstrated a role for psychological interventions in supporting changes in illness beliefs which may facilitate better illness behaviours, that in turn improve prognosis. Future research could aim to provide more robust evidence of illness beliefs in FND and to explore patient's experiences further.

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Section B

Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.

Word Count: 7992 (475)

Abstract

Background: Functional Neurological Disorder (FND) presents as a dilemma for services. There is considerable stigma and uncertainty among professionals about how to treat this patient group, and interactions form a vicious cycle in which symptoms become exacerbated and patients disengage. Research demonstrates that patients are having negative experiences of diagnosis, which may be unique to FND, however why these experiences differ is not understood. The aim of this study is to explore FND patient experiences of diagnosis in comparison to Multiple Sclerosis (MS). Method: Five FND and three MS participants were recruited to take part in semi-structured interviews exploring their experiences of diagnosis. Interviews were analysed using a Multiperspectival-Interpretive Phenomenological Analysis design. Results: **Five** FND group themes were identified; 'Dehumanisation', 'Wanted answers', 'It is all in my head', I'm on my own', and 'Distrust in the NHS'. Six MS themes were identified; 'Uncertainty in the beginning', 'I wanted answers', 'It is a real physical condition', 'Feeling supported', 'The diagnosis was helpful', and 'Changing self-care'. Discussion: Themes highlighted that both groups started from a similar position but had very different experiences of diagnosis which led to a divergence and differences in emotional impact.

Introduction

Functional neurological disorder (FND) refers to a collection of neurological symptoms, that present similarly to other neurological disorders, such as stroke or epilepsy, but without the concurrent pathophysiology (Stephen et al., 2021). Symptoms can include limb weakness, gait difficulties, sensory symptoms, and dissociative seizure-like episodes. It presents more commonly in women (O'Connell et al., 2019), and across a wide age range from 10 to 50 years (Lidstone et al., 2022), with a higher prevalence observed in women who are married and have completed higher education (Butler et al., 2021).

FND is a more recent label under the umbrella of medically unexplained symptoms, representing conditions such as Functional Movement Disorder, and Functional Seizures. It can be complex to diagnose because it is not widely understood by professionals. FND has previously been dismissed as a psychological problem, despite significant physical disability. However, FND is now as common as other neurological conditions and has similar long-term effects to that of multiple sclerosis (MS) and Parkinson's disease (Cock et al., 2018).

Current concepts in FND

Historically, theories have focused on understanding what causes FND with an overreliance on psychological explanations, such as Adverse Childhood Experiences and stress, without much emphasis on physiological mechanisms. There is increasing awareness that not all patients with FND have experienced psychological trauma or stress. In fact, there is mixed evidence, with some studies finding no differences between FND patients and controls on self-reported trauma (O'Connell et al., 2019). Moreover, there is often a delayed presentation of FND relative to adverse experiences, with a lack of clarity regarding how these experiences become physiological symptoms (Espray et al., 2018).

Typically, neurological conditions are identified by observing structural changes in the brain. FND symptoms are now understood to occur via changes to the functioning of brain networks (Hallett et al., 2022; Aybek & Vuilleumier, 2016), with studies highlighting abnormal connectivity between prefrontal and sensorimotor areas, and the limbic system and basal ganglia, areas that are responsible for higher level executive functions, emotion processing and the control of movement (Foroughi et al., 2020). Patients with FND have also been found to have increased stress biomarkers and a dissociation between these biomarkers and perceived stress, compared to healthy controls (Apazoglou et al., 2017).

Diagnosis

FND represents a dilemma for healthcare services, with neurology, psychiatry and mental health services debating responsibility. This is in part due to beliefs about the psychological nature of the condition and that treatments tend to involve psychological interventions. Many professionals lack confidence in working with this patient group (Barnett et al., 2020) and often have concerns about misdiagnosis (LaFaver et al., 2020), despite evidence that FND is more commonly missed, than misdiagnosed (Walzl et al., 2019).

The Diagnostic and Statistical Manual of Mental Disorders, Volume 5 (DSM-5) (APA, 2022) lists FND under the bracket of Conversion Disorder, with diagnosis now based on the inclusion of one or more symptoms of altered motor and sensory function, while a psychological stressor is not necessary. Symptoms should not be explained by other physical or mental conditions and are often marked by incongruent observations and what neurologists describe as “positive signs” of FND. These clinical features, along with a detailed background history, are assessed to provide a positive diagnosis of FND, even when other organic diagnoses are present.

Rationale and aims for study

FND sits at the interface between physical and mental health services and understanding FND patients' experiences and how this is approached by Health Care Professionals (HCPs) is important due to the cyclical nature of these interactions. Studies have shown that HCPs are not aware of patient's subjective experience of their illness, or beliefs about their condition, and they rarely ask (Petrie et al., 2007**).** This is particularly problematic in FND, where the start of effective treatment is synonymous with how the diagnosis is explained (Carson et al., 2016). Furthermore, recent research highlights that FND patients describe unsatisfactory experiences of health care, which may impact negatively on them. For example, Nielsen et al. (2020) found that FND patients felt dissatisfied and misunderstood by HCPs, while a 2021 service evaluation, comparing FND and MS patient-experiences, described significant differences in patient care relating to diagnosis, treatment, HCP relationships and access to community services, with higher overall problem scores for FND patients across these domains (O'Keeffe et al., 2021). MS is a structural neurological condition that presents with similar symptoms and a similar impact on functioning and quality of life as FND (Walzl et al., 2022). However, due to the qualitative nature of these studies it is not clear whether dissatisfaction was linked specifically to the FND diagnosis, as reasons for the differences between FND and MS patient experiences are not fully explored. Being curious about how FND patient experiences differ from patients with structural neurological diagnoses, particularly in relation to emotional/psychological factors, could help to improve service delivery for this patient group and reduce iatrogenic harm (MacDuffie et al., 2020). This study aims to explore patient experiences of receiving an FND diagnosis in comparison to MS and whether the experiences of FND is unique to the diagnosis.

The specific questions to be addressed are:

A) How do people with FND and MS experience receiving a diagnosis?
B) What is the perceived emotional impact of receiving an FND diagnosis and how does this differ to MS?

The term 'FND participants' and 'MS participants' or 'FND patients' and 'MS patients' is used in this study to describe service users who have a diagnosis of either FND or MS. This is in line with the current literature and is the preferred terminology used by FND Hope (FND Hope: Functional Neurological Disorder, n.d.), a service user led charity for people with FND.

Methodology

Design

This study utilises a multiperspectival-Interpretive Phenomenological Analysis (m-IPA) design involving a heterogeneous sample to obtain diverse experiences of receiving a chronic neurological diagnosis. Patients with a diagnosis of FND and patients with a diagnosis of MS were recruited to participate in semi-structured interviews to explore their experiences of diagnosis, which could then be compared.

IPA was chosen to allow for a rich exploration of experience which would allow for the researcher to interpret information pertaining to the emotional impact of these diagnoses. The basis of IPA is to understand the individual's lived experience and internal world. The researcher is an active agent who consciously aims to attribute meaning to the participant's meaning making and how they make sense of their experiences (Smith & Osborn, 2015). It is especially useful when the topic of interest is complex and emotionally nuanced.

Whilst this method of analysis gives a rich and detailed account, it provides a one-dimensional perspective that relates to a specific phenomenon (Larkin et al., 2019); hence

participants are selected from a homogeneous group. However, this study explores patients' experiences of being diagnosed with FND and aims to find out whether this experience is unique to FND, through understanding differences in experiences and the emotional impact. A multiperspectival design allows for this investigation of more complex phenomena through differing perspectives.

Mutiperspectival-IPA design is becoming increasingly common, particularly as a way of addressing some of the limitations of a traditional IPA (tIPA), such that tIPA is a one-dimensional perspective, which has been criticised for not being able to reliably capture the complexity of a given phenomenon (Larkin et al., 2019). Such as with FND, understanding this phenomenon in isolation gives an account that cannot be deemed to be unique to FND unless explored in the context of illness and through comparison to another, similar diagnosis.

There is a tendency to utilise the mutiperpectival-IPA to analyse a dyad, e.g., the perspectives of a patient and their healthcare professional, which integrates a systemic approach. Other studies highlighted the benefits of exploring each participant's experiences separately, rather than as a dyad, which can influence the nature of the data collected (McInally & Gray-Brunton, 2021). By analysing each case separately and forming group themes without the dyad frame, this allows for a narrative without boundaries and means that the experiences can be explored at the individual and group levels before comparisons are drawn, thereby providing richness of data which also retains the focus on the phenomenon under investigation (i.e., the experience of FND). Rather than reducing this experience to what FND is simply relative to MS, the two groups are analysed and themes collated for each in order to capture the nuance that can exist for each.

Participants

Participants were recruited through two services in one large hospital trust in a major UK city. Five FND participants were recruited from a Level 1 tertiary rehabilitation service, who were referred from all over the UK. Three MS participants were recruited through another service for people with a neurological diagnosis who were receiving rehabilitation and under the care of an MS nurse specialist. The samples sizes were determined based on what is traditionally utilised in IPA. There is no specific minimum number required for sample size, and smaller samples are generally preferred as they allow for a reasonably homogenous group and an in-depth and detailed analysis of each individual (Noon, 2018). Participants were identified by the teams according to the inclusion/exclusion criteria detailed in Table 1.

The inclusion/exclusion criteria were developed to reduce differences between the groups and are reflective of prevalence in relation to gender and age group. Participants who had received their diagnosis less than one year prior to the study were excluded, due to the perceived psychological impact of receiving a diagnosis and that it may take time to process this. Participants who had received their diagnosis more than 10 years prior were also excluded to establish a cut-off point and because it was assumed that a diagnosis within the last 10 years may be more accurately recalled.

Table 1

Inclusion/Exclusion Criteria

Inclusion criteria	***Exclusion criteria***
Women aged between 20 and 45 years with a diagnosis of FND or MS, within 1 to 10 years.	Anyone under the age of 18 years. Anyone diagnosed less than 1 year ago. Co-morbid organic neurological disorders. Primary diagnosis of chronic fatigue syndrome or chronic pain.

	Mental health diagnoses other than anxiety disorders or depression. Memory or communication difficulties that may impact ability to engage in the study. Identified cognitive impairments and/or learning difficulties.

Details of the eight participants are included in Table 2. FND diagnosis has not been defined by subtype, as each participant had presented with more than one, including motor symptoms and seizures.

Table 2

Participant Information

Participant	1	2	3	4	5	6	7	8
Diagnosis	FND	FND	FND	FND	FND	MS	MS	MS
Age	29	39	23	26	20	41	35	39
Ethnicity	White British	White British	White British	White British	White British	White British	Black British	Asian British
Year first noticed symptoms	2009	2018	2011	2018	2012	2016	2007	2011
Year Diagnosed	2014	2019	2019	2018	2017	2017	2012	2016
Comorbid Physical Health Conditions	Yes	No	Yes	No	No	Yes	No	No
Mental Health Conditions	None	Anxiety Depression	Anxiety Depression	Anxiety	Depression	Anxiety	None	None
Developmental Diagnoses	None	None	Autism	None	Autism	None	None	None

Interview Schedule

A semi-structured interview schedule (Appendix D) was developed based on some of the themes highlighted by previous studies (Nielsen et al., 2020; O'Keeffe et al., 2021), followed by consultation with a service user expert who was active in FND charities. Four domains were identified: a) first noticing change and seeking support; b) diagnosis; c) episodes of treatment/support; and d) long-term impact. Prompting questions for each domain were designed to facilitate and guide the interview if appropriate. The aim of the semi-structured interview in IPA is to be flexible and person-centred to create the right conditions for the individual's lived experience to emerge (Alase, 2017). The schedule was a guide that allowed avenues of questioning to change according to participants' responses (Noon, 2018).

Procedure

Once the recruiting teams had identified potential participants, they shared a copy of the recruitment poster (Appendix E) and the Participant Information Sheet (PIS) (Appendix F). If interested, verbal consent was sought to share their contact details with the researcher and an initial call was made to go through the details of the study, check eligibility, answer questions, and book the study interview.

Interviews were offered either face-to-face or virtually on Microsoft teams. All participants opted for virtual interviews. After the initial screening phone call, participants were sent the PIS again and Consent form (Appendix G). Participants' consent was accepted through email confirmation and verbally at the time of their interviews and they were sent a link to attend the virtual appointment. All participants consented to recording and interviews were allocated up to 90 minutes, though most were an hour long.

Ethical Considerations

Participants were asked whether there were any practical limitations or adjustments needed for the virtual appointment. All recorded interviews were transcribed and anonymised to retain confidentiality. Data was stored securely and electronically with password protection.

Ethical approval was obtained through the NHS Integrated Research Application System (IRAS) (Appendix H) and access was granted by the host trust (Appendix I). Participation was voluntary and with requirement to opt in. The research procedure was fully disclosed in the PIS including potential risks, and full consent was obtained.

Confidentiality was explained, as well as the exceptions around this in relation to risk. Participants were informed that their involvement would not impact any treatment or waitlist status and no information would be fed back to their health care team. All participants were made aware that they could opt out at any time.

It was made explicit that the study would involve retelling experiences that may cause distress. Information about who to contact in the event of distress was provided. During the initial phone call, participants were also made aware that there is a risk of fatigue, which could result in the worsening of symptoms experienced.

Analysis

The method of analysis conducted in this study was in line with the IPA protocol set out by Smith et al. (2009), which involves 6 steps: Reading and re-reading the transcripts; initial annotations; developing emergent themes; grouping themes; moving to the next case; and looking for patterns across cases. For the multiperspectival analysis, an additional step was

conducted to identify connections and divergence between the FND group themes and MS group themes.

Reflexivity and Quality Assurance

The researcher is an active agent in the process of IPA (Smith et al., 2009) and is making interpretations about the participant's experiences and the meaning they apply to this, through their own lens. The researcher should consider their own beliefs and biases that influence these interpretations. As such, a reflective diary was kept by the researcher (Appendix J). Excerpts of three randomly selected transcripts (Appendix K, L, M) were sent to the Research Supervisor and to the Principal Investigator for review to ensure consistency in interpretations and themes drawn.

Results

The analysis of each group is presented separately, to allow for comparisons to be made. From the analysis, five FND and six MS group themes were identified. Each theme is presented in detail including the interpretation of the participant's experiences and how this relates to the theme, as well as examples from the interviews.

FND Themes

Table 3 details the five FND group themes and the number of participants who reflected each theme.

Table 3

FND Group Themes

Superordinate Themes	Subthemes	Number of participants contributing to theme (Total = 5)
1) Dehumanisation	Feeling disconnected	5

	They didn't care	5
	It was traumatic	4
2) Wanted answers	The label is meaningless	5
	No one knows	5
3) It's all in my head	It's not real	4
	I'm the problem	5
	I must be crazy	3
4) I'm on my own	Have to rely on myself	5
	Don't ask for help	3
5) Distrust in the NHS	They only see FND	4
	What's the point	5
	They weren't transparent	4

1) Dehumanisation

In their stories, participants described what was felt to be an experience of dehumanisation. This was reflected in the lack of humanity and care, as well as harm, that was present in a number of subthemes.

Feeling disconnected

This subtheme reflects the way in which participants described having to disconnect themselves from the condition. This included disconnecting from parts of their body that were affected and dissociating the condition from their sense of self.

"I feel like me and FND are two different people." P1

This appeared to come from a place of unsafety, as though the condition and all things involved were harmful. It also portrayed a lack of understanding about the condition, as though it did not 'fit'.

"...It felt much more like a like a science experiment than, like my body, and I'd had to detach quite a lot from it during those traumatic situations to keep myself safe." P3

Perhaps this reflected the way in which interactions made them feel, as though they themselves are the condition, particularly when being told that this is in their head and something that they are doing.

They didn't care

This subtheme reflects an overall feeling that services and professionals did not care about them as individuals or their experience. Therefore, leaving them feeling neglected by those that are seen to perhaps have a responsibility to care and that their condition was not taken seriously.

"They were just sort of really like, blasé about it. But oh it's just FND. Like, give her some diazepam and send her home." P2

This was further exacerbated by a tendency to want to study them rather than help them. Participants reflected on experiences in which they were an object of interest, rather than reflecting the experience of being a patient and receiving care.

"…they put me in the studies… …like I'd be interesting for their research" P1

"They didn't support me and and it was just like they just they just want to send me home. Uh, and they didn't return our calls. It was. It was a very difficult time." P3

Participants shared feeling lost and alone, that the FND was their problem alone to deal with and there was no one to help.

"Where do I go, if no one is qualified to deal with me and my FND then who's gonna help me?" P1

The feeling of being rejected and abandoned was prominent throughout. Participants reflected on being sent home without support, as well as being repeatedly passed between professionals. The way participants referred to HCPs indicated a lack of connection perhaps due to the inconsistency in HCPs and not having the opportunity to build rapport. Having to undergo repeated investigations may also have reduced their confidence in HCPs and maintained uncertainty.

"I was constantly under somebody who was doing more tests." P4

It was traumatic

Participants shared similar experiences of undergoing lots of investigations and being told that there was nothing wrong. Then when they were given a diagnosis, this did not lead to any answers or treatment, and instead implicated them in the cause. As such most participants reflected on the trauma that was caused by this process, including harm and the loss.

Each participant had a long journey from initial symptoms to receiving a diagnosis. Throughout this process their symptoms varied and worsened. Participants spoke of the harm caused by not being believed. They felt that their condition had been exacerbated by, and even caused by, services, shifting the blame from them to HCPs and reflecting iatrogenic harm.

"…they've ruined so many bits of me." P1

"They thought a lot of my trauma was down to not being listened to in hospital and I think that's all. I was pretty angry about that really." P2

"This wasn't happening to me before you started messing with my body." P3.

There was a powerful sense of loss and grief. Participants reflected on how the process had changed them, changed their circumstances, and changed how they saw themselves.

"…I lost absolutely everything. I was a fairly bright, fairly confident woman, and now I can't write more than a sentence." P1

There was an overall sense of loss of identity and 'becoming the condition'. This was reflected in experiences of others only seeing FND and participants not feeling cared about as a person. FND had taken over and consumed who they were.

"... there's some days where can sort of get engulfed in the, in the diagnosis and get wrapped up in it, and then feel like I am FND." P4

2) I wanted answers

Participants expressed wanting to get better and a desire to have answers and understand what was wrong. However, they were given a diagnosis without an explanation, leaving them unable to make sense of their condition.

The label is meaningless

This subtheme reflects the lack of resolution experienced following the diagnosis, thereby maintaining uncertainty about their condition. Participants' experiences reflected a lack of explanation.

"They didn't say anything about what it was or what caused it. That just told us that they could teach me how to walk again." P3

Participant 2 described being given a diagnosis based on an observation of the pattern of her movements. It was not explained how this observation connected to her experience. Therefore, this lack of alignment between experience and diagnosis perhaps left participants feeling misunderstood and doubting their diagnosis.

"...they said that it was FND because... the movements were distractible now. But they didn't really. They didn't really explain." P2

Participants also described hearing that FND was linked to previous experiences of emotional trauma, which they did not identify with. This may have led to further confusion and disconnect with the diagnosis, particularly given the extreme physical nature of their symptoms.

"Because I just, I just didn't understand how I could be so unwell and how it just not be serious." P2

Participants experiences reflected the arbitrary nature of the term, 'FND'.

"...my connection to the word FND is I've got no, like cool whatever you decide and next is it's TMZ." P1

Participant 3 described feeling hopeful when initially given the label, but that this was misleading because it gave the impression of something understood and known.

"So we kind of were lulled a bit into full sense of security that that everyone would kind of know and accept, that we were kind of like oh, this is a disorder." P3

No one knows

Participants described multiple situations in which they met HCPs who did not understand their symptoms or had not heard of FND, leading to reduced confidence in HCPs and greater fear and anxiety about their condition. There was a sense that the HCPs should know about this as a health condition. Therefore, their lack of knowledge appeared to impact the participants' beliefs about progression and recovery.

"He was just really expressing into it like it shouldn't be this way, and then after that you're then getting a bit worried thinking well if they're thinking this, what should I be thinking." P4

Even when participants spoke about meeting with more experienced HCPs, they expressed still being met with uncertainty, which may have increased doubts about the diagnosis.

"I was initially seen by somebody, and remember really specifically being seen by a consultant and him looking very stressed… And he went, got the head of the department and then got more doctors and more doctors." P1

This sense of no one knowing reflected feelings of hopelessness. Participants expressed hopes of getting better through receiving a diagnosis and treatment. Instead, they received a diagnosis without any subsequent treatment or hope for recovery. Their expectations were not met, and they deteriorated rather than recovered.

"It was frustrating because I wanted the answer to be "it's this and we'll give you these drugs" or we'll do this or, you know." P2

"Because that progressively get worse and it ended up getting worse, for me and… So, it was just a real let down." P5

3) It's all in my head

Throughout the interviews participants shared a feeling that there was an implicit and explicit message that their experiences were in their head. This sense that the problem was psychological rather than physical was captured across three subthemes.

It's not real

This subtheme refers to the participant's having their experience invalidated. This occurred both before and after the diagnosis was given. Participants described being told there was nothing wrong with them, thereby contradicting their experience and communicating that it is not real.

"The hospital were just like, no, you're gonna have to go home. You're fine. We can't find anything…" P5

I'm the problem

This subtheme represents the blame that was felt. Not only did participants describe having their experience denied, but also expressed that they were left feeling responsible for being unwell, that it was their fault.

"But now you've made it my fault that I'm paralyzed. It's my fault and everybody else's lives are affected because it's my fault I'm paralyzed." P1

This was reflected in discussions about cause and about management. Particularly where there was a focus on psychological mechanisms which left them feeling they should have some control.

"... it made it feel like it was me, causing it and that it was more of a mental health issue then a neurological condition." P4

"...it was like, you have to believe you have FND or you won't get better." P2

I must be crazy

With repeated emphasis on the psychological aspects of FND and repeated references to trauma, participants described internalising the blame for their condition and ideas about themselves as crazy. This projective identification led to further feelings of shame. Shame that they had done this to themselves, and shame linked to the stigma of it being a mental health problem rather than a physical condition.

"Because the embarrassment of being crazy is so much worse than the embarrassment of being ill." P1

"I felt like a little bit crazy, like I was like somehow making myself do it when I didn't feel like I was like I could cause I was like, how else can this like happen?" P3

4) I'm on my own

This theme summarises the experiences of participants feeling alone and isolated. Despite seeking support and being under the care of services. They often expressed feeling they weren't being supported and were having to take on responsibility for themselves.

Have to rely on myself

There was a sense that responsibility to get better was on them, signifying a battle that they were embarking on alone.

Participants shared having to do things for themselves, which felt more significant than self-management, but was expressive of a defensive independence and an acceptance that they would not get help elsewhere.

"So I'm slowly like, rehabilitating myself into life, basically." P2

"So I went and bought a wheelchair." P5

To understand FND, participants described having to gather this knowledge themselves. There was the sense that if HCPs didn't know, then they had to figure it out for themselves.

"…it kind of felt like we had to become more of their experts on it and do and do our own research." P3

Don't ask for help

Following their experiences, participants were certain that they would not be likely to ask for help again. This felt to be an avoidance of support seeking due to fears of repeating previous bad experiences. That to re-enter services would be to start another battle or would be seen as making a fuss and that they would be left feeling rejected again.

"It now takes me months to go and build up the courage to just ring the doctors…but don't worry if like you don't want to do it, like I totally understand, sort of thing." P5

5) Distrust in the NHS

This final theme reflected how the participants viewed the NHS after their experience, and the relationship they have to health care now. They described losing trust in the NHS and feeling that they could no longer go to them for support.

They only see FND

This subtheme captures participant's experiences of no longer feeling seen by HCPs. That once they were given the diagnosis, this was all that was seen, not them as an individual. Even when participants described having symptoms that they perceived as unrelated to their diagnosis, they felt this was disregarded by HCPs, leaving them not feeling seen or heard.

"...I hate the word FND now. I just I hate it cause It feels like you just have this big label attached to you and you go to A&E and everything gets associated with that name now umm." P4

Participants experienced having the stigma of FND transferred onto them, being made to feel like they are to be avoided.

"I've got a massive stigma about FND every single department I've been in in every way. It's doesn't want to play with that FND so initially they, if I'd said I had FND you crazy and now it's oh my God, we don't wanna touch it." P1

They weren't transparent

Another feeling was that services had not been open or honest. Participants described interactions with HCPs in which they were left doubting transparency leading to feelings of being deceived and reduced confidence in HCPs.

"That was later…he told me that he actually had no idea what it did. At the time he spoke with confidence as he should do, as a doctor would." P1

"With the push he said…probably be able to go back to work in a few months. I don't think he really believed that." P2

What's the point?

Participants described no longer trusting services to act or to provide something helpful. Experiences may have led to a cost-benefit analysis of weighing up the value of seeking support versus having further negative experiences. Most participants had concluded that it was not worth it, which translated into an ambivalence of wanting to get better but not trusting the process.

"I'm not really sure that I trust NHS. I'm not sure. I think they just gonna tell me I'm crazy again. They're just gonna tell me it's my fault because they did say that that you're crazy." P1

"Nope, no, I hadn't gone back to A&E because it just wasn't… Not that it wasn't worth it…If it's gonna be the exact same, I might as well stay at home." P5

MS Group Themes

Table 4 details the six MS group themes and the number of participants who represented each theme.

Table 4

MS Group Themes

Superordinate Themes	Subthemes	Number of participants contributing to theme (Total = 3)
1) Uncertainty in the beginning	They didn't know	3
	I helped to make the diagnosis	2
2) I wanted answers	Searching for info	3
	Why me?	3
3) It is a real physical condition	A definite diagnosis	3
	There was a physical explanation	3
	There were treatment options	3
4) Feeling supported	They cared	3
	I had someone to go to	3
	In this together	3
5) The diagnosis was helpful	There was urgency	3
	Relieved to have an answer	3
6) Changing self-care	More likely to seek support	3
	Pay more attention to my body	2

1) Uncertainty in the beginning

A common feeling shared in the beginning was uncertainty, when symptoms were not understood or not identified as MS initially.

They didn't know

Each participant described how initially HCPs couldn't offer an explanation, or the explanation was something else and more simplistic.

"They said oh folic acid deficiency we'll give you some folic acid. You'll be fine... However, the symptoms hadn't gone." P6

Even when further investigations were completed that might typically identify markers of MS, there was still not an immediate diagnosis. And so, there was still a sense of uncertainty and therefore anxiety that was reflected.

"...he said but your MRI doesn't say much. You know, there are some lesions here, but it could be for this. It could be from that. There's so many things I can pinpoint it to." P7

I helped them to make the diagnosis

This subtheme reflects the experience of participants sharing information that led to their diagnosis and demonstrates that they were listened to. Participant 7 spoke about having tinnitus and that it was this that directed the HCPs to conclude MS, considering her other symptoms.

"And that's when he said, well, that kind of changes things." P7

Another participant reflected on querying MS with her doctor, which ultimately led to receiving the diagnosis. This reflected a sense of the participants being empowered and heard.

2) I wanted answers

Searching for info

Participants reported googling symptoms and trying to gather more information. This reflected a need for answers and a way of having some autonomy. It was something they could do in the meantime to manage the uncertainty of what their symptoms may represent and what may lie ahead. As such, it was both helpful and unhelpful as reflected by Participant 6.

"…in the meantime, I just kind of googled things myself which probably didn't help to a certain extent, but did as well." P6

Why me?

Each participant reflected on wondering why they had MS, and what made them susceptible. Again, this was felt to represent a need for answers to make sense of something that doesn't make sense and to perhaps feel more in control. The causality was important to them in terms of locus of control and whether it is something that could have been prevented.

"I've always been quite healthy. And you, I always used to say that my sisters, how is it that you know, of all of us, I'm the one who breast- I'm the one who actually breastfed past two weeks." P7

3) It is a real physical condition

One of the most prominent themes that emerged was that getting an MS diagnosis meant that it was understood to be a real and recognised physical condition.

A definitive diagnosis

The participants all shared how they were given a diagnosis with certainty, even though not all the tests were conclusive or even completed.

"...of course, they found the lesions on my brain as well, which made them say, right, no, this this is MS ...but of course, actually my lumbar puncture was inconclusive." P6

Despite the test results, the diagnosis was accepted by participants. Perhaps reflecting the way in which it was communicated by HCPs or perhaps reflecting the acceptability of the diagnosis itself, as a condition that is understood and manageable.

There was a physical explanation

All participants reported that HCPs offered physical explanations in relation to cause and triggers, such as pregnancy and malaria. This link to physical explanations cements this as a real and physical condition, and communicates something about responsibility, that it is not their fault.

"...But she thought it could possibly have been back to when I had malaria, when I was in Africa." P6

4) Feeling supported

This superordinate theme captured the experience of feeling considered and cared for. That participants were seen as individuals going through something, that they were at the centre, rather than the diagnosis.

They cared

This subtheme reflected the feeling that HCPs cared about them and cared about their wellbeing. This was reflected in Participant 6's sense that the HCP had done *"everything she could to reassure me"*.

I had someone to go to

Participants shared experiences of feeling held by someone or by a team.

"I changed MS nurse a few times…but, umm yeah, no, the same consultant I've been with all along, which been really nice." P6

This was reflected in the language used when participant 8 spoke about *"my MS nurse"* reflecting someone that was there for her, highlighting a sense of feeling supported and having developed a relationship.

In this together

This subtheme captures the sense that participants felt they were not alone in this journey, that the HCPs were alongside them throughout the process.

"…I felt alright that yes, there is there people. There's a team who will take care of me." P8

This may also reflect the way in which MS was explained. Participants' sense of not being alone was also felt to represent how common the diagnosis can be and how there are others like them.

5) The diagnosis was helpful

Another theme arising from their experience was the sense that getting the diagnosis was helpful and ultimately led to positive change.

There was urgency

This theme captures the feeling that once the diagnosis was confirmed things progressed quickly and there was then a sense of urgency in the HCPs. This perhaps led to a feeling of reassurance that there was a pathway and a plan.

"…And she puts it all in place kind of straight away, all the different appointment with the MS Nurse appointment, with the consultant …I was quite lucky. It did all happen quite quickly." P6

Relieved to have an answer

Participants spoke about the relief that came from receiving the diagnosis, that it had resolved something. They had an answer and their experience and symptoms made sense. Receiving a diagnosis meant that other conditions were ruled out and perhaps provided a sense of predictability and understanding which matched their experience.

"…just because I was so happy to finally have an answer. I was just taking everything on board. Yes, I can finally do this. I can finally do that." P7

6) Changing self-care

When reflecting on the impact of their diagnosis, a theme around health behaviours emerged. At the beginning of their journey participants described not wanting to make a fuss or not paying much attention to symptoms. This was something that had shifted following the diagnosis.

More likely to seek support

After the diagnosis, participants expressed being more likely to go to the doctor or to share concerns. This felt representative of an overall illness behaviour change as it was also reflected in behaviours towards illnesses of others.

"I do go more than I used to, purely just in case. Umm. And probably more so with the kids as well. Now I will always rather than going oh no they'll be fine." P6

It is possible that this was encouraged by interactions with HCPs and how this was modelled in the organisation of follow up appointments and having a regular HCP to connect with.

"...when I do fall down, I just make a note and next time whenever I had to meet my MS Nurse, I'll talk." P8

Pay more attention to my body

This subtheme reflects increased hypervigilance. This may be linked to having regular contact with HCPs and the expectation of sharing symptoms and changes. Alternatively, it may also be influenced by their beliefs about the diagnosis.

"Whereas now the first thought is all is this symptom? Is this something to do with that? Is it something else? ...I think about it a lot more. I think right, I need to watch this." P6

Discussion

Key findings

All participants described experiencing uncertainty and encountering an initial lack of clarity regarding what symptoms meant. However, as their journeys progressed these experiences diverged. MS participants reported clarity and validation, conferred with a physical diagnosis of MS; this was a positive experience, leading to support from HCPs and to positive changes in their lives in terms of understanding symptoms and managing their condition. In contrast, participants with FND described how the diagnosis was seen as synonymous with mental health and not real and generated further confusion and distress. When given in this way, the diagnosis conferred blame and exacerbated distress, leading to distrust in services. Positive changes – as described by the MS patients – did not follow.

Similarities

On entering the medical system all participants described experiencing uncertainty, particularly themes around HCPs not knowing what was wrong and the participants wanting answers, were reflected by both groups. Both reported that symptoms were initially dismissed, which is a common experience in other neurological conditions (Schrag et al., 2018). Both groups also reflected on wanting more answers in the lead up and following their diagnosis. O'Keeffe et al. (2021) also noted that both FND and MS patients wanted more information about their condition. The tendency to search for information on the internet was seen in both groups. Generally, in neurological conditions, the reason for patients increased use of web-based sources has been linked to limited time and information from consultations with HCPs (Chu et al., 2017; Hoch et al., 1999). Searching for information may also reflect attempts to manage and reduce uncertainty.

Another similarity noted was the tendency for all patients to downplay symptoms in the beginning and to avoid support seeking, which indicated similar illness beliefs around perceptions of cause, timeline, and consequences. Both groups reported experiencing symptoms but delaying access to medical services. They gave similar rationales for this, namely hoping symptoms would resolve and not wanting to make a fuss. However, there was a notable shift between FND and MS patient experiences following diagnosis which led to divergence in illness beliefs and behaviours.

Differences

Diagnosis can be a therapeutic tool (Stone et al., 2016), however, this is dependent on validation and an explanation that is consistent with the patient's experience. This was not the case for the FND participants who expressed being made to feel that symptoms were not real or serious. They shared how the diagnosis was explained via metaphors that were inconsistent

with their experience. There was also a focus on what was not wrong, which can be ineffective in reducing concerns particularly where the information provided is not compatible with the patient's beliefs (e.g., Petrie et al., 2007). A lack of acknowledgement and explanation invalidates the patient's experience, and the explanation needs to make sense (O'Neal & Baslet, 2018). Comparatively, the MS participants expressed having their symptoms acknowledged and accounted for by organic disease, which not only provided some resolution to the uncertainty but led to immediate follow up care.

For MS participants there was a shared a theme that their condition was a real physical condition, which reflected how this was communicated to them. Once the label was given there was an immediate transfer of information about their condition and what to expect. Conversely, FND participants expressed that the label reinforced feelings of it being all in their head; there was an over-reliance on psychological explanations, which were felt to be simplistic, unrelatable and blaming and therefore the diagnosis became meaningless. Psychological explanations point the finger at the patient (Nielsen et al., 2020) and fail to reflect patient's subjective experience of symptoms. Psychological and physiological explanations are often seen as mutually exclusive, and so HCPs focus on psychological explanations may be interpreted by patients to mean that their condition is not physical which can be confusing (Wardrope et al., 2021), particularly as there is often the belief that their condition was precipitated by an injury or illness (Nielsen et al., 2020). FND participants reflected on historical trauma being pushed as a psychological cause of their condition, which is common in this patient group (Rawlings & Reuben, 2016). Whilst this may be reflective of evidence indicating the role of trauma in FND aetiology, there is also evidence for trauma in MS (Spitzer et al., 2012; Polick et al., 2022).

The differences in how the labels were received also felt connected to perceived knowledge of the HCPs and whether the participants had confidence in them. FND participants spoke

about being constantly met with uncertainty and interacting with HCPs who were unfamiliar with their diagnosis. They described having to educate HCPs, making them the experts. This theme has been represented in other studies (Rawlings & Reuben, 2016; Nielsen et al., 2020; O'Keeffe et al., 2021) in which participants with FND have also expressed beliefs that HCPs did not understand their condition. Alternatively, MS participants expressed that their diagnosis was communicated with confidence, symptoms were validated and there was a sense that there was a mutual understanding of the condition. The rejection of the FND label may also be influenced by the attached stigma, a prevalent theme among FND patients (MacDuffie et al., 2020; Wardrope et al., 2021), but less so with MS (Stone et al., 2002). The lack of meaning and stigma can cause harm in that patients may avoid stigmatising sources and the lack of agreement with the diagnosis leads to avoidance of treatments (Rommelfanger et al., 2017).

Emotional impact

A significant difference in themes was apparent in the emotional experiences after diagnosis. FND participants expressed being left with feelings of blame, distrust, shame, and abandonment, which contrasted with the MS participant's feelings of adjustment and acceptance. This felt connected to experiences of psychological explanations for FND symptoms, the lack of treatment pathway or follow up care, and the stigma attached to the diagnosis.

Stigma is prevalent in HCP's attitudes towards diagnosis and treatment of FND (Barnett et al., 2020). This was represented in participant's experiences of being dehumanised and feelings of abandonment and neglect, as previously highlighted in this patient group (Nielsen et al., 2020). Participants reported being passed between professionals, which perhaps is both a consequence of the lack of responsibility assumed by HCPs, but also of patients seeking a

diagnosis that fits (Edwards, 2019). They described interactions with HCPs in which they didn't feel considered as a person, which is likely reflectively of HCPs own biases and negative beliefs about FND (Barnett et al., 2020; Monzoni et al., 2011). The FND participants generally expressed not feeling cared for and similarly to other studies (Robson & Lian, 2017), expressed feeling blamed for their condition. Alternatively, MS participants described interactions with HCPs in which there was collaboration. This was reflected both on an individual level through developing a relationship with one consistent HCP and at a service level through feeling held by a team. This expands on the results from O'Keeffe et al. (2021) who found a significant difference in domains relating to relationships with HCPs and person-centred care for FND and MS patients.

FND participants reflected on the trauma caused by their experience. They described feeling detached from their bodies and experiences, and felt their condition was worse because of these experiences. This reflects the iatrogenic harm known to happen with this patient group (Page & Wessely, 2003; MacDuffie et al., 2020). The experience of having FND becomes a vicious cycle in which repeated negative interactions with services impacts physical health outcomes and progression of the condition (Rommelfanger et al., 2020). FND patients lose trust in services which prevents them from seeking support in the future, as was seen in this study. In comparison, the MS group expressed being more likely to seek support following their diagnosis and being more hypervigilant to changes in their body, indicating changes to illness beliefs and behaviours which impact future physical health outcomes (Sharpe et al., 2010).

Limitations

There are some limitations to consider in this study. Namely that data reflects retrospective self-report accounts of participant's experiences. These accounts may be subject to individual

bias and are limited to what is reported. Whilst there was an attempt to keep the groups as homogonous as possible, the findings reflect a small sample and FND is not a homogonous group generally.

Similarly, whilst there was also an attempt to keep differences between the two samples to a minimum, as set out in the inclusion criteria, there were some notable differences between the two groups. Firstly, the FND sample were all white British women, and a greater proportion were in their twenties. The MS group had a greater BAME representation, with two of the three participants being from a non-white ethnic background and they were also all above thirty-five years of age. There were also differences in other diagnoses. Neurodiversity was present in the FND sample and not the MS sample, and four of the five FND patients had a self-reported mental health condition (depression and/or anxiety), compared to one MS patient. Two FND participants had another physical health diagnosis and one MS patient also had another physical heath diagnosis. Neurodiversity in this instance may have impacted the meaning that they derive from the experience and how they conceptualise the emotional impact. Alexithymia, which refers to difficulties in recognising and expressing emotions, is thought to be common in autism (Kinnaird et al., 2019). This may have impacted how these participants tell their story, and the emotional language they used. People with autism are also more likely to internalise stigma (Han et al., 2022) perhaps meaning that experiences of diagnosis have a more negative impact on the 'self'. Differences in mental health conditions observed between the samples could reflect either premorbid experiences or consequences of the diagnosis. It might be expected given their experience that they would be more susceptible to anxiety and depression and perhaps this would be something worth measuring in future research. Finally, the participants' age reflected a specific life stage which may also have had an impact of their experience of their diagnosis. According to McAdams (2001), in early-to-middle adulthood, people tend to focus on refining their sense of identity and

integrating different parts of their self. Receiving a chronic neurological diagnosis could be quite destabilising at this time, and the FND participants were just entering into this stage of life.

It is not possible to determine causality and whether the differences observed were in fact due to differences in interactions with HCPs. However, these findings reflect and expand on the themes from the other studies of FND patient experiences (Nielsen et al., 2020; O'Keeffe et al., 2021). Whilst measures were taken to ensure consistency in interpretations and themes drawn, it is still possible that the researcher's own biases had an impact.

Clinical implications

There are a number of key insights that can be used to improve the experience of receiving an FND diagnosis:

(1) Training HCPs to understand the diagnosis, including frontline workers. Thereby increasing confidence in diagnosing and working with patients with FND.
(2) Enrolment of a clinical pathway for FND patients to provide appropriate diagnosis and treatment.
(3) A clear explanation of the diagnosis, as described by Stone et al. (2020) that emphasises the positive nature of the diagnosis and focuses on the realness of symptoms, the need for treatment and validates patient's experiences (Carson et al., 2016).
(4) Appropriate referrals to specialist services for further treatment that does not focus solely on psychological factors.

Conclusion

This study has demonstrated the impact of receiving an FND diagnosis relative to an MS diagnosis. What has been shown is that these two groups come into services with the same expectations, but their subsequent interactions lead to a divergence in how they experience receiving their diagnosis and the emotional impact. The fact that FND patients are met with HCPs who lack appropriate knowledge, and there is not a good explanation or an appropriate pathway, leads to divergence between these two groups. This may be remedied with appropriate HCP training, facilitating explanations that are validating and concurrent with physical symptoms, and through the implementation of a treatment pathway.

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Appendices

Appendix A: Prisma Checklist

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	
	23b	Discuss any limitations of the evidence included in the review.	
	23c	Discuss any limitations of the review processes used.	
	23d	Discuss implications of the results for practice, policy, and future research.	
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	
Competing interests	26	Declare any competing interests of review authors.	
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix B: Quality Assessment Tools

Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the study question or objective clearly stated?			
2. Were eligibility/selection criteria for the study population prespecified and clearly described?			
3. Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?			
4. Were all eligible participants that met the prespecified entry criteria enrolled?			
5. Was the sample size sufficiently large to provide confidence in the findings?			
6. Was the test/service/intervention clearly described and delivered consistently across the study population?			

Criteria	Yes	No	Other (CD, NR, NA)*
7. Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants?			
8. Were the people assessing the outcomes blinded to the participants' exposures/interventions?			
9. Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?			
10. Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?			
11. Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e., did they use an interrupted time-series design)?			
12. If the intervention was conducted at a group level (e.g., a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group level?			

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			

Criteria	Yes	No	Other (CD, NR, NA)*
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			

Criteria	Yes	No	Other (CD, NR, NA)*
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Assessment of Case-Control Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated and appropriate?			
2. Was the study population clearly specified and defined?			
3. Did the authors include a sample size justification?			
4. Were controls selected or recruited from the same or similar population that gave rise to the cases (including the same timeframe)?			
5. Were the definitions, inclusion and exclusion criteria, algorithms or processes used to identify or select cases and controls valid, reliable, and implemented consistently across all study participants?			
6. Were the cases clearly defined and differentiated from controls?			

Criteria	Yes	No	Other (CD, NR, NA)*
7. If less than 100 percent of eligible cases and/or controls were selected for the study, were the cases and/or controls randomly selected from those eligible?			
8. Was there use of concurrent controls?			
9. Were the investigators able to confirm that the exposure/risk occurred prior to the development of the condition or event that defined a participant as a case?			
10. Were the measures of exposure/risk clearly defined, valid, reliable, and implemented consistently (including the same time period) across all study participants?			
11. Were the assessors of exposure/risk blinded to the case or control status of participants?			
12. Were key potential confounding variables measured and adjusted statistically in the analyses? If matching was used, did the investigators account for matching during study analysis?			

Appendix C: Summary of Quality Assessment Evaluation

Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group

Study	Baslet et al. (2022)	Chen et al. (2018)	Cope et al. (2017)	Sarudiansky et al. (2020)	William et al. (2018)	Wiseman et al. (2016)
1. Was the study question or objective clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes
2. Were eligibility/selection criteria for the study population prespecified and clearly described?	No	No	Yes	Yes	No	No
3. Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?	Yes	Yes	Yes	Yes	Yes	Yes
4. Were all eligible participants that met the prespecified entry criteria enrolled?	CD	Yes	Yes	Yes	CD	Yes
5. Was the sample size sufficiently large to provide confidence in the findings?	CD	Yes	Yes	CD	Yes	CD
6. Was the test/service/intervention clearly described and delivered consistently across the study population?	Yes	Yes	Yes	Yes	Yes	Yes
7. Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants?	Yes	Yes	Yes	Yes	Yes	Yes
8. Were the people assessing the outcomes blinded to the	No	No	No	No	No	No

participants' exposures/interventions?						
9. Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?	No	No	No	No	No	No
10. Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?	Yes	Yes	Yes	Yes	Yes	Yes
11. Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e., did they use an interrupted time-series design)?	Yes	No	No	No	No	No
12. If the intervention was conducted at a group level (e.g., a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group level?	No	No	No	No	No	No
Overall rating	Fair	Good	Good	Fair	Fair	Fair

Criteria: Yes, No, Other (CD, cannot determine; NA, not applicable; NR, not reported)

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Study	Butler et al. (2021)	Rosales et al. (2020)	Sharpe et al. (2010)	Shipston-Sharman et al. (2022)	Tolchin et al. (2018)
1. Was the research question or objective in this paper clearly stated?	Yes	Yes	Yes	Yes	Yes

2. Was the study population clearly specified and defined?	Yes	Yes	Yes	Yes	Yes
3. Was the participation rate of eligible persons at least 50%?	Yes	Yes	Yes	Yes	Yes
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	CD	No	Yes	Yes	Yes
5. Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No	No	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No	No	Yes	Yes	No
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	No	No	Yes	Yes	Yes
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	NA	NA	NA	No	No
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented	Yes	Yes	Yes	Yes	Yes

consistently across all study participants?					
10. Was the exposure(s) assessed more than once over time?	No	No	Yes	Yes	No
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes	Yes	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	NA	NA	NA	NA	NA
13. Was loss to follow-up after baseline 20% or less?	NA	NA	No	No	No
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	No	No	Yes	No	Yes
Overall rating	Poor	Poor	Good	Good	Fair

Criteria: Yes, No, Other (CD, cannot determine; NA, not applicable; NR, not reported)

Quality Assessment of Case-Control Studies

Study	Ludwig et al (2015)	Stone et al. (2010)	Whitehead et al. (2015)
1. Was the research question or objective in this paper clearly stated and appropriate?	Yes	Yes	Yes
2. Was the study population clearly specified and defined?	Yes	Yes	Yes
3. Did the authors include a sample size justification?	No	No	No

4. Were controls selected or recruited from the same or similar population that gave rise to the cases (including the same timeframe)?	Yes	Yes	Yes
5. Were the definitions, inclusion and exclusion criteria, algorithms or processes used to identify or select cases and controls valid, reliable, and implemented consistently across all study participants?	Yes	Yes	Yes
6. Were the cases clearly defined and differentiated from controls?	Yes	Yes	Yes
7. If less than 100 percent of eligible cases and/or controls were selected for the study, were the cases and/or controls randomly selected from those eligible?	NA	NA	NA
8. Was there use of concurrent controls?	Yes	No	No
9. Were the investigators able to confirm that the exposure/risk occurred prior to the development of the condition or event that defined a participant as a case?	Yes	Yes	Yes
10. Were the measures of exposure/risk clearly defined, valid, reliable, and implemented consistently (including the same time period) across all study participants?	Yes	Yes	Yes
11. Were the assessors of exposure/risk blinded to the case or control status of participants?	No	No	No
12. Were key potential confounding variables measured and adjusted statistically in the analyses? If matching was used, did the investigators account for matching during study analysis?	No	No	No
Overall rating	Fair	Fair	Fair

Appendix D: Interview Schedule

Interview Schedule – Version 2

First noticing change and seeking support

When did you first notice something wasn't right and what was your experience of getting support?

Prompting questions:

- Tell me about when you first noticed something was wrong…
- What did you experience?
- Do you have any thoughts about why your FND/MS started? What do you understand about what causes FND/MS? (*Trauma?)*
- Tell about when you first sought support… Did you go to A&E/GP? How many times before diagnosis?
- What was it like seeking support? How did it feel? How were you treated?

Diagnosis

Tell me about the time you received your diagnosis…

Prompting questions:

- What was your experience of this?
- How long did it take after first noticing symptoms?
- What were you told? How was this communicated to you? What information were you given? How were you left feeling?
- Was there anything that you were told at the time of your diagnosis or in relation to your diagnosis that was not accurate?
- Immediately after the diagnosis what was your understanding of the treatment options available to you? Was rehabilitation mentioned? What was your understanding of how your symptoms could improve and the time-frame for this?

Episodes of Treatment/Support

Tell me about your experience after the diagnosis…

Prompting questions:

- What support have you received? How many times have you been involved in a service? What was your experience of this?
- Were there any differences in the support you received? What was different each time you sought support?
- What were your experiences of healthcare professionals? Did you see various healthcare professionals? What was your experience of this?

- How easy was it to access specialist services? What were the barriers?

Long term impact

Did your experience of diagnosis have any lasting impact on you? How do you now understand this?

Prompting questions:

- How are you now? How do you feel about your diagnosis?
- Do you tell people about your diagnosis? (HCPs/family/friends)
- How do you feel about seeking support? Do you have access to support?
- How do you feel about healthcare professionals and services?
- Is there anything you wish you could change about your experience?
- What has this experience left you with?

Appendix E: Recruitment Poster

Canterbury Christ Church University

RESEARCH PARTICIPANTS WANTED

Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.

We are interested in exploring patient experiences of receiving an FND diagnosis and an MS diagnosis

This is so we can understand the emotional impact of these experiences, which may contribute to the development of services and staff training.

How can you help?

If you are a female aged between 20 - 40 years, and have received a diagnosis of either FND or MS more then a year ago, we would like to hear about your experiences.

To take part in this study [redacted] on, please email [redacted] (Trainee Clinical Psychologist).

[redacted]

Appendix F: Participant Information Sheet

Participant Information Sheet

Research Title

Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.

Research Team

Principal Researcher: XXX (Trainee Clinical Psychologist)

Chief Investigator/supervisor: XXX (Senior Lecturer and Research and Neuropsychology Lead)

Supervisor: XXX (Clinical psychologist)

Invitation

You are being invited to take part in a doctorate level research project conducted by XXX, Trainee Clinical psychologist at Canterbury Christ Church University. Before you decide it is important for you to understand why the research is being done and your what participation would involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Aim and purpose of the study

We, the research team, would like to invite you to take part in an interview to explore your experiences of receiving your diagnosis. We are interested in understanding your experience and the emotional impact of your diagnosis.

We are interested in comparing the experiences of people with Functional Neurological Disorder (FND) and people with Multiple Sclerosis (MS) to understand if these experiences of diagnosis and treatment are different. More research will be needed in order to change the diagnosis of FND, however the results of this research may be useful in informing service level changes, raising awareness of health professionals, and informing larger scale research.

What does the study involve?

If you choose to participate in this study, we will arrange an interview with you in which the principal researcher will ask you questions about your experience of diagnosis. This will be one interview that can take place virtually via a video appointment, or face to face at XXX, depending on individual preference. The interview will be between 30 and 90 minutes long and would be arranged at a time that is convenient for you. Breaks will be offered throughout and can be taken at any time during the interview if needed to help manage fatigue.

If you prefer to have your interview face to face at XXX, then we will be able to reimburse you the cost of parking for any amount up to £10.

Will I be recorded and how will the recorded media be used?

Interviews will be recorded and transcribed by the principal researcher, XXX, who will be conducting the interviews. This information will be stored securely with password protection. In the process of transcribing all of your personal details will be anonymised and disguised, to protect your anonymity. Audio recordings and transcriptions will be stored securely and with password protection on an encrypted memory stick by the principal researcher for up to 10 years [in case we need to check it]. The transcriptions will be used only for analysis in this study. No other use will be made of these without your written permission, and no one outside of the research team will be allowed access to the original recordings.

Why have I been chosen?

You have been chosen to participate in this study because you have a diagnosis of either Functional Neurological Condition or Multiple Sclerosis. We will be recruiting 8 participants in total.

To participate in this study, you must meet the following criteria: a) be aged between 20 and 40 years; b) must not have other co-morbid neurological conditions; c) must not have a primary diagnosis of fatigue or chronic pain; d) must not have other mental health diagnoses other than anxiety or depression; and e) must not have any memory or communication difficulties that would prevent you from participating in the interview.

Do I have to take part?

Participation in this study is voluntary. If you do decide to take part, you will be given this information sheet to keep and will be asked to complete a consent form. Taking part in this study will not impact any treatment or care you are receiving or waiting for. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. Should you wish to withdraw from the study, you can contact the principal researcher at any time by email or during contact with them directly. You can also tell your healthcare professional, who can contact the principal researcher on your behalf.

What are the possible disadvantages and risks of taking part?

Talking about difficult experiences can be upsetting and may cause distress. In the event that you experience distress as a result of participating in this study, we will direct you to sources of support.

Please also be aware of any physical discomfort that might be experienced from engaging in an interview that may last up to 90 minutes. Breaks can be incorporated when needed.

Finally, some participants may experience worsening of fatigue after participation.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in the project, it is hoped that this work might inform change in the process of FND diagnosis and how healthcare professionals interact with this patient group.

Will my taking part in this project be kept confidential?

If you choose to take part in this study, you will be allocated a Study ID, which will be present on three separate documents: 1) a document with your name and study ID; 2) a document with your contact details and study ID; and 3) the transcript of your interview. All information that we collect about you during the course of the research will be kept strictly confidential. The only exception to this is if you mention that you are at risk of harm, or someone else is at risk of harm, in which case we will be required to share this information with your healthcare professional.

All your information will be anonymised. We will make sure no-one can work out who you are from the reports we write.

What if there's a problem?

If you would like to report a problem or a complaint you can contact XXX at XXX or you can contact XXX at XXX.

You can also make a complaint via The Surrey and Borders Partnership NHS Trust Patient and Advice Liaison Service at https://www.sabp.nhs.uk/contact/pals where you will find an online form as well as contact details.

What will happen to the results of this research project?

This research will be submitted to Canterbury Christ Church University for examination. It will be shared with The Wolfson FND Service at XXX. All shared information will be anonymised.

This research will also be submitted for publication in academic journals such as: Frontiers in Neurology; The British Journal of Health Psychology; and the Journal of Neuropsychology.

If you wish to receive feedback about our findings from this study, please let us know.

Contact for further information

If you would like to participate in this study or have any questions, please contact **XXX** at **XXX.**

Or if you are happy for the researcher to contact you, please let your health care professional know and confirm that you have read the above and consent to your telephone contact and/or email address to be shared via secure email.

Appendix G: Consent Form

Version 2

IRAS ID: **306399**

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.

Name of Researcher:

Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by individuals from research team (those supervising the researcher) for the supervisory purposes. ☐
4. I understand that the information collected about me will be anonymised and stored securely and that the findings will be disseminated, in doctoral research submission, in publication, and possibly a conference. ☐
5. I understand that the research team (those supervising the researcher) may have access to raw and anonymised data for the supervisory purposes. ☐
6. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person seeking consent	Date	Signature

Please tick this box if you would like to receive feedback about the findings from this study ☐

Appendix H: Ethics Approval

[redacted]

Email: approvals@hra.nhs.uk

05 April 2022

Dear [redacted]

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

Study title:	**Functional Neurological Disorder: Understanding patient experiences of diagnosis and the emotional impact, compared to Multiple Sclerosis.**
IRAS project ID:	**306399**
REC reference:	**22/NW/0029**
Sponsor	**Salomon's Institute for Applied Psychology**

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.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

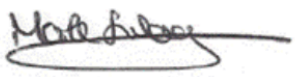
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **306399**. Please quote this on all correspondence.

Yours sincerely,



Mark Sidaway
Approvals Specialist
Email: approvals@hra.nhs.uk

Copy to: [redacted]

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	Version 1	15 March 2022
Interview schedules or topic guides for participants	Version 2	15 March 2022
IRAS Application Form [IRAS_Form_15032022]		15 March 2022
IRAS Application Form XML file [IRAS_Form_15032022]		15 March 2022
IRAS Checklist XML [Checklist_15032022]		15 March 2022
Organisation Information Document		
Other [Amendments as per REC]	Version 1	15 March 2022
Other [Research Poster]		
Participant consent form	Version 2	15 March 2022
Participant information sheet (PIS)	Version 2	15 March 2022
Research protocol or project proposal [Proposal]		02 December 2021
Schedule of Events or SoECAT	Version 1	15 March 2022
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		02 December 2021
Summary CV for supervisor (student research)		02 December 2021

IRAS project ID	306399

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one sitetype.	Research activities should not commence at participating NHS organisations in England orWales prior to their formal confirmation of capacity and capability to deliverthe study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites, as stated in the OrganisationInformation Document.	A Principal Investigator should be appointed at study sites.	No Honorary Research Contracts, Letters of Access or pre-engagement checks areexpected for local staff employed by the participating NHS organisations. Wherearrangements are not already in place, network staff (or similar) undertakingany of the research activities listed in the IRAS form (except foradministration of questionnaires or surveys), would be expected to obtain anhonorary research contract from one NHS organisation (if university employed),followed by Letters of Access for subsequent organisations. This would be onthe basis of a Research Passport (if university employed) or an NHS to

					NHSconfirmation of pre engagement - checks letter (if NHS employed). These shouldconfirm enhanced DBS checks, including appropriate barred list checks, andoccupational health clearance. For research team members only administeringquestionnaires or surveys, a Letter of Access based on standard DBS checks andoccupational health clearance would be appropriate.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHRCRN Portfolio.

Appendix I: Letter of access to host trust

DocuSign Envelope ID: 94693249-E7C0-4AEF-8635-CEDE04D1901B

[redacted] Hospitals NHS
NHS Foundation Trust

[redacted] **Joint Research and Enterprise Services**
G[redacted]

Date: 10th August 2022

Dear [redacted],

Letter of access for research – IRAS 306399

This letter should be presented to each participating organisation before you commence your research at that site. The participating organisation is: [redacted] **University Hospitals NHS Foundation Trust.**

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on **11th August 2022** and ends on **30th September 2022** unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisation(s). The organisation(s) is/are satisfied that the research activities that you will undertake in the organisation(s) are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation(s). Evidence of checks should be available on request to us.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the organisation(s) permission to conduct the project.

You are considered to be a legal visitor to this site/ premises. You are not entitled to any form of payment or access to other benefits provided by this Trust or this organisation to employees and this letter does not give rise to any other relationship between you and this Trust or this organisation, in particular that of an employee.

While undertaking research through **this Trust**, you will remain accountable to your employer **Surrey and Borders Partnership NHS Foundation Trust** but you are required to follow the reasonable instructions of your nominated manager [redacted] in this organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by Surrey and Borders Partnership NHS Foundation Trust or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with our policies and procedures, which are available to you upon request, and the UK Policy Framework for Health and Social Care Research and ICH-GCP.

You are required to co-operate with this Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating organisation prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation(s) will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation(s) terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

[redacted] University Hospitals NHS
NHS Foundation Trust

[redacted] **Joint Research and Enterprise Services**

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation..

Yours sincerely

DocuSigned by:
Subhir Bedi
E78A55E86B3C469...

Subhir Bedi
Head of Research Governance and Delivery

cc: HR department of the substantive employer – Kate Blackman
[redacted] **Trust HR Dept- Sarah Hemmings**
[redacted] **Trust nominated Manager –** [redacted]

Attachment: confidentiality code of conduct

Appendix J: Reflective Diary

Entry 1

My initial research idea has fallen through because of covid. I want to stay close to the original area of research and still do something meaningful. I am hopeful about this new idea, but also concerned about the time remining. Gaining ethics and trust approval has been a long and stressful process, which has further delayed recruitment. At this time I am feeling disconnected from my initial motivation, which was to shed light on the experiences of patients that I have seen in services.

Entry 2

I have been able to begin recruitment, however this feels out of my control. I am waiting for the recruiters from each time to pass me the details of potential participants and it is taking longer than I hoped, particularly for the MS participants, perhaps because the FND recruiter in also my research supervisor and so is more invested. I want to chase the MS team and push things along, I'm feeling impatient, but I am also aware that they are doing this to help me and so feel that I need to be tentative in my chasing and not become a nuisance. In the MS team, only one MS is providing details of potential participants and I am feeling so grateful to him and don't want to put further pressure on that may deter him. I have suggested that I could go in person to speak with the team and aid recruitment, however they have not taken me up on this offer. They are obviously a busy team and I just have to wait.

Entry 3

I have started interviewing FND participants and it is going well. There is so much content to work with and their experiences have shocked me! Whilst I have been aware of what their experiences can be like, from working with this patient group, to have them share these experiences that are so polarised and so similar has been a surprise. I feel ashamed as I represent the NHS and healthcare professionals that they refer to, who have caused them so much harm. I am also the same demographic as some of the participants, a white female in my mid-thirties. One of the participants spoke about the shame she felt given that her father is an immigrant and has always worked so hard and got on with things and now she has to explain that she is doing this to herself, or so she was made to believe at that time. I also have an immigrant father and can relate to that experience of having so much respect for him and not wanting to disappoint him. I wonder if they look at me and resent that I am them but without this awful experience. They have spoken about HCPs only being interested I them because of their condition and wanting to use them for research, this is also what I am doing. I really hope that this isn't another terrible experience for them and that this research leads to something helpful and tangible that changes things for this patient group.

Entry 4

I have started interviewing MS participants and it is going well. I was a bit apprehensive about explaining the research to them because I am aware it does not directly help them, but I am hopeful they will not feel that they are being used or inconvenienced. I am genuinely interested in their experiences. I am also curious about what has motivated them to get involved. Have they had particularly good experiences and so want to be helpful and 'give back'? Will this be a reflective sample? Interestingly I am noticing some similarities in their experiences to that of the FND participants, which I did not anticipate. Their experiences did not start off well either! Another similarity I am noticing is how they talk about their experience, both groups struggle to connect to the feeling, and I am aware that I'm having to be mor explicit about wanting to understand what emotions were evoked for them. I wonder whether this is related to alexithymia and interception for both groups. Perhaps there is more that is similar about them, and I could potentially have included a measure of this, which might have been interesting.

After diagnosis, I am pleased to hear that the MS participant felt cared for and had relatively positive experiences. However, one of the MS participants seems low. I found myself being more curious about this with her and allowing the interview to progress according to what she was sharing and my concerns. I did find myself slipping into my therapist role slightly. At the end of this interview, I have agreed to share these concerns with her MS nurse, with her consent, and will make suggestions about support through neuropsychology services. I am please I got to see her.

Entry 5

I am still waiting for further MS participants. I only have three and would like one more. Whilst this is enough for IPA research, I was hoping to have equal numbers of both MS and FND participants, however it is proving difficult. I have chased the MS team but have not heard much in response. Consequently, I have had more FND participants recruited for me so I am thinking perhaps it would be OK to proceed with 5 FND participants and 3 MS participants. I've discussed it with my supervisors, and they have agreed. Time is moving along, and I need to get on with transcribing and analysing. I can't wait any longer.

Entry 6

I am now transcribing the interviews. I was feeling positive about having completed the interviews, but this feeling has not lasted as I recognise the enormity of this next stage. As I'm transcribing, I am having thoughts about their experiences and wanting to make notes and annotations, but also cautious about jumping into interpretation at this stage, without a whole sense of the interview. I so make some notes but keep these as tentative and more reflective of questions that are being raised for me in this moment. For example, one of the FND participants appeared to be quite fidgety in the interview and at the time I thought that perhaps this was a motor symptom. Now I am wondering whether this was more reflective of how she was feeling in the moment, perhaps she was anxious about the interview. Should I have been paying more attention to this at the time and been curious about it? But then this may have made her feel uncomfortable. Perhaps it's also reflective of what she is speaking about in that moment.

Entry 7

I am finding it really challenging working full time, whilst still trying to complete this project. I feel disconnected from it and resentful that I am still doing it. I decided to book annual leave so I can reconnect and immerse myself in the data during the analysis process. I am now enjoying not having to think about anything else but the research. Some of the interviews were conducted a while ago, but being able to listen again and read through again and again makes it feel like it was only yesterday. I feel passionate about it again and I'm not looking forward to returning to work. I am noticing another similarity regarding trauma and how each of them has had an experience in their lifetime that could fit that description. Yet both the MS and FNS participants, downplay the role of trauma and stress, and the impact it has had. Perhaps this is me acting like all of the other healthcare professionals and putting more emphasis on this than want is subjectively experienced by the participants.

Entry 8

I am back at work now and also trying to write up the results. I have my themes and my supervisors seem to agree with me on these, which I am happy with. However, I am feeling stressed and rundown. I've been off sick, and this has caused further delays adding to the stress. Friends are telling me I should go to the doctors; however, I am really reluctant to do this. I have been reading a lot about the role of stress and how it impacts the body, yet I feel uncomfortable about the idea of admitting my own stress and pathologising it. Perhaps this is related to the experiences I have been hearing about. Despite the evidence that stress is a psychological cause/trigger for many functional and organic disorders, I keep thinking about the participants who have downplayed psychological causes because of the stigma and negative connotations. When I was in the interviews, I remember thinking about how important these psychological factors were and how awful it is that we don't treat mental health with the same respect and care as physical health, and even that fact that we separate them. Yet, in my personal life I am now unable to let go of that stigma that I have been immersed in within their experiences, that is also my own.

Appendix K: Excerpt of FND transcript sent for review.

Participant 2
Umm really, really bad and, erm.

That wasn't really taken seriously seriously in my opinion, I mean, when I was discharged, I literally thought I was gonna die because I couldn't. They, I had to sit in a wheelchair for 10 minutes while they wheeled me out the hospital and I couldn't sit up for that for the for I couldn't sit up. Not taken seriously? Not cared for?

Commented [MF(1)]: Not taken seriously
Lack of HCP care

0:8:35
Interviewer
Yeah.

Participant 2
So then I had. By the time I got to the sort of discharge ward I just had, I just, there was like in tears begging them to let me lie down, and then I lay down and then my husband took, came and got me and we went home but had like like, you know, like I couldn't. I couldn't sit up for more than, you know, 10 seconds really. Distressed, vulnerable. Pleading for help.

Commented [MF(2)]: Distress
Vulnerable
Lack of hCP care

Umm. And I did sort of try. I did try talking to the consultant and the doctor, but they were they they they just they just said it's normal but and they do warn you that you might get a headache but a headache to me is like you know have a headache can you take some paracetamol and not like my head's gonna literally explode if I don't lie down after 10 seconds, and then when you're lying down, it's like there's no hardly any pain at all. And anyway, so. Not listened to, not validated

Commented [MF(3)]: Lack of HCP care
Its all in her head
Overeacting

That happened then. Umm. There's no follow up for any of this, even even viral men- even viral meningitis if you look it up on the Internet, can have some quite, you know, long lasting effects. Not cared for. Left to own devices, to look after herself.

0:9:49
Interviewer
Yeah.

Participant 2
But there's no there's no, you're just discharged. That's it. Like, you know, I think all they said was get umm extend your sick note in 10 days if you're not feeling better. That's it. So yeah. Abandoned.

Commented [MF(4)]: Abandoned by HCPs
Lack of care

Interviewer
How did that feel?

0:10:9
Participant 2
Umm well. I mean, hospitals like prison, right? You wanna get out of there?

Interviewer
Sure

Participant 2
And I was like pleading with them. Like, are you sure this is like, fine. And it just, I don't know, it wasn't right. And then the lack of aftercare when you, when you then get home and look up on the Internet, that there are actually options like a blood, a blood patch. Does not meet subjective experience of seriousness. Feel like she has been brushed off? Neglected?

Commented [MF(5]: Lack of care from HCPs
Abandoned/neglected
Having to fight for support

Umm and things so and that. Yeah. So that was pretty scary. When I got home because I was so ill. And then my husband was pretty worried as well. Fear, uncertainty? Impact on partner.

0:10:48
Interviewer
Yeah.

Participant 2
And then.

I think how long was it before I went back in? It was... I can't remember how long I lasted at home. A week, maybe? a week. It was a week or two weeks at home. Umm and, I think it was a week. I had, I had called out, I called out the GP to my house because I I couldn't get up. Trying to make do at home and not cause a fuss?

Commented [MF(6]: Not wanting to cause a fuss

Umm. And they just said they didn't really know anything about lumbar punctures and gave me some painkillers umm then... lack of hcp knowledge. Didn't know and didn't try to find out. Didn't care?

Commented [MF(7]: Lack of confidence in HCPs
Lack of care from HCPs

Interviewer
But when you say sorry that you couldn't get up, was it the headache still or was it something else? Now that was stopping me.

Participant 2
Yes.

Interviewer
Ohh wow. Gosh. Yes, so you had it that whole time?

Participant 2
Yes, so I could hardly even go to the toilet

Interviewer
Wow

Participant 2

Like because, you know, I had to, like, sit on the toilet with my like my head like horizontal to try, before I could like then like you know, or sometimes I just had to lie on the floor to get anywhere.

But it was just it was just wasn't explained or. Yeah. It wasn't. It was just really scary because it just wasn't what... anyway, so then they got to a point where it wasn't getting better and I then when I was stood up, I started like. It started, I start start, my body started like pulling me over to one side and. I just I think at that point I just... had enough. So we went back to A&E. And then that was another. But this time, because there was no threat of, imminent threat of death. I mean, I was, you know, you just you spend nights in cupboards and in clinics and it's it's not. I know. I know that everything's underfunded. And one doctor tells you one thing. Another doctor tells you another. Umm. I saw a neurologist, they finally decided they would admit me after a few days of us sort of bothering them to really. Fear, uncertainty, unknown. Feeling that they are bothering the HCPs. Lack of explanation – implies lack of care? Lack of consistency in information – leading to distust, lack of confidence in HCPs?

Commented [MF(8]: Uncertainty
Not wanting to make a fuss
Lack of care from HCPs
Distrust in HCPs
No consistency, passing the buck

Umm, and then...

0:13:1
Interviewer
Was that you going back and forth or were you there for a few days before you were admitted?

Participant 2
I was there for a couple of days before I was admitted. They, you just sleep in them, cupboards or or on the, on in these like clinics. Like they are an inconvenience, or in the way?

Commented [MF(9]: Lack of care
It is not serious

Interviewer
Yeah

0:13:15
Participant 2
Like, but it's awful because you know the strip lighting and you're not comfortable. And when you can't stand up, it's not very nice. Anyway. And one doctor will be like, really, like, understanding, and be like, oh, yeah, we'll sort, we'll get this sorted duh duh duh and then, you know, the next day another consultant will come along and just be like "what" like. Anyway, so they from it went from sort of, you know, we'll give you a blood patch within. Inconsistency in care, made to feel like making a fuss?

Commented [MF(10]: It is not serious
Inconsistency
Lack of care

24 hours to actually I had. I think I had. I had the blood pat-. I was in there for, like a week. I was waiting like... waiting, no urgency, limbo.

Commented [MF(11]: It is not serious
Uncertainty

At least four days for an MRI umm because the neurologist said I should have to said should have an MRI to see check what was going on.

Appendix L: Second excerpt of FND transcript sent for review.

PARTICIPANT 1
Umm the first time I noticed when I was 16. Umm. And I was working.

If I'm being honest, I always kind of it was a little bit different because I could always tell that didn't have enough, like as much stamina as people and that sort of thing. A couple of weird things that happened in my childhood, that no one really explained. But when I was 16, I was working full time at a school, and my primary job was er, end of, doing children end of life care. And umm... *Beliefs about the self, relevance of past experience, something inherently different within her? Something wrong with her? Identification of potential for stress or trauma?*

Commented [MF(1]: Belief about the self, there is a problem that exists within her, blame. Trauma

I was at work and I had a seizure at work. Umm, we had a nurse on site. I, then from that point on had umm up to 17 a day.

Umm I was treated uh, saw by the, my local hospital umm they said they had no idea what was wrong with me. And that they needed to send me over to like this specialist at the time, which was the [Hospital] and umm for neurology and. By then was in there for a while. Urgh God. How long was I in there for I don't know. Not, not not more than a month. *Long hospital stay.*

Umm, and they stress test me in there, CT, MRI all of those sort of things and umm... I remember really specifically and this started possibly a very negative spiral with medical medical professionals umm because I must have been, I think I was just about 17. *Reflecting on this as being young and vulnerable?*

Commented [MF(2]: Vulnerable
Young
Needing care?

And I they said to me, I was always seen by multiple doctors, so I was never just a consulted by one, always numerous people. Always people bring in their students, their staff. *Lack of confidence in HCPs? If always seeing someone new (being passed on) and them bringing students... like she is an attraction to be observed/studied.*

Commented [MF(3]: Multiple interactions, multiple professionals, students, years of investigations

Because people were interested in my results, I guess, umm and they all stood around me at about and they said we think you've got a diagnosis of conversion and somatization disorder. And I said OK. *What does that mean? Said with like certainly.*

And they didn't really give. They give a very. Err word I didn't understand. I was on my own.

Commented [MF(4]: Jargon, she is passive, "OK"

0:2:59
Interviewer
I know.

PARTICIPANT 1
They gave words. I didn't I I don't have words I didn't understand. And I was like. OK, what does that mean? And then one of the doctors, one of the women doctor, I said "I'm so sorry". She was about to leave and I was like "I'm so sorry. I have no idea what you said". And she said basically what it means is that it's all made-up in your head. *Feel responsible/silly? For not understanding. Then interpreted as "it's all made up in your head".*

Commented [MF(5]: She is the problem?
Its all in your head

Interviewer
Ah.

0:3:18
PARTICIPANT 1
And I went Oh, what do you mean it's all made-up in my head because I'm not making. I'm not making up for attention. Like I wanna. Like I can't. I wanna work like this has stop my life, not the other way round. Like it's not been that I've had a, you know, just living my best life at the time. Umm she said it just basically means it's all in her head. And I was like oh. *Sense of trying to prove herself? I feel she was quite overwhelmed by this, even telling the story back.*

But OK, so then I was Put into psychiatric care for years from 17 to 20. *What did this mean to her? Psychiatric care? Implies she is seriously unwell. For me I believe that the threshold for inpatient psych support is high.*

And I was initially seen by the head of psychiatry in, I was initially seen by somebody, and remember really specifically being seen by a consultant and him looking very stressed. *She perceived him as looking stressed and assumed that this was about her. This is the head – even he doesn't know what's wrong.*

And saying you're gonna have to wait here. No, wait there for a longer period of time. And he went, got the head of the department, and then got more doctors and more doctors. And they all sat there. And I was on my own again, all under 18 at this point, looking at him like, OK, I've been told this is all in my head. I'm still having 17 seizures a day. *Doesn't fit, it's in her head but very real physical problem.*

And then... But I I don't really know what any of this means. And then the head of the department said, I think you should only see me from now on erm, but can people come and watch? *Like she is an attraction to behold. Not a sense that her care is the priority.*

Like when necessary. And I said... again, I'm all under 18. I'm like, OK, alright. *Looking back feeling like she was taken advantage of?*

Yeah, urm. They didn't want my. My dad would take me to the sessions in the [Hospital]. We went, I think, biweekly, weekly erm which I.... My dad would like to take the time off and drive me to the [Hospital], but he wasn't allowed to. He wasn't allowed to come in and. Erm, and I was under quite intensive psychiatric care. They medicated me erm I was on. *Family pushed out. passive, helpless*

Erm Ooo, not sertraline. I was on, they started- they wanted to medicate me. They started off with sertraline then they wanted me to be on something else and urm. Sorry, sorry, my partners walked past and its threw me off.

0:5:39
Interviewer
OK.

Commented [MF(6]: She is the problem, not believed, having to prove self

Commented [MF(7]: Passive, patient, vulnerable, mentally unwell

Commented [MF(8]: Multiple hcps, specialists, lack of confidence

Commented [MF(9]: Child, vulnerable. In her head

Commented [MF(10]: Made to feel like an attraction
Not a person needing care

Commented [MF(11]: Passive.
Vulnerable.

PARTICIPANT 1
Yeah. So, they initially medicated me and then we did psychiatric support for a couple of years. And they also then did, in that time, a study on me and where they like stress test me in a room where they like flashlights and see if it would cause a seizure and like did this and see if it would cause this, because I was having so many a day. *Time wasted? Again passive, like she was being studied, not cared for did she understand at the time?*

Commented [MF(12]: Wasting time
Passive
Studied
Lack of care

Interviewer
Yes.

PARTICIPANT 1
And I remember the cap being. I don't obviously this was a long, long while ago. So, this isn't, you know, this is the best the I'm trying to give the facts of, not my warp perspective of it but but the cap on and at the tiny TV in the corner of the up the corner of the room and they were like seeing what would react and what how I would react. So, I was part of the study then between the head of psychiatry in [Hospital] and a man in America erm... *warped perspective – projected identification of being crazy*

Commented [MF(13]: Made to feel crazy

So, for about 17, 17 till 20, about 19/20 I was erm I saw her once a week, once every two weeks erm and they, the seizures got better.

But not massively, like I was still having loads and loads. I was still able to, what- but what I was doing was having seizures then like standing up or if I knew I was gonna have a big one I would just sit down and have the like jitter. And then I, or I would go to the bathroom and when I knew I was gonna have a big one. So, I kind of was working out how to manage it erm as best as I could because obviously, I still needed to work. I didn't have anybody like supporting me financially erm. And I still needed to work and all those sort of things erm and then I... from the psychiatry team after the study was done, she said that erm... she doesn't know. *Trying to figure out how to care for herself because no one else was?*

Commented [MF(14]: Self-management
Having to rely on herself

So, what I was told at the last- the the couple of sessions before, she gave me, like, a kind of almost like a a couple of sessions closer together. So, it was like once every two weeks. And then I remember seeing me like a couple of times, slightly closer together when I was like 19/20 and I erm...

She said to me. [Participant 1], this is what we've been looking for is the root, uh, trauma of why you're having these seizures. So, what we've been looking for in the last four years is something like um sexual assault, umm abuse umm major trauma because what we think... *not being transparent, wasting time, could have just asked? No psychoeducation? The belief that trauma is emotional, what about physical trigger? Comorbid problems.*

Commented [MF(15]: Lack of transparency
Wasting time
Its in your head

Appendix M: Excerpt of MS transcript sent for review.

Participant 6
So yes, so, she just said like and I, I think at that stage as well, all I'd ever heard about MS was kind of in a wheelchair. Umm. Like almost dying from it, which I now know isn't true, but my my thoughts of MS were, oh my goodness, you're gonna be in a wheelchair. You're not gonna be able to speak or talk, and then you're gonna die like that was kind of all through my thoughts. But she was very good. And she quick, she said, look, let's, do you what do you know about MS? And I'd like not a lot. Wheelchair can't. We said no, it's not like that. There's all different kinds. *Catastrophising thoughts about what MS is, illness beliefs. Engaged her in conversation – she cares. HCP holds expert knowledge.*

Commented [MF(1]: Catastrophising
Beliefs about consequences being bad
HCP cares
HCP is the expert
Confidence in HCP

Umm so she did, kind of. She had some leaflets ready to give to me and kind of she, she said, look you, everyone's different with MS. You need to just. *Ready with information*

Read up about what you can and can't do, and she said we'll get, make your appointments and this when she said she wanted me transferred to [Hospital] because she felt they had a very good team and if I was gonna have my lumbar puncture up there and all that kind of thing. She said right, I've got to book you you straight in for the lumbar puncture. *Being taken care off, rationale for being sent somewhere better. Like they were taking care of things and laid out a path for her.*

Commented [MF(2]: HCP Cares
Clear next steps
Being taken care of

So she wanted me under [Hospital], so I was like, fine. Umm. So yes, then I have to go and have a whole load of blood tests as well. Umm. So that was a bit of a shock because obviously we kind of had this diagnosed and had to go and sit and do blood tests and all this kind of thing. Umm, but that was fine. We did that. Umm but yeah, she was. She was very good at explaining kind of that. It wasn't the death sentence that I thought it was. *Further tests after diagnosis – continued care. Good at explaining. HCP took time to dispel myths and spoke about consequences.*

Commented [MF(3]: Continued support
HCP Cares
Information
HCP is the expert

0:17:11
Interviewer
Yeah.

Participant 6
Umm, so yeah, and as much as it kind of came as a shock, I've always kind of, we've talked about it. I've looked back and thought. They never could kind of tell you things, because otherwise people worry even more. Don't then, if it's not anything like that, it's a hard position to be in. You can't win. I don't think. Umm but she was very good at kind of explaining that I had, like, from what she was aware I had this relapsing remitting MS. And she said time will tell. We got to do more tests, that she truly believed that was it. *She had thoughts about the hcp, mentalising how they feel, they are seen as person.*

Commented [MF(4]: Relationship with HCP

And it was weird because by this point, I'd started to have, like, some pain in my knee.

Interviewer
Right.

Participant 6

Umm. So I suppose in some ways the well it's kind of relief that I wasn't kind of falling apart or that there was a diagnosis, I suppose. But then I'm kind of like, right, what can I do to help? *Relief, got a diagnosis, what can I do, wanting to take control, not wanting to be passive – because hcps were doing everything and taking care of things?*

Commented [MF(5]: Control
Diagnosis gives relief

Interviewer
Yeah, that's yeah, so shock, but then relief. How? Yeah. Did you? Yeah. How did you feel? Umm In terms of how you were treated by the consultant?

Participant 6
Oh, she was lovely. She was really lovely. I think she. Yeah, she did everything she could to reassure me. She obviously she's dropped the MS. And I was like, ohh. And then she was like right now. She made sure that I kind of understood it wasn't what I was thinking necessarily, she said yes. OK, it can happen, but also, like, you've got to understand it, it can... There's lots that can be done these days and. *Built relationships with hcp, felt cared for, supported. She did everything she could – went above and beyond?*

Commented [MF(6]: Relationship with HCP
HCP cares
HCP did everything they could

Umm she said she couldn't go through everything with me, but she was like, look, you'll have more appointments. We'll go through. We'll tell you lots of different things and what we can and can't do. And she puts it all in place kind of straight away, all the different appointment with the MS Nurse appointment, with the consultant and having the lumbar puncture and all of that. She said, I'm going to get that all set up straight away. I mean again, I was quite lucky. It did all happen quite quickly. *Taken time, felt cared for? "We" in this together, not alone, collaborative, happened quickly, no waiting.*

Commented [MF(7]: HCP Cares
In it together - not alone.
No waiting - being taken care of

Interviewer
Oh lovely. So it sounds like you you felt quite cared for in that moment.

Participant 6
Oh very much.

0:19:29
Interviewer
Not just in that appointment, but also in terms of what was happening next. It was kind of all… you said, you felt reassured. And I guess that a lot of that is because she's then said, you know, and then this is gonna happen next and we'll set up these appointments and yeah.

Participant 6
She definitely didn't leave me kind of in the unowned, thinking what now? She made sure I kind of *understood what was going to happen and all that kind of thing. So that was, yeah, that was lovely. Not left with uncertainty.*

Commented [MF(8]: Cared for
No uncertainty

Interviewer
What happened next? What? Yeah. So what was it like afterwards in terms of your continued care?

Participant 6
So then I so I went and had blood test, obviously. Then I went home and then there was…

A bit of a wait for the lumbar puncture. I seem to remember it. I wonder if I've got it here. Hold on. Let's just grab this diary. I keep a umm like 5 year diary now. That kind of tells me everything that I'm doing and what's happened. But yeah, I have the lumbar puncture. I think it was kind of September time. *So many things happening and quickly… taken care of?*

So yeah, then I kind of, because it was being transferred to [Hospital]. It was a little bit harder in that umm.

Yeah. So it's a little bit harder in that I have to obviously wait for the appointments and kind of see what was going on, but they did. Like I said, they did do it quite quickly. *Did have some waiting, but still viewed as they were doing things as quickly as they could, not their fault, just the way it is. – they have done everything right.*

And I had. Umm. So I had the lumbar puncture. I believe it was the September umm that was my first appointment. So obviously in the meantime. I just kind of Googled things myself which probably didn't help to a certain extent, but did as well. *Waiting was ok, did lead to googling things. Needing to not be passive? Anxiety?*

Umm and then I was referred after that after I said I wouldn't have another lumbar puncture, I was referred to a consultant there umm at [Hospital]. Who I saw, I think it's it's October, November time towards the end of the year.

Umm. And. Again, I felt she was just really brilliant, really thorough. She kind of she did all the examinations with me. But by this point I'd had quite a few other symptoms, like weakness in my hands, loss of sensation. *More symptoms, getting worse, but feeling cared for, did the examinations with me – not to me, not passive.*

Umm my knee kept giving way. So it kind of all felt a bit scary because I kind of thought felt like I'd been given this diagnosis and suddenly I was falling apart and it was a bit like ah. *Things getting worse after diagnosis.*

Umm. But when I saw the consultant she was very reassuring and she said, look, it can happen like this. This is why. But she also kind of looked back on my records and was like, you could have had this for 10 years. *Normalised. This is what they expect, they have seen it like this, confidence in them.*

Commented [MF(9]: Things progress quickly
Being taken care of

Commented [MF(10]: HCPs doing everything right
No one to blame

Commented [MF(11]: Anxiety
Seeking information
Needing to act/not be passive/be in control

Commented [MF(12]: HCP cares
Trust in HCP
Not passive

Commented [MF(13]: Normalisation, validation
Confidence in HCP