Exploring the Experiences of Neurologists and Patients Undergoing the Diagnostic Journey for Functional Neurological Disorder

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To my family, thanks for the emergency zoom calls and the pep talks.

To my friends, thanks for waiting for me. I think it's about my turn to get a round in!

Overview

This thesis portfolio comprises three parts:

Part One: Systematic Literature Review

Background: Functional Neurological Disorder (FND) is a distressing condition with no confirmed cause. There are approximately 8000 new cases in the UK alone per year. It is a positive diagnosis, with tests available to identify clinical features that are distinctive to FND. Until 2013 it was thought to be caused by psychological distress alone, however this is no longer the case. This review aimed to explore the experiences of patients as they interacted with health care systems during the process of being diagnosed with FND. Method: Five databases were searched: Academic Search Premier, CINHAL Complete, Medline, APA PsycArticles and APA PsycInfo resulting in 11 qualitative and one mixed-methods papers to review. The papers were quality assessed before a narrative synthesis was conducted to provide a narrative of the patients' experiences. The narrative included three chapters of before, during and after diagnosis. There was uncertainty and stigma as outdated assumptions about the psychological cause of FND was directed towards them. However, there could be times of validation and relief if they were able to speak to a health care professional that understood their condition.

Part Two: Empirical Paper

Background: In the UK, neurologists are the clinicians most likely to diagnose Functional Neurological Disorder (FND) with research suggesting that approximately 30% of neurology patients have FND. There is little understanding of the impact this area of their work has on neurologists, or the meaning they make of their experience. Without this knowledge, the effect it may have on neurologists' wellbeing and job satisfaction, or the healthcare experience of patients with an FND diagnosis, cannot be identified.

Method: Semi structured interviews were held with ten UK based neurologists who have experience of diagnosing FND. The interview transcripts were analysed using interpretative phenomenological analysis (IPA).

Results: Superordinate themes of system failure, diagnosis and identity matters were developed. Within these superordinate themes were subthemes covering areas including: lack of FND services, time constraints for consultations, whether FND should be part of a neurologist's role, the importance of the doctor-patient relationship, the use of resources, communication difficulties, the meaning of identifying as a neurologist, and the problematic language often used when referring to FND patients.

Discussion: Underpinning all the themes was the widely held view that FND is a psychological issue and, as such, can attract the same stigma that other mental health issues often attract. Additionally, as medical professionals, neurologists do not see conditions they understand to have a psychological cause as within their remit. This view is problematic as the etiology of FND is still unknown, it does not necessarily have a psychological cause and to assume otherwise is incorrect and can be very unhelpful. The societal narrative around mental health influences not only the neurologists but the systems around them which impacts on the provision of FND services and training.

Part Three: Appendices

Total word count (excluding appendices): 18,856

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Part 1 – Patients experiences of interactions with health care systems during the FND diagnostic process

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1.1 Abstract

Background: Functional Neurological Disorder (FND) is a distressing condition with no confirmed cause. There are approximately 8000 new cases in the UK alone per year. It is a positive diagnosis, with tests available to identify clinical features that are distinctive of FND. Until 2013 it was thought to be caused by psychological distress alone, however this is no longer the case. This review aimed to explore patients' experiences of interactions with health care systems during the FND diagnostic process. Method: Five databases were searched: Academic Search Premier, CINAHL Complete, Medline, APA PsycArticles and APA PsycInfo resulting in 11 qualitative and one mixed-methods papers to review. The papers were quality assessed before a narrative synthesis was conducted to provide a narrative of the patients' experiences. The narrative included three chapters of before, during and after diagnosis. There was uncertainty and stigma as outdated assumptions about the psychological cause of FND were directed towards them. However, there could be times of validation and relief if they were able to speak to a health care professional that understood their condition.

Keywords: Functional Neurological Disorder, FND, patient experience, healthcare providers

1.2 Introduction

Functional Neurological Disorders (FND) are a group of disorders which can affect any part of the neurological system. They are the second most common reason for attendance at neurology clinics after headaches, with an estimated 8000 new diagnoses every year in the United Kingdom [1]. Common symptoms include dissociative seizures, movement disorders such as tremors, jerks and spasms, limb weakness, dystonia, gait disorders, sensory impairment of body parts (reduced sensation to certain areas of the body), visual impairment such as tunnel vision and cognitive symptoms which effect memory and concentration. Whilst they might appear comparable in nature to other neurological disorders, they are different in several ways, the

foremost being that they do not have a known causal pathology [2]. Whilst the symptoms of FND are considered medically unexplained, it should not be confined to a 'last resort' diagnosis, rather, it is a positive diagnosis which is established through specific investigations and tests [3]. These investigations aim to identify either the 'internal inconsistency' of the symptoms – whether the symptoms are always present, or incongruity of the symptoms with currently recognised structural neurological disorders [4]. The practice of making a rule-in rather than rule-out diagnosis is recent relative to the history of FND. When the fifth edition of the Diagnostic and Statistical Manual (DSM V) was published in 2013, it stipulated new criteria for diagnosing FND, with a requirement that "there must be clinical findings that show clear evidence of incompatibility with neurological disease." [5]. This was contrary to the previous edition (DSM IV) which required that a "thorough medical investigation has been performed to rule out an etiological neurological or general medical condition" [6].

The diagnostic approach was not the only change in the latest version of the DSM, the previous term for FND, 'conversion disorder', was renamed 'conversion disorder (functional neurological symptom disorder)' in a bid to illustrate that the symptoms are no longer always assumed to be associated with psychological factors, or more precisely, a conversion of psychological symptoms into somatic symptoms. In recognition that there might sometimes still be a psychological element in FND, the DSM V has removed the diagnostic criteria that psychological factors are judged to be associated with the symptoms and replaced it with an option to specify whether the disorder is present with or without a psychological stressor [5]. This latest understanding of the disorder is a marked change from the historically held conviction that FND was always the result of unresolved trauma or an expression of stress. This outdated way of understanding the disorder can be demonstrated by some of its alternative names, such as 'psychogenic' or 'psychosomatic' disorder, names which suggest it is 'all in the mind'. To add to

the lack of clarity surrounding FND, there are also labels which, rather than informing us of what it is, tell more about what it is not, these include ‘non-organic’ or ‘non-epileptic’ [7]. Moving into more dismissive territory is the term hysteria, a word originally coined in ancient Greece to refer to women whose ‘wondering uterus’ has caused an excessive emotional reaction, the term was used in the DSM [8] until it was replaced in 1980 [9]. Perhaps of even more concern are the labels which suggest a level of deception, ‘factitious disorder’ or ‘malingering’ are descriptions which clearly imply the patient is inventing the symptoms for medical attention or some other type of gain [7].

Efforts have been made to inform and educate clinicians of these recent changes to the diagnostic procedures and the overall philosophies surrounding FND [10]. The internet has become a source of information, which can be utilised by clinician and patient alike [11]. This plethora of information is vital if clinicians are to move away from the uneasiness they often feel when diagnosing FND [7], an uneasiness which may be grounded in a fear of misdiagnosis, a fear said to be exacerbated by the findings of a frequently cited paper by Slater [12] which suggested as many as two thirds of ‘Hysteria’ diagnoses were later discovered to be organic [13]. The concern of misdiagnosing can be understood when considering the detrimental outcomes of not treating certain neurological diseases, for instance, without treatment, epilepsy could lead to the possibility of a reduced lifespan, physical injury to the body and neurological injury to the brain [14]. However, the risks associated with misdiagnosing FND as epilepsy or other neurological conditions are not insignificant. Iatrogenic harm from the use of antiepileptic drugs or other medical interventions is likely [15]. Additionally, there may be limitations imposed in areas such as type of employment allowed or driving restrictions [16].

The struggles that clinicians experience over diagnosis can lead to consequences for their patients, not only because of the risks associated with undergoing unnecessary investigations, but

also due to the risk of being misdiagnosed as identified above. Without the expected story of symptom, diagnosis, intervention and cure they are left without a narrative to understand their condition, and therefore can struggle to accept it [17]. Canna and Seligman [18] suggest there is a 'quality-of-care crisis' where patients with symptoms which lack a known corresponding physical cause, experience de-humanisation in bio-medical settings. Their clinical encounters can leave them feeling stigmatised and without access to adequate treatments. The way the diagnosis is communicated can have therapeutic implications as patients who accept the diagnosis have better clinical outcomes than those who do not [19-21].

To improve patients' encounters with health care providers (HCPs) and perhaps their clinical outcomes, the diagnostic process needs to be better understood. There are studies that cover this area, either specifically or as a part of a wider understanding of the patient's lived experience, however many of these have used self-report questionnaires, such as Arain [19] who used a 14 item questionnaire which asked yes/no questions such as 'PNES means I am crazy' or 'doctors have no clue what causes my seizures', or Cope et al [22] who asked participants to rate between 1-100 how much they understood their diagnosis or whether they were hopeful regarding recovery. These limited response options can be useful to identify a general sense of how patients feel as they interact with HCPs as they go through the process of being diagnosed with FND, but they do not provide the rich data that can be gathered via methods which allow for freedom in the responses given.

The aim of this review is to explore how patients with FND experience the diagnostic process, and to discover the meaning they apply to this experience. There are no other existing systematic reviews with this aim, however there are two that have some relevance to understanding the FND diagnostic process for patients. Rawlings and Reuber [23] conducted a systematic review of patients' accounts of living with psychogenic non-epileptic seizures (PNES), in

their results they reported themes that covered diagnosis and encounters with healthcare professionals. However, their review was limited to the experiences of patients with PNES, rather than those with other FNDs such as functional movement disorders (FMD). Varley et al [25] conducted a review on the clinical management of FND, the scope of their review covered the wider topic of diagnostic methods, treatments and interventions, and the experiences of healthcare workers, patients and caregivers. Their results included a very limited, one paragraph, report of patients describing HCPs as key to their experiences.

Therefore, the purpose of this review is to gather an understanding of what is known regarding the diagnostic process of FND from the perspective of patients. The research question is:

"How do patients experience interactions with health care systems during the FND diagnostic process?"

1.3 Method

1.3.1 Search Strategy

A comprehensive search was carried out in June 2024 utilising the EBSCOhost search engine. The following electronic databases were selected: Academic Search Premier, CINAHL Complete, Medline, APA PsycArticles and APA PsycInfo. These were selected as they cover medical, psychological, and general databases which enhances the probability that all relevant studies were detected.

1.3.2 Search Terms

The following search terms were decided upon through supervisory discussion and scoping searches:

Patient* experience* OR patient* perspective* OR patient* view* OR patient* satisfaction (all fields)

AND

Diagnosis OR Diagnoses OR Diagnosed (all fields)

AND

Functional neurological disorder* OR FND OR conversion disorder* OR functional movement disorder* OR nonepileptic attack disorder* OR NEAD or nonepileptic seizures OR medically unexplained symptoms OR MUS OR PNES OR psychogenic nonepileptic seizures (all fields)

1.3.3 Screening and selection

The inclusion and exclusion criteria implemented are shown in Tables 1 and 2.

Table 1

Inclusion Criteria

Inclusion Criteria	Rationale
Patients with a diagnosis of FND has participated in the research.	It is the experience of the patient that is of interest
The study covers the of patients' interactions with the health care system during the period of their diagnosis of FND	It is the patients' experience of the diagnostic process that is of interest
The study is of qualitative or mixed methods design	The patient experience is of interest, which can be best discovered through qualitative data
The participants are over 16 years of age and drawn from adult services	People under 16 or under 18 in paediatric services are likely to experience their healthcare through their parent or caregiver

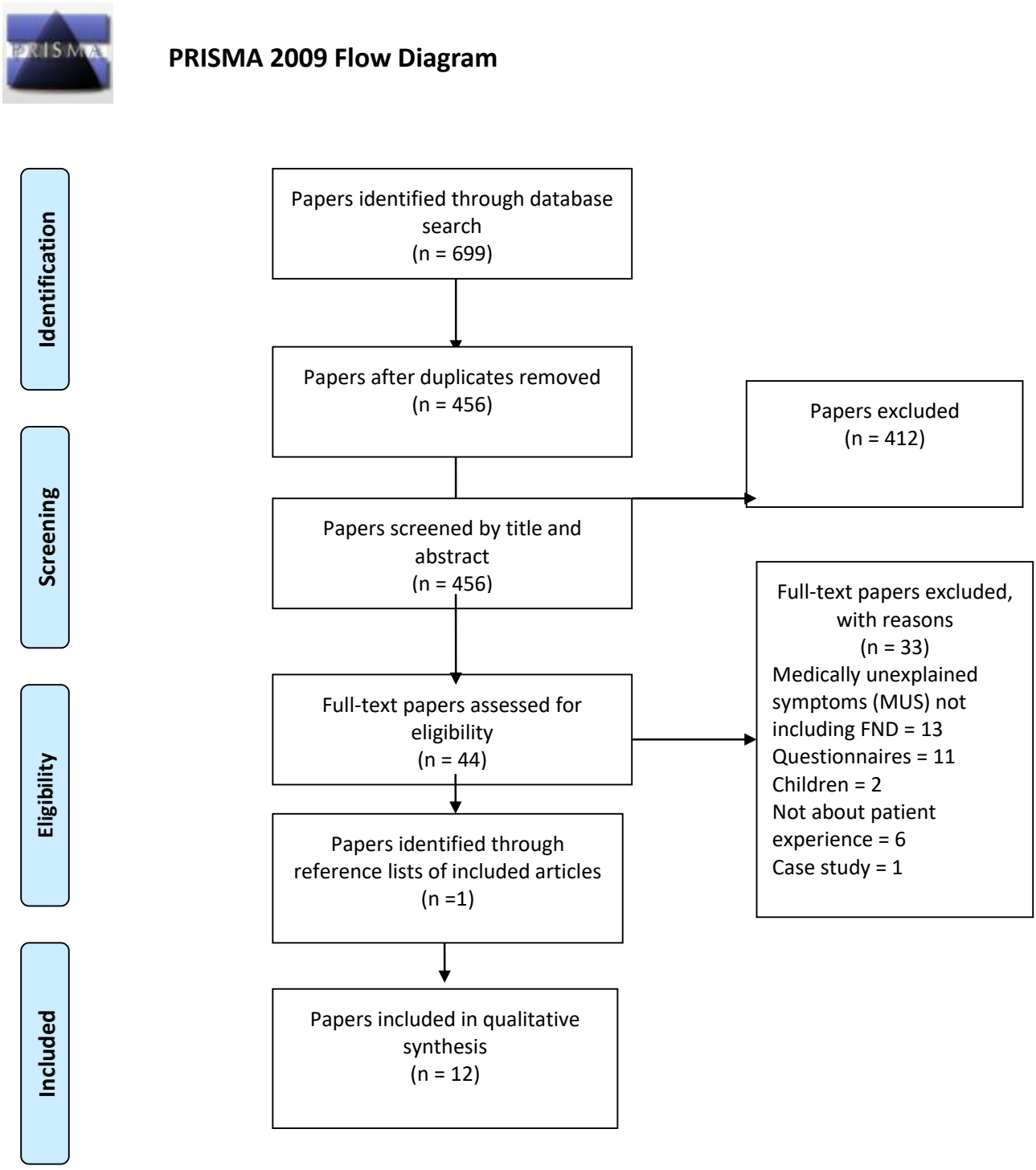
Table 2

Exclusion Criteria

Inclusion	Rationale
Papers that were not published in English	To enable the researcher to understand the study as funding for translation costs was not available
Papers that were not published in academic journals	To ensure quality and rigour of papers

Figure 1

Prisma Flow Diagram of Article Screening Process (Moher at al., 2010)



1.3.4 Quality assessment

The National Institute of Health and Care Excellence, (NICE [25]) quality appraisal checklist for qualitative studies was used to assess the quality of the papers included in the review (see Appendix G). It was chosen as it provides a framework from which a thorough assessment of the relevant characteristics of qualitative research can be conducted, and any factors that may affect the trustworthiness a study can be identified. The checklist includes fourteen questions covering theoretical approach, study design, data collection, trustworthiness, analysis, and ethics. There are prompts and guidelines to support the scoring process for each of the fourteen criteria, at the end of the process an overall score of ++, + or – is allocated depending on the extent to which the checklist criteria have been fulfilled. To ensure a degree of reliability in the scoring, a third of the papers, which amounted to four papers, were randomly selected to be reviewed by a peer trainee clinical psychologist who was blind to the original scores allocated by the researcher. All four papers were allocated the same scores and therefore it was felt the scoring given by the researcher was appropriate. None of the papers were excluded due to poor quality; nine were awarded the highest score of ++, and three scored the moderate score of +. The data extraction table includes the overall score of each study (see Table 3). Please also see Appendix H for a summary table of scores for each paper across the 14 questions of the quality assessment tool.

1.3.5 Data extraction

A data extraction form was designed specifically for use in this review by adapting a data collection form template provided by the Cochrane Collaboration [26]. Using the sections included in the template as a guide, all irrelevant sections were removed leaving only sections pertinent to the information required to complete this review. Please see Appendix I for an example of the data extraction form.

1.3.6 Researcher Position

The first author is a white-British female who is employed as a trainee clinical psychologist and previously worked as a psychotherapist. As such they hold certain assumptions about the nature of human behaviour and the way in which people create meaning from experience. These assumptions were held in mind during the data interpretation; however, it is acknowledged that they would have influenced the interpretations. Regular supervision, completing a reflective journal and reflexivity were employed in an endeavour to minimise researcher bias.

1.3.7 Data analysis and synthesis

The papers included in this review are qualitative in the main, however there is one mixed method study. The methods of qualitative analysis differed across papers and the research aims varied, although they all included participants' accounts of their interactions with the health care system. Therefore, narrative synthesis [26] was identified as the appropriate method of synthesis as it has the flexibility to include data from diverse study methods. Importantly, it allows for the creation of a coherent narrative of the data which seemed appropriate as the aim of the review was to focus on the participants' accounts of their experiences.

Following the guidance of Popay et al. [26], each paper was reviewed thoroughly, and a detailed data extraction was completed. A preliminary synthesis was developed initially by reading the results section of each included study methodically to identify any data that was relevant to the review question. Text and quotes that related to experiences of interactions with health care professionals and services were identified and highlighted and clustered together in themes. Once this had been completed for all papers, patterns, differences, and relationships in the data between studies was explored and the final themes were developed.

1.4 Results

1.4.1 Characteristics of included studies

Eight of the studies included in this review were based in the UK [28-35] one in Canada [36], one in Norway [37] and two in South Africa [38-39]. Most participants were recruited from hospital settings with only two studies [28,29] recruiting from the community. Bazydlo and Eccles [28] through the FND charity FND Hope and Carton et al [29] as ex-patients of the National Society for Epilepsy. There were a total of 177 participants, across the 12 studies, who contributed qualitative data included in this review. This total does not count the same participants twice, as two studies were 'salami publications' [38,39]. 140 of the participants were identified as females and 37 males. The mean age of participants could be identified in eight of the studies [28,29,31,33,35,37,38,39], the rest gave the age range in decades. The youngest participant whose accurate age was given was 16 and the oldest 67, however, one study [30] gave an age range into the 70s. Only four of the studies mentioned the ethnicity of participants which were [36] 4 white, 1 south Asian; [38,39 – same participants] 6 white, 4 'coloured' (these papers were published in South Africa where this term is still used to describe people of colour), and [34] 8 white, the ethnicities of all other participants is unknown. Participants in nine of the studies [29,31,32,34,35,36,37,38,39] were diagnosed with a functional seizure disorder, however, they differed in the term used to describe the condition. The alternative names used were; non-epileptic attack disorder (NEAD) [29,35], non-epileptic seizures (NES) [34,36], psychogenic non-epileptic seizures (PNES) [31,37-39] and functional seizures [32]. The participants in the remaining three studies [28,30,33] had a diagnosis of functional movement disorder (FMD).

The research aims varied across papers, including receiving an FND diagnosis, experiencing a change in diagnosis from epilepsy to FND, the perceived treatment needs of patients with FND and life with FND. There were several methods of analysis used, however, all included semi-structured

interviews, and all covered the experience of interacting with health care professionals during the process of receiving a diagnosis of FND. All papers were published between 2003 and 2022, four were published before the DSM V was published in 2013 with the new diagnostic criteria, four were published between 2014 and 2016, but collected their data around the time of the change in criteria, and 4 had been published in 2020 or afterwards. The 4 later papers did not assume there was a psychological causation for FND but the previous 8 did (see Table 3 for the data extraction table).

Table 3

Data Extraction Table

ID #	Author(s), year of publication, study title and country	Participant(s)	Method of data collection & analysis	Research aims	Key findings	Quality score
1.	Bazydlo & Eccles, 2022 Living with functional movement disorders: a tale of three battles. An interpretative phenomenological analysis UK	*N* = 10 (female = 8, male = 2) Age *M* = 41.6 Age range 24-66 All participants had a formal diagnosis of functional movement disorder for at least 12 months. Range was 13 months – 6 Participants were recruited from the community through the FND charity FND Hope. The research was advertised on their website, social media and patient engagement platforms	Semi-structured interviews Interpretive phenomenological analysis (IPA)	The study investigates the experiences of people with functional movement disorder to gain an understanding of their needs and the impact of their condition.	Three superordinate themes which covered the internal, interpersonal, and systemic battles faced by participants: Intrapersonal battle: The tug of war with the secret agent within. • Symptoms were described as an internal struggle characterised by feelings of oppression, loss of control and powerlessness resulting in a crisis where participants felt disconnected from their own bodies. Interpersonal battle: Navigating stigma and self-preservation. • Stigma and misunderstandings are faced from both healthcare providers and society in general. This leads to struggles with self-esteem which in turn leads to social withdrawal. Participants see education about FMD as necessary to promote a better understanding of the condition and to reduce stigma. Systemic Battle: Pursuing hope and treatments against helplessness and passivity. • Challenging interactions with the healthcare system left participants feeling inadequately supported and neglected. The lack of options for treatment left participants with a feeling of helplessness.	++

					The study highlights the need for a more collaborative approach to treatment between healthcare providers and patients and suggests there is need for a compassionate, holistic method of treating FMD.	
2.	Carton, 2003 Non-epileptic seizures: patients understanding and reaction to the diagnosis and impact on outcome. UK	*N* = 84 (female = 65, male = 19) Age *M* = 32.2 Age range 16-64 All participants had a previous diagnosis of epilepsy which had been changed to non-epileptic attack disorder (NEAD) after evaluation at the assessment centre of the national society. Participants who had a clear NEAD diagnosis and no coexisting epilepsy were recruited from the community via letter.	Semi-structured interviews Content analysis	To assess patients' understanding of and their reaction to a diagnosis of non-epileptic seizures (NES) and to explore how this affects clinical outcome	Understanding of diagnosis: • 63% of participants did not have a clear understanding of their diagnosis and some believed they still had epilepsy. Reactions to the diagnosis: • Confusion – participants did not recognise psychological precipitating factors. • Anger - this was frequently directed at the previous incorrect diagnosis. • Relief – being told they did not have epilepsy and therefore there were greater chances of recovery, was a relief for some participants. Psychological impact • The diagnosis of NES caused increased anxiety and lowered self-confidence in participants. It led to more social isolation and created barriers to employment. Seizure status • Around half of participants reported seizures had reduced by 50% or more, one third reported they were seizure free. Factors contributing to outcome. • Anger was attributed to poor outcome. • Good understanding of the diagnosis contributed to better outcome.	+

					The study highlighted the need for tailored treatment approaches based on patients' understanding and reaction to the diagnosis.	
3.	Dickinson et al., 2011 Patients diagnosed with nonepileptic seizures: Their perspectives and experiences. Canada	*N* = 5 (female = 3, male = 2) Age range 30-50 Ethnicity: 4 = white European origin, one = south Asian origin Participants were referred to the study immediately after receiving a formal diagnosis of psychogenic nonepileptic seizures from neurologists in two major Canadian hospitals	Semi-structured interviews Thematic content analysis	To examine how patients with nonepileptic seizures (NES) make sense of their illness experience considering the obstacles to treatment they face	Participants explored their illness narratives, their explanatory models, their treatment seeking experiences and the impact the diagnosis had on their lives. Illness narratives • Participants' illness narratives were related to early life events such as assault, head trauma, and witnessing epilepsy or more recent stressful events such as assault, divorce, death, and court proceedings. Illness prototype and explanatory models • Participants used different illness prototypes (epilepsy and anxiety) to understand their illness. This influenced their preference for drug treatment or psychotherapy. Those who modelled their illness on epilepsy were more likely to self-impose life constraints. Illness experience • The study identified the dualistic impacts of various factors on participants' illness experiences. These included social situations, personality traits and medical communication. The study emphasizes how patients' experience of NES is complex and variable depending on factors such as medical communication, social support, and personal history.	++

4.	Dosanjh et al., 2021 What is it like to live with a functional movement disorder? An interpretative phenomenological analysis of illness experiences from symptom onset to post diagnosis. UK	*N=8,* (female = 7, Male = 1) Age range 20s-70s Participants had a formal diagnosis of FMD – no limit to recency of diagnosis. Participants were recruited from outpatient clinic attendances or caseload list of a neurology department at a large NHS teaching hospital	Semi-structured interview Interpretive phenomenological analysis	To understand the impact of FND on patient's lives and gather insight into the sense they make of their experiences	Three superordinate themes and eleven subthemes: 1. Something is wrong with me. • Who is in control? ○ My body has a mind of its own. ○ It's not getting sorted. • Who am I? ○ I'm not myself. ○ Having to let go of my old life. • Who believes me? ○ People expect too much. ○ Dismissed and silenced. 2. At last! What now? • Someone understands! • What can help me? 3. Living my life with it. • Not in control of myself. • I want my old self back. • I'm proud of myself. The paper highlights the many losses experienced by participants throughout their illness, including loss of identity and loss of credibility. It reports that diagnosis can offer relief, and for some they are able to adapt well, however, for others the lack of a cure can lead to disappointment and patients remain distressed and struggling. The stigma and misunderstanding surrounding FMD could lead to feeling invalidated, however, positive interactions with HCPs were valued and deemed important to well-being.	++
5.	Fairclough et al., 2014 Understanding the perceived needs of patients with psychogenic nonepileptic seizures.	*N* -12 (female = 9, male = 3) Age *M* = 43.8 Age range 17-64 Participants had all received a diagnosis of psychogenic non-	Semi-structured interviews Thematic Analysis	To understand participants perceived treatment needs and expectations of psychological therapy in order to inform	Four key themes with twelve sub themes: • Return to normality: ○ Loss of normality ○ Desire to re-start life Participants felt distressed by how their lives had been changed by their condition, they reported feelings of embarrassment and	++

UK	epileptic seizures (PNES) within the preceding 12 months of the study.
	
	Participants were recruited from a PNES psychological therapy treatment waiting list of a large neurology department of an NHS hospital.
		treatment and management of patient group	hopelessness. They were uncertain that their desire to return to a life free from seizures would ever be realised, this uncertainty was worse for the participants who held the understanding that their illness was organic.
			
			• Post-diagnostic limbo:
			  ○ In the dark
			  ○ Confidence in diagnosis
			  ○ Making psychological links
			  ○ Feeling lost to services
			
			Participants felt caught in 'limbo' after their diagnosis, as they felt uncertain about their condition. This was exacerbated by the lack of clear information and inadequate support they received from healthcare professionals. Participants were left feeling abandoned, lost, and unsure about their future treatment paths.
			
			• Uncertainty and apprehension about therapy
			  ○ Finding answers
			  ○ Emotional release
			  ○ Taking control
			  ○ Avoiding further disappointment
			
			There was uncertainty and apprehension among some participants about psychological treatment as they were unsure if it could meet their needs. For some this was linked to previous disappointment with services due to treatment failures and misdiagnosis. For others, it was liked to doubt that their condition was psychological in nature. Conversely, for some participants there was a sense that psychological therapy could help them find the answers they were seeking about their condition.
			
			• Need for validation.
			  ○ Feeling dismissed
			  ○ Being understood by others

					Participants needed validation by healthcare professionals as they felt the diagnosis was viewed as lacking legitimacy. They felt dismissed and misunderstood which led them to feeling frustrated and isolated. They wanted the impact of their condition recognised and a more empathetic approach from the healthcare system. Overall, the study found that participants' concerns are not always well addressed by the healthcare system. It highlighted the need for better, clearer communication about PNES from healthcare professionals.	
6.	Karterud et al., 2010 Changing the diagnosis from epilepsy to PNES: Patients' experiences and understanding of their new diagnosis. Norway	*N* = 10 (female = 6, male = 4) Age *M* 27.3 Age range 16-61 Participants had a diagnosis of psychogenic non-epileptic seizures (PNES) having previously been diagnosed with epilepsy.	Semi-structured interviews Phenomenological approach inspired by Giorgi (1985)	To understand how patients experienced a change in diagnosis from epilepsy to PNES. In particular which aspect of the diagnosis was particularly difficult, to what extent their needs were met by the health service and which factors were associated with a successful clinical outcome.	The study reported five themes plus the emotional reactions to the new PNES diagnosis. There was also a follow up study reporting seizure prognosis. Themes: • PNES – a difficult diagnosis to understand. The majority of the participants found the explanations from healthcare providers confusing and lacking meaning. • PNES – a threat to the identity Participants' self-identity was challenged as they adjusted their understanding of their condition from 'neurological' to 'psychological'. • Transfer of responsibility Participants felt their new diagnosis came with a shift in responsibility from the health care professionals to themselves and they felt abandoned to manage their condition. In addition, they felt guilt and embarrassment in a way they had not felt with their initial epilepsy diagnosis. • The patients felt they were not included in the diagnostic process.	+

					Participants were frustrated by the definitive way their diagnosis was delivered. They lost trust with the medics when they felt their opinions were rejected and there was no common understanding of their illness. • Factors that had the greatest contribution to coping with the PNES diagnosis. Participants considered understanding the reasons for their seizures and meeting others with the condition vital to allow them to cope with having PNES. However, the factor that had most influence on this was being taken seriously by health care professionals. The emotional reactions to the PNES diagnosis: • Relief/happiness. • Aggression. • Anger/frustration. • Disappointment. • Fear. • Shame/stigmatisation/blame. Follow up study – seizure prognosis and factors influencing prognosis: • 3 participants seizure free. • 3 participants were better than before PNES diagnosis. • 2 participants were unchanged. • 1 participant was worse. • 1 participant was unreachable. Factors that may have influenced prognosis included acceptance of PNES diagnosis and understanding of causes of seizures. Overall, the study emphasises the importance of support and comprehensive care for this patient population.	
7.	Loewenberger et al., 2021	Participants included in full study:	Questionnaire/semi-structured interviews	To explore the preferred names for functional	The study reported a scale of preferred terms and offensiveness for functional seizures and three qualitative themes with nine subthemes.	++

What do patients prefer their functional seizures to be called, and what are their experiences of diagnosis? – A mixed methods investigation. UK	*N* = 39 (9 = female ,32 = male) Age ranges: 18-25 (*n*=8) 26-35 (*n*=10) 36-45 (*n*=9) 46+ (*n*=12) Participants from this group who also participated in qualitative interviews: *N* = 13 (female = 11, male = 2) Ages not given, however all will be 18+ Participants had a formal diagnosis of functional seizures with onset ranging from 1-8 years. Participants were recruited from a regional neuropsychiatry service.	Thematic analysis/Wilcoxon Signed Rank	seizures and the participants' experiences of being diagnosed.	Preferences for terms: 1. NEAD 2. Functional non-epileptic seizures 3. Functional seizures 4. Dissociative seizures 5. Conversion disorder 6. Psychogenic non-epileptic seizures 7. Psychogenic seizures 8. Medically unexplained seizures 9. Somatoform disorder 10. Pseudoseizures 11. Hysteria Offensiveness of terms: Terms that suggested a psychological cause were considered the most offensive. There was a significant overlap in the confidence intervals of offensiveness scores which indicated a heterogeneity in how offensive the terms were perceived. Qualitative analysis. Three Themes with nine subthemes: • Shared understanding o Provision of an explanation o Individuality o Being taken seriously o Not epilepsy An understanding of the causes and symptoms of the condition, as well as a meaningful explanation which could be shared with others was important. Feeling taken seriously, reassured, and supported helped to mitigate healthcare professionals' lack of knowledge. The

					diagnosis was a relief both as it had taken so long to get it and because it was not epilepsy or another potentially fatal condition.
					• Feeling alone
					  ○ Not knowing
					  ○ Faking it/to blame
					  ○ Feeling dismissed
					  ○ Self-initiated research
					The lack of sufficient answers and long and difficult waits for diagnosis left participants feeling alone. The lack of knowledge about the condition from healthcare professionals and lay people added to their feelings of isolation and uncertainty. Stigmatizing attitudes from health care professionals left participants feel accused of faking their symptoms. They felt abandoned by them throughout the diagnostic journey, this led participants to conduct their own research into the condition.
					• Sense of hope
					  ○ Importance of hope
					Hope occurred when participants felt listened to by healthcare professionals and had gained an understanding of the condition. This gave them a sense of how they could live well despite of their diagnosis.
					The study highlights the need for a shared understanding between clinician and patient for the best outcome. The need for awareness of the stigma attached to some of the terms commonly used to describe functional seizures so that offence is not taken.	

8.	Nielsen et al., 2020 A qualitative study on the experiences and perceptions of patients	*N* = 11 (female = 9, male = 2) Age *M* = 44.3 Age range 21-67 Participants had a diagnosis of FMD	Semi-structured interviews Thematic analysis	To explore the experiences and perspectives of patients with functional motor disorder	The study reported six themes: • The burden of living with Functional Movement Disorder (FMD) Participants experienced significant physical and emotional burdens because of their diagnosis. They experienced frustration and distress due to uncertainty about the prognosis and the lack of support from health care practitioners. They reported feeling isolated and lonely	++

with functional motor disorder. UK	Symptom phenotypes included tremor, gait disturbance weakness and mixed movement disorder. Symptom duration ranged from 1- 30 years	as they were excluded from society due to accessibility issues, pain or embarrassment. • Nobody knew what was wrong. Participants reported feeling distressed due to health care practitioners not understanding their condition, this was despite seeing multiple practitioners over a protracted diagnostic process. Undergoing multiple tests which did not identify a cause for their symptoms left them feeling frightened as they remained in the dark to the reasons for their illness. • Dissatisfaction with psychological explanations Participants were left dissatisfied when they were given psychological explanations for their condition. Some did identify previous psychological issues including trauma, but they did relate this to their movement problems. • Patients feel abandoned. Participants reported feeling abandoned and let down by healthcare providers. They described their interactions with them negatively citing poor treatment that left them feeling shamed. Only one participant had a different experience, and they described their health care provider as open minded who listened and believed them. • Iatrogenic harm Inappropriate treatment due to a lack of understanding and proper management of FMD by healthcare providers sometimes led to iatrogenic harm. This included unneeded medication and harmful physical therapy. • Powerlessness

					Participants expressed feeling powerless as they were unable to access effective treatment. This was exacerbated by the lack of clear diagnosis and the perceived abandonment by the healthcare system. The study emphasised the critical need for improving understanding, the diagnostic process, and the management of FMD by the healthcare system.	
9.	Pretorius & Sparrow, 2015 Life after being diagnosed with psychogenic non-epileptic seizures (PNES): A South African perspective. South Africa	*N* = 10 (female = 8, male =2) Age M 39.2 Age range 19-55 Participants had a diagnosis of psychogenic non-epileptic seizures (PNES). Participants recruited from an Epilepsy unit and a Neurology department of a large hospital	Semi-structured interviews Thematic Analysis	To explore the experiences of people who have been diagnosed with PNES and to discover the challenges they have faced and the resources they have utilised.	The study reported the results through the lens of Bronfenbrenner's ecological system. There were seven themes, four under the 'challenges' heading and three under the 'resources' heading. Challenges: • Unexpected seizures Microsystem – Safety became a primary concern as unexpected seizures could both cause physical injury or put the participant in danger from interpersonal assault when they were experiencing one. Exosystem – The inability of academic and occupational environments to adapt to the needs of the participants prevented them from continuing with their usual daily living. • Medical professionals Microsystem – The relationship with medical professionals was often seen as a challenge due to the lack of trust. They were seen as lacking in understanding about PNES. Participants felt they either misdiagnosed PNES as epilepsy or did not believe their symptoms were real. • Belief systems Macrosystem – The idea that PNES might be caused by a psychological condition did not fit with the belief systems of participants or those close to them. They also felt stigmatised and discriminated against because of the association of mental illness with PNES. • Family	++

					Microsystem – Concern about not worrying their families was a challenge to participants. This would lead to them attempting to hide their condition from family members. Resources: • Social support Microsystem and mesosystem – Strong social networks helped to mitigate the feelings of isolation and sadness. They also acted as a barrier to concerns about safety. • Medical professionals Microsystem – Finding a medical professional who was able to provide the correct diagnosis and treatment supported coping and resilience. Macrosystem – Medical professionals who believed in the disorder could use their position of power to support participants' explanation about their diagnosis to those who doubted them. • Religion and spirituality Microsystem and mesosystem – Praying helped participants cope with their diagnosis as they found it comforting and it provided them with strength. Macrosystem – The belief that their PNES was a part of a plan by a higher power enabled participants to make sense of their suffering. The study highlights the need for increased awareness and knowledge about PNES among healthcare professionals.	
10.	Pretorius, 2016 Barriers and facilitators to reaching a diagnosis of PNES from the patients' perspective: Preliminary findings.	*N* = 10 (female = 8, male =2) Age M 39.2 Age range 19-55 Participants had a diagnosis of psychogenic non-	Semi-structured interviews Thematic analysis	To examine the subjective experiences of patients during the diagnostic process of psychogenic non-epileptic seizures (PNES).	The study reported six themes, three categorized as barriers and three as facilitators to reaching a PNES diagnosis. Barriers: • Inexpert healthcare providers Participants' PNES was frequently misdiagnosed as epilepsy which resulted in being treated incorrectly with anti-seizure medication. It often took multiple consultations before a correct diagnosis was received. During the process of diagnosis participants experienced	+

South Africa	epileptic seizures (PNES). Participants recruited from an Epilepsy unit and a Neurology department of a large hospital		healthcare providers as lacking in empathy with negative and disbelieving attitudes. • Loss of independence Driving and employment restrictions due to seizures led to feelings of frustration and a reduction in perceived quality of life. • Limited medical insurance Financial implications arose when medical insurance did not cover treatment. This was exacerbated by the lengthy, and often unnecessary, tests that were involved. Facilitators: • Social support Emotional and practical support from friends, family and colleagues was highlighted as significantly helpful as participants went through the diagnostic process. When healthcare providers were well informed about PNES they facilitated timely, accurate diagnoses. The need for educating all healthcare providers was seen as vital if the PNES diagnostic procedure was to be improved. • Comprehensive medical insurance For the participants who held comprehensive medical insurance, the ability to obtain whichever consultations and treatments required facilitated diagnosis. The study highlights the need for accurate, timely PNES diagnoses to prevent inappropriate, expensive epilepsy treatments and improve patient outcomes. This can be achieved better if healthcare providers are trained more thoroughly about PNES.

11.	Thompson et al., 2009 What's it like to receive a diagnosis of nonepileptic seizures? UK	*N* = 8 (all female) Age range 20s-60s Ethnicity = white European All patients had received a diagnosis of non-epileptic seizures.	Semi-structured interviews Interpretative phenomenological analysis	To provide insight into the patients' experience of receiving the diagnosis of non-epileptic seizures (NES)	The study reported six main themes, two relating to the nature of NES and living with the condition and four relating to the impact of the diagnosis. Nature of NES: • The experience of living with nonepileptic seizures. Participants linked their experiences to their personal histories, which often included trauma and stressful life events. Seizures felt unreal, they left the participants feeling overpowered and helpless. Loss and isolation were a major factor. • Label and understanding. The diagnosis could provide legitimacy after a long search for an explanation. It could be seen as a relief that it was nothing more sinister. Participants who understood the diagnosis as psychological were open to psychotherapy treatment but those who believed in a physical cause found the idea ridiculous. Impact of diagnosis: • Being left in limbo land Participants spent long periods of time not knowing what was wrong and undergoing medical investigations which did not provide answers. They felt abandoned which led to significant emotional distress. • Doubt and certainty. Doubt about the accuracy of the diagnosis was experienced by the participants but also the doctors as demonstrated by the continued prescribing of antiepileptic drugs. Participants self-doubt about the legitimacy of their symptoms led to self-blame and guilt. • Feeling like a human being again The diagnostic process could be validating for participants, this was especially true if they had a positive relationship with their neurologist and found them approachable and knowledgeable. • Emotional impact of diagnosis. The diagnosis could elicit a range of emotions. For some there was relief as they had some certainty after such a long period of	++

					uncertainty. However, for some there was confusion as they attempted to make sense of the diagnosis. Anger was the most reported emotion, as participants reflected on their misdiagnoses or the trauma to which they attribute their diagnosis. The study emphasises that while the link between trauma and NES is true for some it is not always the case, and this should be considered during the diagnostic process. Overall, the study highlights the need for supportive clinical approaches to manage the complexity of an NES diagnosis.	

12.	Wyatt, 2014
	
	The experience of adjusting to a diagnosis of non-epileptic attack disorder (NEAD) and the subsequent process of psychological therapy.
	
	UK
		N = 6 (5 = female, 1 = male)
		
		Mean age 47.3
		
		Age range 29-55
		
		All participants had a sole diagnosis of NEAD.
		
		Years since onset of NEAD symptoms ranged between 2-44 years
		
		Years since NEAD diagnosis ranged between 1.5 – 5 years
		
		All participants were undergoing sessions with a psychologist
			Semi-structured interviews
			
			Thematic analysis
				To explore the experience of adjusting to a diagnosis of NEAD and engagement with therapy	The study generated six main themes with eight subthemes however only reported on four themes as two were not considered pertinent to the study.
					
					• Understanding NEAD
					  ○ It's a long-winded business…you get brushed off
					  ○ Sometimes you think what the hell have I got?
					  ○ We've got a label but no way of taking it off.
					
					The participants experienced frustration and rejection as they went through the lengthy diagnostic process. Once they received the diagnosis there was some validation. However, it lacked meaning for some, they were left feeling confused and distressed. This was exacerbated by the idea that there may be a psychological basis for the condition.
					
					• I can't deal with you… relationships with professionals.
					
					Participants' relationship with healthcare professionals was often combative and challenging. Being told their diagnosis was psychological in nature left them feeling disbelieved and accused of faking their symptoms.
					
					• Experience of psychological therapy
					  ○ You're a bit odd…go and see this person.
					  ○ Going deeper.
						+

The initial responses to the idea of therapy were mixed. For some therapy could be yet another failed avenue of treatment. The connotations of seeing a psychologist worried some and others were confused as they were seeing both neurologists and psychologists which did not help them to understand the base cause of their condition. There were some who felt that therapy could give them a deeper understanding of their condition.

- Adjusting to life with NEAD
    - My world has shrunk… but I've got my control.
    - Take me as I am or not at all.
    - Is this my life forever?
- There were many ongoing challenges for participants as they adjusted to life with NEAD. Managing future expectations around their condition was difficult, the thought that it would remain a major influence in their lives left some feeling hopeless. The expected negative societal views of NEAD led to feelings of isolation, powerlessness, and loss.

- *Support and burden.*
- *People just think I'm a nutter.*

These themes were not expanded upon in the study.

Overall, the study highlighted the need to improve the awareness of NEAD with health care providers so that stigma might be reduced. It concludes that therapy assists in the adjustment to life with NEAD and posits that psychologists are involved at the first point of diagnosis to reduce anxiety.

1.4.2 Narrative synthesis

After synthesizing the findings of the papers three distinct themes with ten subthemes were identified. The themes created a narrative as they followed the participants' journey as they progressed through the FND diagnostic process. The first chapter (or theme) covers the story as the participants waited for their FND diagnosis, followed by a chapter on the story of their experiences receiving the diagnosis, the final chapter of the narrative tells the story of participants post diagnosis experiences. See Table 4 for themes and included studies.

Table 4

Themes and Included Studies

Study ID Number		1	2	3	4	5	6	7	8	9	10	11	12
Main Themes	Sub Themes												
Journey to diagnosis	The long wait	X		X	X			X	X		X	X	X
	Misdiagnosis	X	X	X	X	X	X		X	X	X	X	X
	Dismissed	X	X	X	X			X	X		X	X	X
Receiving the diagnosis	Lack of HCP knowledge	X			X	X	X	X	X	X	X	X	X
	Making sense of it	X	X	X	X	X	X	X	X	X		X	X
	Validation	X	X	X	X		X	X				X	X
	The good doctor	X		X	X		X	X	X	X	X	X	X
After the diagnosis	Lack of confidence in the diagnosis		X	X		X	X		X	X		X	X
	Abandoned	X		X		X	X	X	X			X	
	Rude HCPs	X		X	X		X	X	X	X	X	X	X

1.4.3 Journey to diagnosis

1.4.3.1 The long wait

The findings of eight studies highlighted the period of time from commencing symptoms to gaining a diagnosis as lengthy and confusing for participants, leaving them feeling frustrated and scared.

Thompson et al. [34] used a quote spoken by one of their participants *"being left in limbo land"* (p. 510) as a theme name to emphasise a feeling of helplessness that participants experienced as they waited, unable to move forward with their lives, until they were able to understand what was happening to their bodies. They reported the *'negative emotional implications, in some cases resulting in a sense of great distress and desperation, of the long wait'* (p. 510). The journey to diagnosis, described as '*long and arduous'* where '*for all patients there were significant periods with insignificant answers'* by Loewenberger et al. [32, p. 5] gave participants the time to imagine the worst:

"You start scaring yourself almost about the things you read and whether they would apply to me" [30, p. 332]

Many of the participants endured multiple medical investigations that did not provide answers:

"I struggled for a long time…I felt like I was going from one doctor to another, and nobody had a clue" [39, p. 3]

Neilson [33] explained that receiving negative results after tests such as MRIs or nerve conduction tests was not reassuring but frightening, this was highlighted by their participant who explained:

"Because I went for the DaTSCAN, then I went to see the consultant and he showed be the brain results on the screen and told me what the normal levels should be. And said, 'well you don't have Parkinson's disease, but I don't know what it is that's wrong and then he said 'you don't look very

happy'. But I was plunging into the unknown then as I hadn't a clue what the diagnosis was." [33, p. 8]

Six of the eight studies highlighting this area were of high quality, they varied in their methods, this divergence allows for a confidence that this is a transferable trait. The two moderate quality studies lacked information on the rigorousness and reliability of their data analysis. Of the four studies that were not included in this area, one was part of a salami study, and their other paper was included. The three remaining were focused on the treatment needs of patients with FND, or the reaction to a change in diagnosis from epilepsy to FND.

1.4.3.2 Misdiagnosis

Being misdiagnosed was common amongst participants, some had spent many years with an incorrect diagnosis, even reaching into decades [29]. Other participants lived with the emotional burden of having their diagnosis changed frequently:

"They have changed my diagnosis six times, is there any wonder I am angry? [37, p. 42]

The consequences of living with misdiagnosis were far reaching with iatrogenic harm clearly a risk for the many participants who were prescribed medication including anti-epileptic drugs, or drugs for a presumed diagnosis of Parkinson's such as benzodiazepines which could have seriously negative side effects:

"Initially they thought it was epilepsy and I was given tablets for it" [39, p. 3]

"I saw five different neurologists…each one started me on a different medication… they all diagnosed me with epilepsy." [39, p. 3]

Misdiagnosis also had a huge impact on the way many of the participants had lived their lives, including the type of work undertaken, driving vehicles, or even having children:

"…significant information that had affected my career prospects and decisions not to have children… I felt I had been cheated and wanted my life back again." [29, p. 290]

"They wonder now why I'm depressed. I'm depressed because I know my life's been wrecked from misdiagnosis…" [34, p. 511]

Confidence in this theme was high as 11 of the 12 papers included in the review contributed to this theme. For some of the papers, this was their area of interest and so it is unsurprising that it appears as part of the story, however, all the papers whose interest was of the wider experiences of people living with FND reported misdiagnosis as an issue for their participants. The one paper that did not contribute to this area [32] was the mixed methods paper, whose focus was investigating participants preferred names for FND, their semi-structured interview schedule focused on the experiences of receiving the diagnosis and the explanation provided so was less likely to elicit answers that included misdiagnosis.

1.4.3.3 Dismissed

One of the outcomes for participants who had been found not to have a non-functional diagnosis but were yet to receive an FND diagnosis was the sense that they were dismissed by HCPs. Wyatt et al. [35] described them feeling frustrated and rejected as they dwelled in the no man's land between diagnoses. Participants reported being 'fobbed off' by HCPs:

"It's they didn't believe you…'well nothing makes sense so you can't be experiencing all these…" [30, p. 333]

Participants felt shame when they felt like they were rejected by doctors as if they were not ill enough to warrant any time or resources. Doctors who expressed that they would not be treating patients with FND were experienced as disbelieving or not wanting to help rather than perhaps not feeling able to:

"Cause you're not physically ill, they don't think you're ill" [35, p. 803]

"Yeah, he said you haven't got a, you haven't got a brain tumour, and you haven't got cancer. I've got other patients. Like he said, because I didn't have cancer, he didn't want to help me" [33, p. 10]

For participants in the pre-diagnosis stage, feeling dismissed paved the way for other emotions including feeling angry, lost, let down, unsupported and neglected:

"I was angry… I couldn't understand why these people weren't getting me the help I need… It was like everyone was washing their hands of me and weren't doing anything to help" [32, p. 5]

"I was discharged again without any explanation and just left… it was frustration, it was anger…" [34, p. 511]

This theme was supported in eight of the papers of high and moderate quality, and included IPA and TA methods, three of the papers that did not contribute were high quality but focused on reaction to diagnosis and treatment needs. The moderate quality paper that did not contribute used CA and was lacking in rich data.

1.4.4 Receiving the diagnosis

1.4.4.1 Lack of HCP knowledge

Participants' struggles did not end when they were eventually given an FND diagnoses, a major issue identified for participants who were receiving an FND diagnosis was the confusing way the diagnosis was delivered. Consultations were either jargon heavy, or lacking meaning, and participants struggled to hold on to information when it was delivered in unfamiliar language which used unhelpful terms to describe their condition. Instead of delivering a confident and comprehensive explanation, participants were often left on the receiving end of an ambiguous, confusing account of their illness:

"The neurologist was so vague; he didn't really know what he was on about." [35, p. 803]

The sense was that it was as unknown to the HCPs as it was to the patients. This apparent lack of knowledge led to it being described as 'an enigma for professionals' [31]:

"It's an unknown thing really, in the way of the medical situation, like sort of thing, it hasn't been quite got to grips with in the medical profession yet." [31, p. 298]

"The doctor couldn't understand or explain it." [38, p. 36]

Experiencing medical professionals as having as little understanding created a barrier to those seeking diagnosis. The lack of any sense of certainty about why they had developed the condition, with just a blanket assertion that it was caused by stressful life conditions or previous trauma, left participants speculating about their past if they did not have an obvious life event to attach it to. The absence of any options for treatment that did not include psychological therapy left participants feeling they had no concrete next steps which they perceived as potentially helpful to them. The uncertainty surfaced as distress and frustration:

"It's overwhelming… there's a lot of unknowns with [the condition]… I found it quite frustrating and scary to think how I'll deal with this" [32, p. 5]

Frustration was not the domain of the participants alone; at times it surfaced and became visible during consultations, which may have in turn linked back into the participant's distress:

"One doctor became frustrated and said, 'I don't know, I don't know what else to do'" [39, p. 3]

This was a high confidence theme with ten high and moderate quality papers contributing. Both of the papers that did not contribute utilised a version of content analysis, one was of moderate quality paper that was less rich in data. In contrast, Dickenson et al. [36] was high quality across all areas, however, its focus was on the illness experience of participants and therefore less likely to cover this topic.

1.4.4.2 Making sense of it all

Without effective explanation from HCPs, or explanations that lacked personal meaning, participants found their diagnosis difficult to understand and were left bewildered by their condition:

"So now I must say I have PNES and I don't know how I can explain this to anybody else when I don't even understand it myself." [37, p. 42]

A prominent reason given for confusion over FNDs were the variety of labels used to describe it. Participants criticised terms such as 'non-epileptic' for including something it was not rather than what it was:

"If it's not epileptic then why would you put 'epileptic' in the name?" [32, p. 5]

When the term 'psycho' was included in the name it instilled fear due to the connotations with mental illness and 'pseudo' caused issue as it implied fakeness:

"…I knew I wasn't making it up…it really upset me because it made me very frustrated and I started to question myself, like, 'am I crazy? Have I gone insane?'" [32, p. 5]

Participants were left with little choice but to attempt to make sense of the condition themselves, this was challenging due to the sheer amount of literature available. As there is no single comprehensive understanding of FND or its causes, participants found themselves being taken down various digressions as they sought to gain knowledge about their condition:

"I was looking to see what I could find out that was parallel with what I was having, but I found It was very, there's so much information out there, that it's just kind of, oh-ho, I just, I didn't get too specific, because it just led off in so many directions, there's so many different possibilities and there's so many different, I just, I backed off from it." [36, p. 456]

"It's like trudging through mud in a maze" [28, p. 9]

Participants found useful sources of information to aid understanding of their condition were the reliable online resources such as neurosymptoms.org. The thorough information was presented in ways that held meaning and was comprehendible to participants. They were also able to feel less isolated with their condition when reading about the personal accounts of other FND patients on these sites. Meeting other FND patients was also seen as important for gaining insight into the condition and learning coping strategies:

"When I talk to others, I understand my own situation better" [37, p. 44]

This theme was another high confidence theme as 11 out of the 12 papers contributed, and the one paper that did not contribute was one of the salami publications. This suggests that across all study aims included in this review, participants were finding themselves having to make sense of what was happening to them due to lack of resources and information from HCPs.

1.4.4.3 Validation

The sense of being somehow to blame for their symptoms, or worse, being accused of faking them, was a commonly held view across all studies. So much so that participants sometimes doubted themselves:

"You start to think, 'well, why aren't they finding anything, am I making it up, or is there something I can do myself to stop it?'" [34, p. 511]

Therefore, receiving an FND diagnosis was a step towards ridding participants of the internalised doubt that caused them such distress:

"It's not in my mind, I'm not making it up. That was all I was bothered about really… there is a reason why this is happening." [34, p. 511]

The stigma attached to the 'faking it' label was carried by many participants, so when they were given validation that their condition was real, and they felt they were believed at last, the emotional impact was great:

"He told me about the condition and I just couldn't believe somebody actually believed me… I cried, all my frustration had come out 'cause I was being believed and not being made a fool" [35, p. 803]

The damaging consequences of not validating participants' experiences, or demonstrating clearly that they are believed was outlined:

"It's more important and vital that doctors… be vigilant in saying it's not fake, we should be dealt with, with respect. That's the one thing above everything else, deal with us with dignity and

respect, because the moment you write us off, is the depressed we get and the more desperate to get results." [36, p. 457]

Eight studies contributed to this theme, all four of the papers that were not included were thematic analysis papers. In contrast to experiencing validation from HCPs, Fairclough [31] reports a theme of 'needing validation' and pointed out that because of this their participants purposely sought it from other sources than the health care system.

1.4.4.4 The good doctor

In contrast to the detrimental effects resulting from the many negative experiences reported by participants across the studies, a key positive effect was found when the participant perceived their relationship with their HCP as warm and collaborative:

"It made you feel better knowing that somebody was interested in what was the matter with you. Rather than somebody who just made you feel as though they didn't care less" [30, p. 334]

It was rare to hear reports of only positive interactions with HCPs, however Neilson [33] found that often participants could report of at least one 'praiseworthy' clinician who listened to and believed their patients:

"I've got a very good doctor and he's been looking it up. And he's been very supportive." [33, p. 10]

The value of feeling listened to after long periods of being ignored was evident and appeared to bring relief and a sense that there was a newfound purpose to the medical consultations:

"It's the first time in four years that somebody's actually listened to me, that actually wants to diagnose me and actually find out what the problem is" [36, p. 456]

[The neurologist] "made me feel very different from anyone else had… He is interested, and that felt really good" [34, p. 511]

The lack of an obvious path of treatment was a predominant story across papers, therefore when HCPs spoke about proactive care plans it was unexpected. Bazydlo [28] reported participants being 'stunned' by such an undertaking by a neurologist:

"She was really amazing, it was almost like the starting gun at the start of a race… Instead of constantly being fobbed off by everyone else… she listened and said, 'OK, let's see what we can do'" [28, p. 9]

11 papers were included in this area of the synthesis, with only the moderate paper with less rich data excluded, this identifies that the importance of the relationship with HCPs reaches across the aims and methodologies of the other studies in the review.

1.4.5 After the diagnosis

1.4.5.1 Lack of confidence in the diagnosis

There were many examples of participants doubting their diagnoses and there were several attributing factors to this. For some participants their history of misdiagnosis left them with a feeling that diagnoses were not necessarily fixed and that they were simply another opinion of neurologist that could be easily replaced by a medic in the future:

"In two or three years' time they might tell me it's a different one" [31, p. 298]

"I'm thinking 'well he's right'… and some days I think he's wrong" [34, p. 511]

The reliability of the diagnosis was put into question for participants who had a previous diagnosis of epilepsy that had been changed to FND, but their neurologist continued to prescribe anti-epileptic drugs. This action seemed to demonstrate that the medics themselves had no faith in the accuracy of the new diagnosis and so participants remained doubtful themselves:

"[The neurologist] 'says he wants me to come off the tablets when I start seeing [the psychologist]" [34, p. 511]

When participants understood their diagnosis to have been made based on exclusion of non-functional disease rather than a positive diagnosis it left them unconvinced:

"…You can't find anything specifically wrong with me. My brain MRI is clear. The EMGs are clear. So it has to be functional neurological disorder…" [33, p. 8]

Four of the papers included in this review were published before the change in diagnostic criteria in 2013, and four were published shortly afterwards, suggesting their data will have been collected before the changes. The positions of the researchers of those papers supported the idea that FND was psychological in nature. When some participants were informed that their condition had a psychological cause they had difficulty in accepting the link. Whilst they accepted that this could be the case for some people, they were unable to identify any personal past traumas or life stress that meant it could apply to them:

"So I can't make a correlation between that side of it… because there's nothing that's happened – that's caused damage, psychological damage or anything like that, that'd cause this to happen as a result" [31, p. 298]

For others the psychological explanations did not make any sense, based on their preconceived ideas about what they understood mental illness to be, they found the idea that something psychological could cause such obvious physical symptoms impossible to believe:

"Well, there has to be something wrong, like it can't be just mental."

"Oh no! That's nonsense. It's impossible… Because it's real. It really happens."

[38, p. 36]

Of the eight papers that were included in this area, four were published pre-2013 and three were published in 2014 and 2015. The implied psychological causation was a key issue for the lack of confidence in diagnosis in these papers. However, this was also true of the paper included that

was published in 2022 which cited the doubts about the psychological nature of their given diagnosis as well as concerns about it being diagnosed by exclusion.

1.4.5.2 Abandoned

There was widespread feeling of being abandoned by services once the diagnosis had been delivered. Participants reported receiving no clear post-diagnosis follow-up plans leaving them feeling unsupported and neglected and, because participants did not fully understand their diagnosis, they felt stuck. This feeling was then intensified when they were left to manage on their own, without the support of HCPs participants were left feeling powerless and vulnerable. Whilst some participants were offered continued appointments with neurologists these could feel lacking in purpose and pointless:

> *"You go and see the neurologist, but they can't do anything for you – 'we'll see you at your next appointment' – which makes you think, why go to the next appointment because what's the point?... It feels like a waste of time"* [28, p. 8]

A reason for this sudden lack in support was given by Karterud et al. [37] when they suggested that an FND diagnosis is accompanied by a transfer of responsibility from health care services to patient. Services no longer felt the obligation to treat the 'disease' as it was no longer their jurisdiction leaving patients to cope with their own diagnosis:

> *"If only I had epilepsy, then I would be offered help from a multi-professional team at the epilepsy centre. With PNES I feel I'm on my own, and dealing with the attacks is my own responsibility"* [37, p. 43]

This theme was identified in seven papers across all methodologies represented in this review. All three of the moderate quality papers, with questions about the rigorousness of the analysis, were excluded from this theme.

1.4.5.3 Cruel and rude HCPs

Distressingly, a theme that was identified in ten out of the twelve papers reviewed, was of the negative, rude, and sometimes cruel interactions participants had experienced with HCPs. Patronising attitudes were prevalent, with the accusation that participants faked their symptoms widespread:

"I was told several times I was faking it for attention… not only in the emergency room, also by my psychiatrist." [39, p. 3]

"The worst term I've heard was when a nurse was telling another nurse that I was 'faking it' and I thought, 'yes, because I love to be [in hospitals] in my free time'" [32, p. 5]

"I'm being treated as somebody who fakes epilepsy" [35, p. 802]

Disclosing their diagnosis made participants feel vulnerable as they felt unable to challenge the often-disbelieving response from HCPs which would leave them feeling silenced and shamed:

"I had a GP say to me: 'It's a unicorn condition' which I found quite offensive… I was taken aback and I didn't say anything but I wish I had" [28, p. 8]

Participants acknowledged there was a stigma attached to their diagnosis and it made them feel unsafe in health care settings, some decided against revealing their diagnosis if they believed it was possible, a decision that appears justified when hearing some of the comments being made:

"…at the emergency reception they said, 'just let him lie there and shake, it's only psychiatric" [37, p. 42]

This comment potentially reveals the crux of the matter as similar links are made elsewhere, Neilson [33] reported that '*most participants interpreted psychological explanations as meaning that the doctor did not believe their problem to be real or worthy of concern'.*

This was a high confidence theme with ten studies contributing. The papers that did not contribute were the moderate quality, paper with less rich data and a high-quality paper which was focused on treatment needs.

1.5 Discussion

This review synthesised the findings within 12 studies concerned with the experiences of people who were living with FND as they went through the process of FND diagnosis. As the focus of this review was the participants' experiences of interactions with the health care system as they went through the process of being diagnosed with FND, it was only the parts of the studies that pertained to this that were synthesised.

The story that emerged was that these interactions were experienced very much as a three-stage journey, with distinct chapters telling the story from pre to post diagnosis. The first chapter covered the time before receiving the diagnosis when the patients experienced long waits and misdiagnoses, they would often feel dismissed at a time when they needed reassurance. During the following stage of the journey, when receiving the diagnosis, there were difficulties as the lack of knowledge about FNDs made understanding the diagnosis difficult and patients were left to make sense of it themselves. For some the diagnosis came with validation, their long and arduous journey of doubt suddenly made sense, and when the HCP showed interest and empathy, and discussed plans for treatment, the positive effect it had was palpable. During the final stage of the journey, after the diagnosis, doubt returned for some as the diagnosis was met with scepticism, for many it felt as if they had been abandoned to manage a diagnosis that nobody really understood. At times, the diagnosis was partnered with unwanted opinions from some HCPs who did little to disguise their negative attitudes and beliefs that patients were faking it.

The emotional impact of this journey was apparent throughout the narrative as it was beset with confusion, doubt and uncertainty, helplessness, frustration and anger. Most of their emotions are second to systemic stigma surrounding mental health and emerging awareness about the causes, diagnosis and treatment of FND over the last 20-30 years. Interestingly, whilst the studies in this review had different aims, used different methodologies, were focused on

different FNDs (functional seizures or functional movement disorder), and were completed in both the UK and other Western nations, they all told a similar story in relation to the experience of participants with FND as they journeyed through the diagnostic process. Perhaps this can be linked to the Western trend for separating the mind and the body in the organisation of healthcare systems. These factors give weight to the participants' experiences of feeling that the HCPs they encountered along their journey did not recognise their condition as belonging to their field of interest or expertise. This may have been expected in four of the papers that were published when FND was thought to have a purely psychological cause, and even understood in the four papers that were published in the three years after the change in criteria, however the four papers that were published between seven and nine years after the change to the criteria were still reporting long delays in diagnosis, multiple investigations and stigma associated with having a diagnosis of FND.

The narrative synthesis (NS) reveals a tale of people for whom power dynamics have a clear and substantial role in their lives. Understanding power dynamics is crucial as power influences how society operates. In relationships, power dynamics shape interactions, they affect how people communicate, how messages are delivered and received. Power shapes society in the way decisions about the distribution of resources, privileges and opportunities are made. An ideal tool that can be employed to support understanding of the power play identified in this NS is that of the power threat meaning framework (PTMF [40]). This framework is a tool designed to offer a perspective on the origins, experience, and expression of emotional distress and troubled or troubling behaviour. It was originally developed as an alternative to traditional models of psychiatric diagnosis, and the promotion of a more formulation-based approach. The framework employs simple questions to elicit an understanding of what has happened, and the meaning that has been attributed to those experiences. The questions include (but are not limited to): what has

happened to you? (how is power operating in your life?), how did this affect you? (what threats did this pose?), what sense did you make of it? (what meanings have you attached to these events?) and, what made it better? The PTMF also integrates all the information from these prompts into a story to provide a clear narrative. The value of capturing this narrative could be seen in the development of neurologists' training on FND. Healthcare systems are already inherently hierarchical [42] and medics must find a way to navigate this power imbalance between themselves and all their patients. However, if the impact of power that patients with FND experience across many aspects of the lives can be demonstrated, training can be refined so that neurologists have a more comprehensive understanding of the particular challenges their FND patients face. This may lead to changes in practice as neurologists can reflect on their training and address any biases they may have inadvertently acquired about FND. See Figure 2 for the NS narrative applied to the PTM framework.

Figure 2

PTMF formulation for NS

Power Threat Meaning Formulation for Narrative Synthesis Results		
Impact of Power	Core Threats	Meanings
Biological • Functional neurological disorder • Medication Interpersonal • Dismissed from services. • Rude and negative HCPs Legal • Inappropriate driving ban	Bodily • Loss of function and disability • Invasion through medical investigations • Poisoned by unnecessary medication. Relational • Feeling rejected by services in the lead up to diagnosis. • Being abandoned by services after diagnosis	Patients feel: • Afraid and uncertain • Abandoned and rejected. • Helpless and powerless • Inferior • Blameworthy • Invaded • Betrayed • Controlled • Shamed and humiliated

Economic & Material • Employment restrictions Social & Cultural • Loss of shared experience of family • Lack of knowledge about FND Ideological • The discourse and stereotypes around FND and mental health • The lack of scrutiny towards medics and those who hold the power in health services.	• Being shamed and humiliated by HCPs due to beliefs about FND. Emotional • Overwhelmed by hard to manage feelings generated by helpless situation. • Struggle to get emotional needs met from non-empathetic services. Economic & Material • Threats to financial security as employment restrictions due to misdiagnosis. • Threats to ability to obtain goods and services due to illness preventing work. Social & Community • Exclusion from community due to stigma around FND. • Loss of status when seen as having a psychiatric illness • Hostility received from HCPs. Knowledge and meaning construction. • Lack of opportunity to make sense of FND due to HCPs lack of knowledge and inadequate explanations. • Devaluing of own knowledge about FND	• Emotionally overwhelmed. • Excluded • A sense of injustice • Abnormal

	• Imposition of discourse about FND from powerful services and individuals. Identity • Threats to identity as a worker or parent • Discrimination due to belonging to stigmatised group. • Experiencing personal abuse directed from HCPs who hold influence.	

What Made Things Better?

- Encounters with HCPs who were empathetic and interested.
- A sense of being listened to and understood.
- Meeting with medics who have knowledge of FND and can explain it in ways that make sense.
- Discovering useful information on FND websites with stories about other people with FND that reduce the sense of isolation and feeling 'abnormal'
- Validation when getting a diagnosis that recognises there is something wrong and they are not faking their illness

Narrative Synthesis Story

The time waiting from the beginning of symptoms to FND diagnosis was a time fraught with confusion, uncertainty, and fear. Patients' experiences of their bodies behaving in such an unusual way, for which there are no clear reasons, left them free to fear the worst. During this time the patients felt powerless as they waited at the behest of services. Biological power was in operation as the patients experience life with a body which they could not rely on to perform as needed, when needed. During this period, patients spoke of undergoing multiple investigations and tests to ascertain exactly what condition they had. These invasive procedures raised more

questions than answers, patients were left to imagine the bodily threats they were facing, they felt helpless and afraid.

Biological, economic, and social power impacted on patients' lives as they were misdiagnosed. Bodily threats in the form of the use of unnecessary drugs endangered the physical health of patients, posing a very real threat to the body. The social and economic impact of misdiagnoses was clearly felt as some patients had lived their lives under an assumption that they were suffering from conditions that restricted their abilities in areas of work and family. Some patients experienced the loss of cultural and social capital as they were excluded from cultural norms such as traditional family units and shared experiences such as bringing up children. The privilege of being able to drive a vehicle, giving access to cultural and social activities without relying on people or public services was lost to some patients. Patients could lose economic power as their employment roles were restricted which, in turn, could limit their ability to obtain goods and services.

Feelings of anger, being lost and neglected were felt by patients who experienced being dismissed from services. The impact of interpersonal power, the power to look after or not, to care or not to care, gave rise to emotional and relational threats. When relational threats arise from those who are central to our wellbeing, such as health care providers, the threat of being rejected can feel life threatening. This was coupled with difficult to manage emotional threats such as anger which could give way to feelings of rejection, injustice, and unfairness.

Interacting with HCPs during the process of receiving the diagnosis could be experienced both negatively and positively. For some patients the delivery of the diagnosis was marred by confusion and misunderstanding as the HCP appeared unsure about FND and was unable to provide a meaningful explanation about the condition. The power of cultural capital, which includes access to valued knowledge, was evident here, leaving patients open to threats to their

knowledge and meaning construction. To make sense of what was happening to them, patients investigated FND themselves, the information was often confusing as the differing explanations and names did not give them clarity. When patients read that FND was psychological in nature they questioned if they were 'crazy', the ideological power of societal discourse and stereotypes attached to a perceived mental health condition left them open to threats of exclusion from their communities, and discrimination due to stigma, leaving them feeling shamed and excluded. However, when the information was clear and informative, or when it shared the stories of other patients with FND, it helped to normalise their condition.

When the diagnosis went well it gave patients a sense of validation, their doubts and uncertainties that had been with them since their symptoms began were banished. Trusting relationships with interested and empathetic medics helped to dismiss the shame and gave them hope and a belief in treatment pathways.

In the time after the diagnosis doubts remained for some as they did not accept a diagnosis they felt might be changed again by medics who did not seem convinced they had got it right. Patients struggled to make connections to the psychological aspect of the condition they were told there must be. The ideological power of the medics is strong as there is lack of scrutiny about their knowledge. Patients' knowledge and meaning construction is again threatened as the discourse about their condition is imposed by the medics, their knowledge about themselves is disregarded by medics who 'know better' than them. This leads to feelings of being controlled and blameworthy as they feel forced to accept the situation.

Interpersonal power is at play again as services withdraw their care and the responsibility for their condition is handed over to the patients. When there were no offers of clear treatment plans the relational threat of being abandoned and neglected left patients feeling betrayed and lost. Their emotional wellbeing was threatened as patients struggled to get

their needs met by rejecting services who lacked empathy. Patients' encounters with health care services could leave them feeling exposed and vulnerable as they faced frequent accusations that they were faking their illness. HCPs used their positions of power to create a narrative that stigmatised and belittled the patients, who felt shamed, humiliated, and emotionally overwhelmed.

1.5.1 Strengths and Limitations

This review was clear in its aims and question and used appropriate search strategies to ensure the relevant literature was located. There was potential bias as only papers written in English were reviewed, this leaves the possibility that there are other stories that remain unheard. However, there were studies from multiple countries with different healthcare systems, demonstrating that the narrative revealed in this study crossed geographical and political boundaries, at least in the Western world.

The quality of the papers was mostly high, they were quality assessed by two reviewers with high inter-rater reliability (no disagreements), the papers findings were convincing in all but one of them. There was strength in the inclusion of a range of methodologies used in the studies included in the review as it gave confidence that the themes uncovered were transferable traits. Despite all papers using qualitative methods there was a lack of information about the researcher position in half of the papers and it was unclear in one. These leaves the potential for unknown researcher bias.

The themes were well supported across studies, the least supported theme was still represented by seven of the 12 studies. Quotes were extracted from every paper; however, some were referenced more than others as there was variance in the quotes available that were associated with the interactions with health care systems specifically.

1.5.2 Implications and future research

This review has highlighted the challenges that continue to be faced by people diagnosed with FND as they interact with health care systems. To the date the papers were published there was evidence that changes to the diagnostic criteria and the most recent understandings of FND were not reaching the diagnostic procedure and clinics of HCPs. The continued assumption that FND is a psychological problem attracts widespread stigma resulting in the themes identified in this review.

The need for training and development in understanding around FND is identified across all HCPs. The long waits and multiple investigations experienced by patients might be reduced if the neurologists who are responsible for making the diagnosis adapt to the recommended rule-in diagnostic methods that are specific for identifying FND. If they can familiarise themselves with the literature which aims to support the diagnosis delivery, patients may feel less confused and have confidence in their diagnosis. While training neurologists may improve some aspects of interacting with health care services for patients with FND, there is still the situation of HCPs in the wider health care system whose beliefs and attitudes are impacting FND patients. GPs, hospital workers, and ambulance staff were all mention in the literature as contributing to the distress of patients with FND, therefore wider training and readily available information would be beneficial.

The review also highlights the positive affect of interactions with HCPs who are warm and empathetic. In light of this, a compassionate approach free of judgement where patients' concerns

are addressed and validated is required. However, this may only become more widely available as the understanding of FND is developed and improved, as suggested above.

As previously stated, many of the studies included in this review were published before or around the time of the publication of the DSM V. Many of the participants experiences were from before recommended changes to the diagnosis of FND came into place. However, it is now more than a decade since the DSM V was published. Revisiting some of the areas of research covered by the studies with data collected from people who have more recently been through the FND diagnostic process. Or identifying any changes to practice experienced by patients with FND since the DSM V was published could identify if the developments in the field of FND have started to reach wider health care systems.

1.6 Conclusion

The question of how patients experience their interactions with health care systems as they are diagnosed with FND is answered through the research summarised in this review. It tells a story beset with challenges as patients face uncertainty and doubt due to lack of comprehensive information about the condition they are diagnosed with. They are further challenged as their diagnoses is assumed to be psychological in nature and this attracts stigma and sometimes ill-treatment from the people they entrust with their care and wellbeing.

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Part 2 – Exploring the lived experience of neurologists throughout the process diagnosing Functional Neurological Disorder and delivering this diagnosis to patients

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2.1 Abstract

Background: In the UK, neurologists are the clinicians most likely to diagnose Functional Neurological Disorder (FND) with research suggesting that approximately 30% of neurology patients have FND. There is little understanding of the impact this area of their work has on neurologists, or the meaning they make of their experience. Without this knowledge, the effect it may have on neurologist's wellbeing and job satisfaction, or the healthcare experience of patients with an FND diagnosis, cannot be identified.

Aims: This study seeks to learn about the lived experience of the neurologist who makes and delivers the FND diagnosis. By gaining such insight, a greater appreciation of any challenges they might encounter, and support needs they might require, could be gained.

Method: Semi structured interviews were held with ten UK based neurologists who have experience of diagnosing FND. The interview transcripts were analysed using interpretative phenomenological analysis (IPA).

Results: Superordinate themes of system failure, diagnosis and identity matters were developed. Within these superordinate themes were subthemes covering areas including lack of FND services, time constraints for consultations, whether FND should be part of a neurologist's role, the importance of the doctor-patient relationship, the use of resources, communication difficulties, the meaning of identifying as a neurologist, and the problematic language often used when referring to FND patients.

Discussion: Underpinning all the themes was the widely held view that FND is a psychological issue and as such can attract the same stigma that other mental health issues often attract. Additionally, as medical professionals, neurologists do not see conditions they understand to have a psychological cause as within their remit. This view is problematic as the etiology of FND is still unknown, it does not necessarily have a psychological cause and to assume otherwise is incorrect

and can be very unhelpful. The societal narrative around mental health influences not only the neurologists but the systems around them which impacts on the provision of FND services and training.

2.2 Keywords

Functional Neurological Disorder, Neurologists, Diagnosis, Interpretative Phenomenological Analysis, Stigma

2.3 Introduction

Functional neurological disorder (FND) is an umbrella term for a disorder said to "exist at the intersection of the brain and the mind" [1]. Functionality of the central nervous system (CNS) is impaired, and the fault is thought to lie within the sending, receiving, and deciphering of messages within the CNS [2]. A common analogy used to help explain the disorder is that of a computer that does not work as it should; on investigation, the hardware of the computer is found to be undamaged, and the fault is found to be a bug in the software that runs the computer, the bug can crash the computer or cause it to operate slowly [3]. Whilst this explanation is helpful when explaining the condition, the situation is more nuanced [4] and the absence of 'damage to the hardware' is not certain. It is understood to have pathophysiological and neurobiological bases, which may include psychological processes in some, but not all, patients [5]. There is gathering evidence which identifies structural and connectivity differences on fMRIs and MRIs of FND patients across various neural networks. Abnormalities have been identified in the orbitofrontal cortex, the anterior cingulate cortex, and other limbic structures. Signs of heightened activity in the limbic system with increased amygdala sensitisation and amplified connectivity between the amygdala and the motor control circuits may account for the motor and movement symptoms often associated with FND. Changes in the limbic and salience network also signify a potential cognitive/Bayesian model where sensory inputs are overridden by the patients'

predictions about their sensory or motor functions. Predisposing psychological factors remain a feature for some FND patients but it is absent for the majority, therefore FND cannot be certainly attributed to a single etiology, rather it is likely to be multifactorial [6-9].

Symptoms of FND include limb weakness, disorders of movement (such as tremors, spasms, and gait issues), disturbances of the senses (sensitivity to light, blurry vision or loss of vision, heightened startle response, heightened sensitivity to touch causing pain), cognitive difficulties (such as memory loss and concentration difficulties) and functional seizures (loss of consciousness and awareness, common seizure behaviours and sensory changes) [10]. Over the history of FND there have been a proliferation of terms used to describe it, questionable names such as hysteria are not unheard of even in recent times, more commonly names such as conversion disorder, psychogenic disorder or somatisation are used. However, these suggest only a psychological etiology which is not supported by current evidence, for this reason the use of the term 'functional' is now favoured, as it more accurately describes the disorder as an issue with the functioning of the CNS [11].

If FND is a disorder that exists where neurology and psychiatry meet [12], and if, "Neurologists take care of the body, and psychiatrists tend to the mind" [13, p. 2] then it is fair to question who takes responsibility for the patient whose disorder bridges both specialties. There are neuropsychiatrists who specialise in this area, but their numbers are scarce; in 2021 there were 64 consultant neuropsychiatrists working in the UK [14]. This was in comparison to 1562 consultant neurologists [15] and 7782 psychiatrists [14] in the same year. The low availability of such specialists means it is likely that neurologists are the clinicians who will diagnose FND. This likelihood increases due to the tendency to refer patients who present with symptoms of FND to neurology departments in the physical health focused National Health Service (NHS). The estimates of how many of the patients attending neurology clinics are patients with FND vary

between six and thirty-three percent [16 -18]. However, Stone et al. [19] suggest that around six percent of neurology patients receive a sole FND diagnosis, and approximately thirty percent receive a diagnosis where organic disease can only account for some of the symptoms presented. With figures so high, it is reasonable to consider how neurology professionals feel about making and delivering this diagnosis, which historically was "not regarded as a problem within the territory of neurology" [20, p. 16]

Understanding how neurologists feel about this aspect of their role is even more important when considering the long-held view that the relationship between clinician and patient, along with positive patient expectations about their diagnosis and potential treatment, is important regarding clinical outcomes [21]. To benefit from treatment, it is vital that FND patients have confidence in the diagnosis they have been given [22] and if the patient feels relieved by the diagnosis, their outcome is predicted to improve [23]. The beneficial effects of a good and trusting doctor-patient relationship have been considered a 'placebo effect'; a powerful, positive mind-body response that stems from the context surrounding the delivery of treatment, rather than the treatment itself [24]. Research which studied the patient-practitioner relationship in a population of participants with a physical illness suggests that, if patients receive two integral elements of this placebo; 'cognitive care' - which influences their beliefs about the illness and the effects of treatment, and 'emotional care'- the warmth, support, reassurance, and empathy shown by the clinician, then the outcome is significantly improved compared to patients who do not receive them, both in terms of pain perception and speed of recovery [21].

Many people however, report issues when speaking about their experience of receiving an FND diagnosis. Some patients say they feel misunderstood, they believe their symptoms have not been investigated adequately [25]. For others, they have a sense of not being believed or feel accused of inventing the symptoms [26]. Some say they have experienced feeling rejected,

ignored, and belittled [27] and for many, the diagnosis leaves them feeling left in limbo [28] and feeling alone [29]. The reason for these poor experiences may be explained by the underlying opinions some clinicians have expressed about FND. Medical students who were questioned about their attitude to medically unexplained symptoms (MUS), a term used to describe any disorders which cannot be medically explained, such as FND, admitted to not considering them as legitimate. Furthermore, they reported that this attitude was acquired through their interactions with senior physicians who they described talking negatively and dismissively about these patients [30]. In a survey of 400 doctors from the Southeast of England in which 284 responded, 262 (93.2%) agreed or strongly agreed that patients with medically unexplained symptoms were 'difficult to manage' [31-32].

The relationship that many neurologists have with FND could be described as complicated. For many, a clear understanding of the disorder is lacking, due perhaps to FND not being covered in neurology textbooks for many years [33-34]. It was not until 2016 that the neurologists' mainstay, the Handbook of Clinical Neurology, produced a volume on the disorder [34]. There has been a lack of clear guidelines on how to diagnose and treat people with FND [35], which leaves neurologists unsure of how to relay a diagnosis that they may not fully understand, to a patient that they believe might not want to hear it. In a commentary paper, Hallett [36] described the situation as a 'crisis', due to the overwhelming number of patients, the lack of understanding of the disorder, the lack of certainty in how to make the diagnosis, and how to treat the patients after diagnosis. He added that many of the patients will reject the diagnosis and seek additional opinions in the hope that they will eventually get a diagnosis they feel more confident in.

Whilst there has been an increase in interest in the subject of FND over recent years, the few studies that have investigated the phenomenological experience of the process of an FND diagnosis have generally been directed towards the experience of the patient [37-40]. Studies

investigating the experience of neurologists are scarce, in the main they use questionnaires [41-42], and this method does not give participants the opportunity to express their views outside of the set questions. However, Kanaan, Armstrong and Wessely [43] conducted a study which focused on the way neurologists communicate the diagnosis of conversion disorder to their patients. They approached all consultant neurologists (N=35) practising within an NHS area (their description) by email and recruited n=22. Participants were interviewed and given the subject 'conversion disorder' with no further definition, the interview guide was limited but did ask for examples of patients who had conversion disorder and what diagnostic process they had followed. They analysed the data using a grounded theory approach, their finding was the concept that neurologists would limit their truth telling during consultations with patients with conversion disorder, citing that they do this to preserve the therapeutic relationship, which they believed could be damaged if they informed the patient that they suspected a psychiatric disorder. The findings of this study might be considered limited due to the use of the term 'conversion disorder', whilst it was appropriate at the time of the study as this was the term used for FND at the time, it does suggest FND is a psychiatric disorder. Therefore, even if the authors did not lead the participants to discuss it in this way, the impression is there and may have set up a level of response bias. The data collected during that study was also used to understand how the neurologists viewed conversion disorder [44], this analysis of the data found that neurologists have more knowledge than they claim to have about conversion disorder, however they understand it in the context of deception or 'malingering'.

The current study aims to take a different perspective and seeks to learn about the lived experience of the neurologist who makes and delivers the FND diagnosis. This approach will seek to reveal the sense they make of this area of their role. By gaining such insight, a greater

appreciation of any challenges they might encounter, and support needs they might require, could be gained, leading to potentially more job satisfaction, better patient care and outcomes.

The research question is, 'How do neurologists' make sense of their experiences of making and delivering a diagnosis of FND?'

2.4 Method

This is a qualitative study using semi-structured interviews to allow for participants to provide rich data (see Appendix J). Interpretative Phenomenological Analysis (IPA) [45] was the chosen methodology due to the desire to delve into participants interpretations of their experience, so better understanding might be sought over the meaning of these experiences to them. Through the double hermeneutic, central to analysis in IPA, the researcher's interpretation of the participants' interpretations also allows for an even deeper level of exploration that other approaches, such as reflexive thematic analysis (RTA) would not allow for [46]. Another advantage of IPA, over RTA, in relation to the rationale of this study, is that it keeps an idiographic focus, with the aim to tease apart the nuanced interpretations not yet understood about these experiences in this group of professionals.

2.4.1 Participants and Procedure

Ethical approval was gained from the University of Hull, Faculty of Health Sciences Research Ethics Committee (see Appendix D). Recruitment took place between October 2022 and April 2023. The study was advertised via the 'Trials and Surveys' webpage of the Association of British Neurologists, the website of the Functional Neurological Society, and via personal neurology contacts. Snowball sampling was also used via participants. The aim was to attract between 6 -10 participants as recommended in IPA literature [45,47-48]

Table 5

Inclusion Criteria

Inclusion Criteria	Rationale
Be a practising neurologist in the NHS in the UK	It is the experience of neurologists working in the NHS that this study is interested in. Neurologists that work privately are likely to have more choice and autonomy which will change the type of experience they have
Have experience of making and delivering a diagnosis of FND	Understanding the experience of making and delivering a diagnosis of FND is the purpose of this study

Exclusion Criteria	Rationale
Not consenting to audio recording of the interviews	A recording is required for transcription and analysis purposes

Participants who responded were contacted via email or telephone to arrange a convenient appointment for an interview via video call on Microsoft Teams. At this point participants were asked to confirm they met the inclusion criteria. Those who agreed to an interview were then sent a participant information sheet (see Appendix E) and a consent form (see Appendix F) to be signed and returned prior to the interview taking place.

On the day of the interview, the researcher asked whether the participant was in a private, confidential place and could talk freely, given an opportunity to ask any questions they may have and were reminded that the interview would be audio recorded. None of the participants had returned the consent forms so they were asked to confirm they had read the form and give their consent verbally once the recording had begun. The following participant demographics were

collected verbally prior to the interview commencing: age, gender, location of training and years of practice.

The interviews lasted between 25 and 76 minutes, with the mean being 54 minutes. All participants were allocated a code attached to their data to keep the process anonymous and were reminded of their right to withdraw their data until analysis had taken place. Debrief sheets (see Appendix K) were emailed to the participants after the interviews were completed. These contained a list of sources of support; however, no obvious signs of distress were detected by the researcher during the interviews.

2.4.2 Analysis

Transcripts were produced from the interviews that had been conducted over Microsoft Teams and were checked against the audio recordings. Any mistakes were corrected to ensure they were verbatim. Where only audio recordings were available, i.e. if the interview had been conducted over the telephone, transcripts were created. Each line was numbered on all transcripts to assist in the analysis. In accordance with IPA directions [48], each transcript was analysed fully before the researcher moved on to the next one. The researcher's initial responses to the transcript were noted as they began to explore the meaning of the words to the participant. The researcher chose to read through the transcript, underlining what felt important before attempting to describe why it was important, as well as free associating what came to mind as they read through the transcript. Both recommended methods [44] allowed for more in-depth reflection and interpretation. Whilst being immersed in the data, notes were made of linguistic and conceptual elements before experiential statements, the summaries of what was deemed important from the initial note taking, were created. Connections between them were identified, thus enabling emergent themes to be generated. The emergent themes were then analysed and

grouped together to identify subordinate and superordinate themes. This process was completed on all transcripts before cross-case analysis identified group subordinate and superordinate themes. Supervision was utilised throughout the analysis process to assist in exploring the coherence and plausibility of the interpretation (see Appendix N for example of data analysis).

2.4.3 Researcher position

As IPA employs double hermeneutics it is important to be transparent about the researcher's background and experiences as they will certainly influence the research direction and findings.

The researcher is a White British female trainee clinical psychologist who was brought up in the UK. Being a trainee clinical psychologist has a strong influence on her views on mental health and she is aware of stigma that often accompanies all issues considered psychological. However, in contrast she has a family background heavily steeped with professions that champion the medical model, including two family members who were general practitioners, as well as several others who work as nurses. Through conversations with family, she is familiar with a medic's interest in the diagnostic process and the satisfaction that can be obtained when a medical diagnosis is deduced from a set of symptoms, this knowledge gives her an insight into the position of the participants as medical clinicians.

These influences were discussed and reflected upon in supervision and remained in the awareness of the researcher throughout the study (see Appendices A & B).

2.5 Results

Ten neurologists were interviewed for the study.

Table 6

Participant Demographics

Pseudonym	Gender	Age	Years Practising	Country of Training
Jane	Female	38	8	UK
Dawn	Female	48	20	UK
John	Male	48	15	UK
Viki	Female	43	13	Poland
Saad	Male	62	27	Pakistan/UK
Peter	Male	48	21	UK
Abida	Female	55	14	Pakistan/UK
Kalu	Male	52	20	Nigeria/UK
Jaya	Female	60	25	India/UK
Ansh	Male	38	7	India/UK
		Male to female ratio 5:5		
		Mean age = 49.2		
		Mean years of practice = 17		

Table 7

Themes

Superordinate Themes	Subordinate Themes
System failure	"They're not gonna fund *'that!'"*
	"Barely surviving to do your own stuff"
The process of diagnosis	"Doctor as drug"
	"She had millions of scans, millions"
	"It's a bit of a maze"
Identity matters	"Where's the lesion?"
	"I feel like I'm being a counsellor… but without any counselling training"
	"That's something that neurologists often find amusing"

2.5.1 System Failure

All participants mentioned working within a system which they considered was not fit for purpose. They saw it as failing their patients and themselves on several levels, including the availability of suitable and much needed services, and the pressures on resources. The inadequacies they identified left them feeling abandoned, overwhelmed, exploited and unprepared.

2.5.1.1 "They're not gonna fund that!"

A systemic failure to provide a network of FND services across the nation was identified by most of the participants. The lack of FND clinics locally, *"there's no functional neurological clinic" (Jane)* was of great concern. Ansh seemed exasperated as he emphasised the difficulty they faced, his voice tone sounded urgent, and when he questioned whether the researcher understood the situation, it felt as if he was telling them something he thought they could not comprehend:

"*We struggle big time referring patients, big time. Do you understand? There's nowhere dedicated, allocated, no service available" (Ansh)*

Ansh was not alone in his distress, Abida appeared deeply impacted by the situation she felt powerless to change as she struggled with the reality of her patient's predicament:

"I was feeling so upset, that young female, nobody to help, what am I going to do? I'm just sending her somewhere, I don't know where I'm sending her…Nobody will be helping you. It's it's it was difficult, it was really difficult." (Abida)

When participants considered the possibility that in trusts other than their own, there were options available, the sense of unfairness was palpable:

"I think in other trusts they have very clear pathways, and they have, uuum a psychologist, a psychiatrist, a team is just waiting to get the patient" (Viki)

This imagined, fully staffed, FND service that is ready to spring into action which Viki describes is unlikely to exist, even in trusts with dedicated FND services, so perhaps it is not about what other services have. It may be that Viki feels that she is not doing enough, and she is able to relieve some of the pressure she applies to herself by externalising the reason she is unable to help in the way she wants to.

The uncertainty produced by the inconsistencies in available FND services causes anxiety from the initial consultation:

"So when I, when I see a functional patient, there's a tiny bit of me, I'm always looking at the postcode…." (John)

"The moment you're diagnosing, you're talking to the patient and the other half your brain is thinking, 'ohh, what will happen now'" (Jaya)

The idea that they want to help but they might not be able to feels very difficult to manage. John says it is a tiny bit of him that is looking at the postcode, but if the postcode tells him he is unable to provide the follow-up treatment he wants to, he may begin to feel guilty, and the tiny bit that is distracted may grow as he attempts to think of a solution which does not exist for his patient. Jaya's admission that half her brain is thinking about what options there are for her patient also suggests she is not fully present with the patient during the consultation, as she manages her concern for her patient whose options are severely limited.

The postcode lottery of the situation was defined by Peter, it appears that he feels guilt that he leaves his patients to fend for themselves:

"*Depending on where they live, you know, they might have a, have a neuropsychology service that they can access. It's difficult for patients in* [names area] *because there isn't a service that we can refer to there, which is very difficult. So, you make a diagnosis, then tell them to look on the Internet, and then you're basically sending them off" (Peter)*

Perhaps, however, his description of the lack of support bestowed on his patients parallels the lack of support he feels is offered to his profession. As he goes further, he cites the undervaluing of FND services by commissioners as the reason for the lack of FND pathways:

"... I mean I I guess it's seen…with all the pressures in the NHS, it's possibly seen as like a maybe non-essential service or maybe a luxury service even… So I think it's probably often quite low down on the priorities for, for commissioners to see…" (Peter)

The idea that such services are an unnecessary extravagance is a strong example of the othering of FND and demonstrates a tendency for prioritising physical health over mental health. When John emphasises the word 'that' it is as if it would be ludicrous that FND services would ever take precedence:

"Nobody's funding. I mean, I guess nobody's funding anything at the minute anyway, but like, they're definitely not gonna fund that!" (John)

2.5.1.2 "Barely surviving to do your own stuff"

Every participant spoke about the pressures they faced when working with patients with FND. On the surface the leading narrative was of the issue of time constraints in neurology clinics, meaning they were not designed for the longer consultations participants said were required for FND:

"It took me 45 minutes, it was a 20 minutes slot but it took 45 minutes" (Ansh)

If it were as simple as overrunning appointments, a solution of double appointments slots for FND patients could potentially resolve the issue. However, there is a suggestion from Peter that the situation is worse than simply time management:

"I just haven't got the time to deal with it. I'm completely swamped" (Peter)

His use of the word swamped gives rise to images of drowning in something muddy, something that is hard to clean off, it gives a sense that FND is something he is stuck with dealing

with. Whilst Peter seems to reject the idea of FND management in its entirety, his view is objective and does not appear to blame FND patients directly. However, there was a hint to an underlying source of frustration, which appeared to be directed towards the patients, rather than the system, when Dawn hesitated before using the term 'these patients'. Her tone as she spoke the words seemed to express annoyance over the impact of overrunning clinics on her work/life balance:

"It feels that then eventually you're giving up your own time to see [pause] these patients" (Dawn)

Jane also appeared to direct her frustration towards the patients, the use of the word 'landing' when applied to the patients with FND, suggests she feels she has been dumped upon by a higher power that has the choice whether to make her (work) life difficult or not:

"Landing us with all of these functional neurological disorder patients can be a big problem" (Jane)

The tone of the comments felt exclusionary to the researcher and could demonstrate a marginalisation of FND patients, almost as if there is a feeling that they are not entitled to neurologists' energy and time. Viki seemed to qualify this lack of ownership when she describes struggling to cover both her 'own stuff' and 'anything else':

"Basically, you don't have time for anything else because you're just barely surviving to do your own stuff" (Viki)

The insinuation here is that neurologists may not be the most appropriate specialists to work with FND patients, this assertion may stem from the outdated belief that FND is purely a psychological problem:

"They have some problem, which is not neurological, it is psychological" (Abida)

Whilst it makes sense from the perspective of the neurologists who have not undergone psychological training and do not consider this a part of their role, the impact of this viewpoint is

problematic, both when understood within the context of the unequal status between physical and mental health services within the NHS, and the idea that the two areas of healthcare are mutually exclusive. The separation of mind and body may have seemed logical in the past but as knowledge changes it is no longer appropriate. This disparity between the two areas of healthcare, coupled with the idea that services either deal with mind or body, might help to explain the participants' apparent reticence to view FND as an area of their role.

2.5.2 The Process of Diagnosis

When the participants reflected on the diagnostic process, there were themes on the importance of the clinician/patient relationship, extensive testing, and difficulty in communicating the diagnosis. Interestingly, these themes seemed to be specifically directed towards interactions with patients with FND, and not to patients with non-functional neurological conditions. This distinction between patient groups could imply that FND may be considered to rank lower on a scale of importance compared to non-FND, and perhaps, that neurologists feel less confident when working with patients with FND than when working with other, more familiar conditions.

2.5.2.1 "Doctor as drug"

The power of the doctor-patient relationship and the importance of validating the patient experience was recognised as key to clinical outcomes.

"I think that... to make them feel that we do acknowledge and appreciate them can make them feel better. If you look at all the clinical trial data that we do in medicine, there are about 20 to 40 percent of people in the placebo group who do get better, so there is a placebo effect...This means placebo does work" (Saad)

John borrowed the term 'doctor as drug' from a medic acquaintance to contextualise the significance of a positive relationship between patient and doctor:

"She says, 'Doctor as drug' is what she talks about. I don't know if that's a recognized thing or not, but it's just the sort of, the seeing, the talking and the laying on of hands, and the listening…and the validation of that process, and that's valuable to people" (John)

He emphasised how 'valuable' it is to people, the notion being it is the patient half of the duo that takes comfort from the situation. Perhaps though, when he reflects on his role as a medic involved in the care of a patient with FND, it is he who feels reassured. When Dawn speaks about the necessity of a solid doctor patient relationship, she struggles to explain the consequences of a lack of trust, and it is here where she reveals that her concerns are specific to FND:

"I do think you've got to have a really strong doctor patient relationship for it to work. If they don't have trust in you, it just won't..they're not gonna….It's so…it's so much more important with this one that they believe that they've got that diagnosis, isn't it? And if… and if anything weakens that doctor- patient relationship, I think it could weaken the strength and understanding of the diagnosis and that could be problematic" (Dawn)

There is a sense that she feels without the trust, the patient might question the diagnosis, Dawn may be concerned as she is aware that a strong, positive diagnosis is linked with better outcomes for FND patients. Perhaps she is relieved when her patients accept the FND diagnosis when so often they are seeking a strongly physical diagnosis, with a clear physical cause, and clear physical treatments, such as medicines or physiotherapy, because they are beholden to the same medical model, and the stigma, around mental health or conditions perceived to be connected to the mind.

Peter admits he doubts himself when a patient he diagnoses with FND does not fully accept the diagnosis. A disclosure which suggests a lack of certainty not present when diagnosing non-functional neurological disorders:

"*Uh, I guess always in the back of your mind when patients are refusing to accept and demanding that there must be another explanation, always there's that seed of doubt in the back of your mind, thinking, have I covered all bases? And what what what if they're right?" (Peter)*

His struggle with the final sentence was striking, as if he did not want to admit he sometimes doubts he is right. It felt like there was a fear underpinning his concern, but it was not clear if it was a fear of not being able to help, a fear of complaint or litigation, or maybe a fear of not being a 'good' doctor. There are tests which are used to positively diagnose FND, including EEG or some specific signs that may be indicative of various motor symptoms, but it is often harder to diagnose than for non-functional neurological conditions. However, this lack of certainty in a diagnosis does exist for other non-functional conditions in the early stages, such as MS, it would be interesting to discover if Peter's doubts transfer to that type of situation or if it is solely when diagnosing FND?

2.5.2.2 "She had millions of scans, millions"

Whilst FND is no longer understood to be a diagnosis of exclusion (it is not a diagnosis arrived at only when all others are negative, but a positive diagnosis, made using appropriate methods specifically designed to identify FND), it was clear from the participants that often it is only after a series of scans that the diagnosis is confirmed, as explained by Viki:

"I know it's not supposed to be an exclusion diagnosis, it's not supposed, you kind of supposed to kind of know that it is and, then confirm. But sometimes, to me it still feels like I'm excluding things and then if nothing's found…" (Viki)

When the issue of resources was raised, it was often about the amount of testing that was commonly used during these investigations. Ansh's exaggeration felt like an attempt to drive home the point:

"She had millions of scans, millions!" (Ansh)

His frustration was echoed by Jane who seemed irritated by the amount of scans her patient had undergone. However, the emphasis that her patient was not found to have a diagnosis that she recognised as a 'neurological disorder' hinted that it was not the number of scans alone that was the issue:

"And then I saw her moving when no one was looking, and I said,' she's not got, she's not got a neurological disorder'. And I suppose sometimes you can be a bit frustrated by that, because you're like we've just done three MRI scans. There's a massive waiting list for MRI scans, and she, you know… and then there is that element of, for goodness sake!" (Jane)

When she says she saw her patient moving when no one was looking, it could be interpreted that she believed it was a deceitful act, that she only moved *because* she thought no one was looking, that there was malingering on behalf of the patient. Even if this is not Jane's belief, then her apparent view is that the costs incurred through MRI scans are only of value if they identify a non-functional neurological disorder. Exposing an outlook that costs associated with FND are not warranted, which if true, is incongruous with the fact that scans are commonly repeated when previous ones have revealed no pathology. Perhaps the reason for the seemingly unnecessary repeats is found when Jaya explains the magnitude of the responsibility to get it right:

"The responsibility on the first person to see the patient is immense, or else you know they get misdiagnosed with epilepsy which is…the worst thing that could happen. And that's not uncommon, that's not uncommon" (Jaya)

The responsibility she feels to get it right appears multi-layered, is it because she feels if she gets it wrong then others will see that she is not a good doctor? Is there an element of imposter syndrome? The pressure to uphold an expert position in the hierarchical medical system leaves little room for the humanity of the medic or the lack of 100% accurate diagnostic tests for some conditions. Or are her words demonstrating the conflicting pressures of needing to reduce

unnecessary spending of resources on a diagnosis that is not included in her speciality's allocated budget, with the fear that missing a hidden non-functional disease will leave them responsible for a misdiagnosis and the consequences that comes with that?

2.5.2.3 "It's a bit of a maze"

Participants admitted to struggling with communicating an FND diagnosis to their patients. For some, they recognised that at times their approaches had been problematic and likely to have caused distress to their patients:

"I've got an approach that I've bashed together the hard way, a decade's worth of being a neurology consultant, improved on after catastrophic consultations and things that have gone wrong and you think, well, we're not going to say that again" (John)

"Patients would not have been happy with the way I had dealt with it, or they seemed to feel that I had belittled their symptoms" (Jaya)

Ansh admits communication difficulties; however, he appears to direct them towards '*these'* patients wanting a prognosis:

"It's hard to communicate, hard to explain to them. It is, it is one of my challenges you know. It's hard to deal with these patients because, sometimes they ask for a prognosis" (Ansh)

When he says it is hard to deal with the request for a prognosis, it seems he is suggesting that only FND patients require this. Furthermore, that there is only prognostic uncertainty with FND, however this is not the case, and prognosis is known to be uncertain for other neurological disorders. It feels that perhaps the uncertainty lies in his knowledge of FND which is why communicating with his FND patients is more difficult for him. The fault of difficult communication being laid with the FND patient is repeated when Dawn spoke about her problems:

"She was just at her wits end and just didn't understand, she didn't understand it and there was almost no way of getting her to understand it" (Dawn)

When she says her patient was at her 'wits end' it seemed possible that there was an element of countertransference occurring and the frustration she identified, rather than sitting with her patient, stemmed from her. Perhaps this frustration was that she did not have an adequate way of communicating a diagnosis that, she herself had inadequate training on. Her further comment reveals uncertainty and a sense of being lost:

"It's a bit of a maze, which way is this going to go?" (Dawn)

Her use of the word 'maze' suggests she is aware she must reach a goal, but she cannot see it and she does not know the route to find it.

When Kalu explains his technique for delivering an FND diagnosis, his voice is raised and seems dismissive:

"I tell them I can't explain the symptoms, this is not a disease process that we deal with because there is no pathology that we are dealing with here… then I discharge them straight away saying there's nothing more I can offer here" (Kalu)

If Kalu genuinely believes there is no physical pathology than it is understandable that he believes it is not within his remit to keep patients with FND on his caseload. However, this is not strictly the case given current understandings about FND. It appears he feels the need to see functional and non-functional neurological disorders as black and white, a view which perhaps is compounded by the way services are structured and funded. However, the nuance of the situation is explained by Viki when she discusses the frequent overlay 'organic' and functional neurological disorders. It is at these times where the neurologists' skills are perhaps most needed as they attempt to differentiate between the two disorders:

"The art is to try and disentangle which is which" (Viki)

Her use of the word 'disentangle' conjures up images of a mass of knotted wires which all look the same but are integrally different in their uses, separating them and labelling them

correctly takes time and patience and could not be done successfully if rushed. Perhaps this reflects how neurologists might feel as they strive to manage their clinics with the time and resources restraints they are under?

2.5.3 Identity matters

The matter of identity was spoken about within the context of how the logic of the 'wiring' aspect of neurology fitted their individual interests, how they could not identify with the 'counselling' required for FND patients. There was also discussion about the dismissive and derogatory comments which, at times, were vocalised by their neurology colleagues. There was discrepancy when the participants seemed keen to distance themselves from the brashness of their colleagues, whilst subtly agreeing with some of the content.

2.5.3.1 "Where's the lesion?"

When the participants discussed their reasons for entering the field of neurology, themes of 'logic' and 'lesions' were mentioned:

> *"I mean, a lot of people go into neurology because they like the logic of it. And so, a little bit of it is a sort of nerdy, sort of electronic wiring diagram approach to the assessment, where you think well, they've got these symptoms…where's the lesion?" (John)*

When John describes this idealised process of symptoms leading to an obvious physical cause, it is as if he believes pinpointing the cause means he can correct the issue, that he will be able to do something tangible. The sense is that this will allow him to feel in control of the situation, being in control is perhaps behind the language used to describe non-functional neurology as being 'real':

> *I think a lot of doctors, including myself, we kind of want things that are real, things that we can say: "this is this, and we can treat it with this" (Jane)*

If non-functional disorders are described as real than it infers that FND is not real. Perhaps holding this view alleviates some of the pressure that comes with the medical model and the expectation that medics should be able to fix the problem, if something is not real it cannot be expected to be repaired.

The differentiating between functional and non-functional disorders continues when Jane describes her interest in 'scientific' disorders:

"The thing is you, in a way you study medicine, and you study neurology because you're interested in…often it's because you're interested in scientific, you know, seizure disorder, where you see the EEG changes" (Jane)

Her explanation seems to stem from a 'seeing is believing' mentality, however, just because something cannot be seen does not mean it is not real. Her classification of a seizure disorder that is identified through EEG changes as scientific suggests that a seizure that is not identified this way is unscientific. However, if this were true then, as FND is currently a psychiatric diagnosis, the implication is that psychiatry is not scientific. This view might reveal something about her personal beliefs about mental health not belonging in the field of medicine, or at least not holding the same priority as physical health.

The precedence of what he describes as an 'organic' disorder over functional disorder is seen when Ansh speaks about his role as a neurologist:

"We have been trained to only look for organic pathology. So, abnormal scan, abnormal EEG, abnormal blood test, abnormal … everything abnormal" (Ansh)

His words appear to be another example of the othering of FND and putting it into a category of disorders that do not really exist. When he explains that his role is to look for 'everything abnormal' he appears to neglect the reality of the person with FND's symptoms. If they are having seizures or are unable to walk, or any other symptoms associated with FND, then

there clearly is something 'abnormal' going on. If he does not believe that there is something abnormal occurring, then it appears he may be questioning the legitimacy of the symptoms. Additionally, he may not have considered that the knowledge to know what to look for, or the technology to find it, has not been developed sufficiently for the most recent opinions about what FND might be. This is something that has been considered by Saad as he reflects on the current understanding of FND and expresses that the patients should not be held responsible for the lack of awareness about the disorder:

"I think there will be quite a few things that we would know in the future that we don't know yet. But that's not the patient's fault, that's your own fault, it's the fault of the science" (Saad)

2.5.3.2 "I feel like I'm being a counsellor…but without any counselling training"

Some of the participants felt they had been prepared to work with patients with functional disorders right at the start of their career:

"Yeah, it's, it's felt to be, kind of, the bread and butter of neurology to some extent, everybody knows about it and accepts it and expects it" (Peter)

For others, this was not the case, instead it was considered an unexpected element of their role and a lack of FND specific teaching was cited as an issue:

"There's a real lack of training…I remember you never really get told about it…before then I hadn't really ever been told about it properly or taught how to talk to people" (Jane)

Jane's claim that she had not been taught how to talk to people with FND is interesting as it suggests she believes their communication needs are somehow different to other patients. If she expresses empathy and validates the concerns of her other patients when discussing their diagnosis, what is it that she believes is expected of her when consulting her FND patients? Perhaps a clue to the crux of Jane's concerns can be found in Kalu's statement about his

preference for ‘pathology’ where he reveals an assumption that any patient that presents with FND will be experiencing deeply embedded psychiatric problems:

“As a neurologist we like to give a pathology, we like to treat a pathology and we not, we do not have the time to dig in-depth into psychiatric problems” (Kalu)

Whilst he is correct that FND, due to a potential quirk of history because of lack of understanding of its true cause, is currently a psychiatric diagnosis, there is no certainty that a patient will be experiencing psychological issues, which is what he appears to be suggesting. However, Kalu is not alone in expressing the parameters of his role and asserting his reluctance to work with people psychologically. Ansh proposes it is his role as an organic doctor that means he does not consider mental health:

“My background is medicine, pure medicine, before neurology, so I think organic only. I don’t think you know… mental health. Basically, we are organic doctors, we are not neuropsychologists”” (Ansh)

His use of the word ‘pure’ in his statement may imply something special in the type of medicine he has practiced, and by extension that working with mental health is somehow less important or in some way polluted. This rejection of anything to do with their patients’ mental health is continued by Jane:

“You’re not actually a psychiatrist, or a psychologist, you’re not interested in that” (Jane)

She appears to associate working with FND as working with mental health and therefore dismisses it because it is not within her role parameters. However, when Dawn confesses how she is sometimes made to feel during follow ups it sheds another light on the matter:

“I don't necessarily feel like I'm being a doctor when I'm following up FND patients. I feel like I'm being a counsellor…but without having any counselling training [laughs]” (Dawn)

She laughs as she makes her point but there is a sense that she is attempting to cover up some feelings of inadequacy. Her admission that she does not feel like a doctor when she is consulting with FND patients suggests she is far from her comfort zone. If her experience reflects that of the other participants, then their comments that, on the surface, imply a sense of superiority may instead be an attempt to disguise a perceived shortfall in their ability to contain a patient's emotional response to a difficult diagnosis.

2.5.3.3 "That's something that neurologists often find amusing".

Some of the participants reflected on the negative and critical comments they frequently heard spoken by their colleagues. Dawn struggled when choosing the words to describe these overheard remarks, she appears to want to soften her criticism of her colleague when she prefixes the word 'negative' with 'slightly':

"But you yeah, in handovers, you'll get little comments that don't... I just…they're slightly negative about FND as a thing. Ohh, which sort of reveals their underlying thoughts if you know what I mean" (Dawn)

When Peter discloses the response to FND patients is often met with *"a snigger"*, he attempts to justify the behaviour of his fellow clinicians:

"I guess people can, with functional disorder, can behave in odd ways and present in odd ways. Which kind of defy the, you know, the normally expected patterns of neurology, and I suppose that's something that neurologists often find amusing" (Peter)

When he comments that the patients' presentation does not follow expected patterns, he implies that this is something they are 'doing wrong' which may suggest a deliberate action on behalf of the patient. The attempt to frame FND as something to be trivialised potentially reveals their own insecurities on the subject, it is perhaps this insecurity that leads to some participants allowing themselves to be drawn into conversations which can seem mocking in nature:

"I often catch another neurologist in the coffee room who's just seen someone FND, and it's… it's that sort of, 'hard work, ohh God, I need a coffee'." (Dawn)

"I said to that adult neurologist, 'so there's this patient I need to refer who's having, you know', I think I said, 'non-convulsive events' and she went, 'ohh great!' and I just kind of laughed and I was like, 'yeah, I know, sorry!'" (Jane)

What may be getting missed when colleagues engage in this type of flippant conversation are expressions of difficulty experienced by some neurologists when working with FND. Perhaps it taps into their struggle with not feeling they are able to 'fix' the condition. As medics this is a central function of their role, and so maybe the real response being sought is not a comical collusion but an offer of support and understanding.

2.6 Discussion

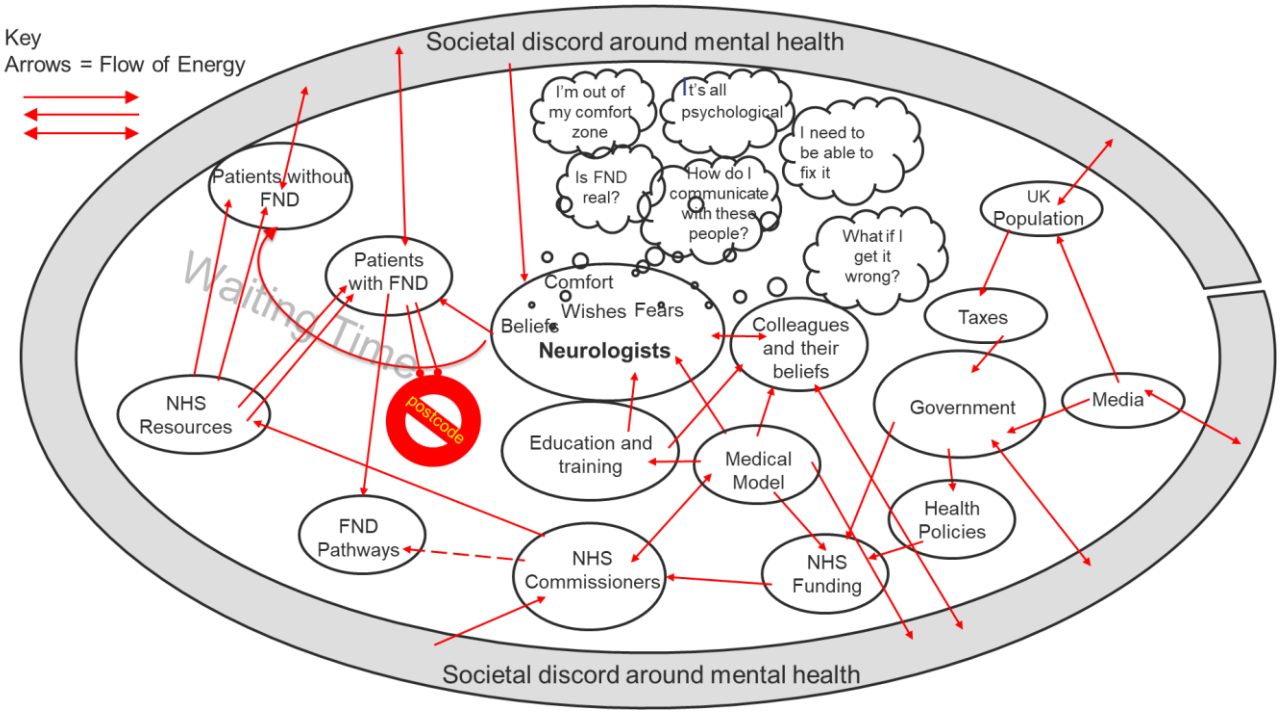
This study explored the lived experiences of neurologists as they provide neurology services to their patients, specifically their patients who are diagnosed with FND. It has highlighted some of the difficulties faced by participants which impacts on both their internal and external worlds. Many of the findings in this study correspond with findings from previous studies [25-27] which focus on the patient experience of attending neurology services. When participants expressed how they felt they had belittled their patients, had doubts about the reality of FND as a diagnosis, and were concerned that their patients might accuse them of not investigating their symptoms thoroughly, they match, almost to the word, the findings of papers exploring the patient experience. The similarities are even more interesting when it is considered there has been a span of twenty years in which the papers have been written. The reason there has been little change in the process and experience of FND diagnosis over the past twenty years (and longer) might be understood when considering the widely held assumption that FND is a psychological issue, caused by psychological distresses such as trauma or overwhelming life stresses. This

mistaken assumption matters when coupled with the knowledge that psychological disorders carry a stigma that is not found for physical health disorders [49].

How the power of this stigma operates and results in the themes found in this study can be explained by applying the situation to Hagan and Smail's [50] power mapping model. The visual summary of the structuring of power (see Figure 3.) highlights the explicit and implicit influences that impact on people and organisations, used here it helps to explain the societal influences on neurologists and how these influences effect the way they feel and experience working with patients with FND. Hagan and Smail describe these influences as 'The Impress of Power' which they divide into three key areas defined as, the person, proximal influences, and distal influences. The influences of 'the person' include their mental and physical experiences such as beliefs and wishes as well as bodily sensations that accompany feelings such as fear and comfort. The proximal influences are those that closely surround the person and include education, work, and professional and personal relationships. Distal influences cover broader societal areas such as politics, economics, culture, and media.

Figure 3

Power map of results.



2.6.1 The Person

The participants' beliefs and fears were evident throughout the interviews. There was a recurrent sense of the othering of patients with FND. Othering is described as a process of identifying people who are considered different from the self or the mainstream and is used to strengthen a position of power and privilege [51]. When participants express the belief that patients with FND somehow matter less than others, it corresponds with society's beliefs around what are perceived to be mental health problems. The UK parliament states that nine out of ten people with mental health problems experience stigma and discrimination, with stigmatising views embedded within public opinion, including in those who are considered knowledgeable about mental health issues [52].

Participants' identity as a neurologist was clearly important with many repeating that they were neurologists over and above anything else, and that it was the scientific element of neurology that appealed to them so much. There is widespread agreement that neurologists are highly respected in the field of medicine, it is considered a difficult subject, so much so that there is a term, 'neurophobia' to describe medical students fear of the subject [53]. In contrast, psychiatry has been called, 'a non-medical speciality for failures' [54] and is considered to be less prestigious, less scientific and conceptually weak [55-56]. These differing views of medical specialities may suggest one of the reasons why participants may have wanted to distance themselves from the psychiatric element of FND.

It is important to note that it may not be as simple as neurologists believing they are above dealing with FND, that it is beneath their level of skill to have to consider such trivial matters. An alternative perspective could be that neurologists' lack confidence about their ability to deal with FND. FND is not easy to diagnose or explain, whilst there has been an increase in information about FND available to neurologists, it must be sourced through individual effort, there are no

comprehensive ‘how to’ manuals on FND routinely provided to neurologists. The research studies around potential pathophysiological causes of FND are in their infancy and the cause is still up for debate. Neurologists are trained in the biomedical model; they are skilled in recognising patterns of symptoms, interpreting detailed scans and diagnostic tools and matching them to a diagnostic category. They are admired for their ability to find concrete solutions to tangible problems. When there is no solution to be had they can be confident that they have exhausted all known treatment options. The vague and uncertain domain of FND might be considered the opposite of the neurological conditions, such as epilepsy or acquired brain injuries, which neurologists often cite as their reason for their interest in neurology. Their inner belief may be that they do not have the expertise to adequately diagnose a disorder they have received scant, if any, training on. Moreover, they may feel bewildered that they are expected to somehow accept this, often-unanticipated, addition to their role or risk being accused of being arrogant and uncaring, finding themselves with nowhere to turn to for support.

2.6.2 Proximal

The main proximal influence that was evident during the interviews was the influence of other neurologists. There was a slightly incongruent element of wanting to be part of the neurologist ‘in group’ whilst detaching themselves somewhat, but not completely, from the more disagreeable views of their colleagues. There were examples of collusion with neurologists who appeared frustrated at the thought of seeing FND patients, and unkind comments and ridicule were excused. Tajfel and Turner’s [57] social identity theory can help to explain these dynamics; belonging to a group is important for the sake of a positive sense of self and an understanding of a person’s place in the world. For neurologists, keeping in mind the previously mentioned prestige attached to the role, being part of this group not only allows them to feel slightly elevated in position to other professional ‘out groups’, such as psychiatrists, but it positions them in a far

superior place than the out group of patients with FND. This sense of social identification would be devastating to lose, so remaining as a valued member of this group is critical, therefore allowances are made, and uncomfortable conversations are tolerated.

2.6.3 Distal

Participants spoke of their doubts that commissioners would fund FND services, concerned that in a financially squeezed NHS, FND would be seen as an unjustifiable expense against the needs of more deserving services. This concern has merit when considering that despite government strategies such as 'No health without mental health' [58], which aimed to achieve parity of esteem for physical and mental health services, mental health services still lag behind physical health services as integrated care boards (ICBs) fail to prioritise them in the face of budget restraints and the desire to clear physical health waiting lists [59]. The NHS is considered to poorly serve people with co-existing mental and physical health conditions and the integration of mental and physical health services is insufficient [60]. In an NHS Providers report [61], more than half of NHS trusts surveyed did not believe that their commissioners would meet the government commitment to parity of esteem. In the same paper it was reported that the criteria for distribution of additional funding for liaison psychiatry services was not developed and the complexity of funding decisions meant they often failed to tackle the issues they were designed to.

Participants whose catchment area covered a wide geographical area were concerned that their patients' postcode might prevent their ability to refer them to FND services that had been commissioned. The legitimacy of these concerns is realised when consideration is given to the structure and processes involved in the provision of health care services in local areas. Such provisions are dependent on a blend of organisations including local authorities, public health, and commissioners, it is therefore unsurprising that there are geographical variations in health care services [58]. The 'postcode lottery' of healthcare provision is well documented [62-65], the office

of health improvement and disparities (OHID) and NHS England produce 'Atlases of variation' [66] which aim to identify unwarranted variation in healthcare provision across the country. This variation in services inevitably leads to health inequalities which was recognised in the Marmot Review [67], the review stated that action was required by the NHS and others to combat health inequality, and that without effective local delivery systems, and policies focusing on health equity, any national objectives could not be met. Whilst the government at the time accepted the recommendations of the review, successive governments have not prioritised such action [68] and health policies have in fact had the opposite outcome. On ground level such policy decisions are symbolised by a lack of services depending on local decision makers' priorities, which circles back around to the very legitimate concerns of the participants as they take note of their patient's postal address.

2.7 Strengths and Limitations

A key strength of this study was, whilst adhering to the requirement for a homogenous set of participants, namely neurologists working within the NHS in the UK, there was diversity across the participants in terms of gender, age and ethnicity, and clinical experience. This helped to account for cultural and social differences that might influence the way in which the participants experienced their work, and in turn the meaning they made of those experiences. However, a limitation which must be considered is that all participants responded to a call for participants, they may have had a particular interest in FND which might not be reflective of the wider neurologist population.

2.8 Researcher Interpretation

Reflexivity is an elemental factor in IPA research, from the research topic choice to the identification of findings considered the most important, the researcher's background and previous knowledge and perspectives will form the template from which the study is developed.

As previously stated in this document, the researcher is a trainee clinical psychologist with family connections in the medical field. As such they position themselves as having insight into both the stigma often attached to issues perceived to be related to mental health, and to the value placed on the benefits of the medical model, with its clear framework for diagnosing disease through identifiable biological factors. Whilst this position provided some balance, it also played a role in the oscillating views of the researcher throughout the research process. Perhaps using the phrase 'rollercoaster' is a little trite when describing the researcher's journey with and through the data, however, in this case it is apt.

The interviews were conducted with a predetermined sense of respect and gratitude for the neurologists who had agreed to allocate time to the project, however there was also an underlying belief that these were the people accountable for the, often unsatisfactory, sometimes unacceptable, service that patients with FND received when using NHS neurology services. During the interviews there were times when it would be impossible not to appreciate the difficulty the neurologists often found themselves in as they navigated the management of a disorder which they did not feel prepared for personally and were not allocated the resources to prepare for systemically. However, there were moments when the content and tone of their words were challenging to hear as they appeared to show intolerance for patients with FND, their dismissive and rejecting manner was confronting and upsetting.

The analysis of the data revealed a consensus that FND was a problem for neurologists, exposing some views that were not necessarily in line with the most recent understandings of FND. It was evident that some neurologists felt abandoned to manage what many believed was a psychological disorder, and therefore not their problem to deal with. At times they exhibited compassion for the patients they did not know how to help, and at times they did not. This alternating stance was reflected by the researcher in their reactions to the neurologists' words. At

times there was compassion and empathy for the neurologists who worked so hard and felt that nobody was addressing the problem, their concerns dismissed or ignored by those with the power to change a system which was not fit for purpose. However, at times there was anger and frustration as the researcher connected to the experience of the FND patients that were lost in the debate, who were marginalised, sometimes ridiculed, often disbelieved and whose voices remained unheard. These differing emotional pulls can be seen in the writing up of the results where the attempt of balance occasionally fails as the most keenly felt perspective of the moment prevails.

2.9 Future Research

Using IPA, which takes a deliberately idiographic view, as the methodology for this research, excludes the option of generalising the results. There may be a benefit for taking a more nomothetic stance in future research to enable more scope for transferable or even generalisable data.

2.10 Clinical Implications

The findings of this research bring into focus several important matters that are clinically relevant. These include the widely held belief about the nature of FND belonging largely to the mental health arena; the stark reality of how neurologists experience their work with FND and the impact that this must have on both them and the people going through the diagnostic process; and the lack of specialist FND services available across the UK.

There is no known single cause of FND [69], and in most published studies more than fifty percent of FND patients included do *not* report current psychological stressors or histories of trauma [70], yet, as evidenced in this research, it is still commonly assumed that FND patients have psychological issues. Many do not understand the neurobiological abnormalities in FNDs and not everyone is clear on clinical signs or other diagnostic tools which should be used to help give

positive diagnoses. It appears that currently not enough is done to ensure that neurologists are kept up to date with developments in the field. As the knowledge around FND improves, it is important that it is widely shared and presented to neurologists so perhaps the stigma that so often accompanies an FND diagnosis can be reduced. This could be achieved through additional training and ensuring that time for training is protected. Adjusting the way in which services are operated so that patients with suspected FND can be offered longer appointments might help reduce the concerns about overrunning clinics and the impact this has on neurologists and their other patients.

The stigma associated with FND is central to another dominant matter highlighted in this research. Throughout their interviews the participants expressed their concern about having to work with FND, occasionally they overtly articulated annoyance about the situation. But even for the participants who might outwardly claim to be more tolerant of it, their use of language at times seemed to marginalise patients with FND, this might be indicative of an unconscious bias and be reflective of strongly inbuilt narratives. Uncovering and challenging unconscious biases can be a confronting experience, without this however, things are unlikely to change. It is beyond the scope of this paper to address the wider issue of societal stigma towards what are considered mental health problems, but perhaps by drawing attention to its existence within neurology services, neurologists might reflect on how their internal beliefs and external actions may contribute to the systemic stigma that effects a significant percentage of the patients they consult.

This research clarifies the critical need for dedicated FND services, staffed by FND specialists of all necessary professions. The existence of specialist clinics for other disorders is commonplace, it seems amiss then, especially when considering the huge burden on resources that FND is said to be, that there are scant few specialists in FND. If there is a chance that such services are to be funded, there needs to be a broadening of whose voices influence funding

decisions responsible for the provision of FND services. A multi-disciplinary presence in service development roles, challenging the dualist view of the mind and body, would be helpful to any service that serves those with functional disorders.

2.11 Conclusion

This study highlights how neurologists make sense of their experiences of making and delivering a diagnosis of FND. Many express challenges in this area of neurology work, it seems that the classing of FND as a purely psychological condition is still widespread, despite the changes to the diagnostic criteria and development in the understanding about the causes of FND. Neurologists often see FND as a role that falls outside of their speciality, perhaps a combination of the lack of awareness of the causes of FND, the lack of diagnostic tests for FND, and the way services are organised and funded, and societal views on mental health all play a part. There is systemic, embedded stigma directed towards mental health issues within society, it has power to influence peoples' attitudes and the decisions they make, and neurologists are not immune to this influence. They are of our society, as are the commissioners who decide on the provision of FND pathways, and too the people who allocate government funding and resources, stigma influences research choices, further impacting on the knowledge of FND. All these decisions trickle down to impact the diagnostic process of FND, often leaving neurologists struggling and exhausted by the situation. It is not enough to take a surface level view and condemn neurologists for admitting to challenges they experience, especially when they are mostly just about surviving.

2.12 References

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Part 3 : Appendices

3.1 Appendix A: Reflective statement

Reflecting on this research journey is quite a task, in the main this is because it has not been straightforward, and it has not been timely. Due to some difficult life events that disrupted my process through the course, it has taken me longer than expected to complete this thesis. I am positive that I am not the only student who has had a rocky research journey, and perhaps it is useful for those who are currently experiencing difficulties to know that it can be temporary. When there is turmoil in your personal life, and you are juggling academic and clinical demands, pacing, being organised, seeking support and primarily, practicing more self-compassion is essential (admittedly, the self-compassion bit is not always easy). Clinical psychology training has standardised core competency development, but despite this, training is an individual journey, with different challenges, different successes, and different time scales. I have come to realise that there is no benefit in comparing yourself to others, for they are not sailing your ship, and you are not sailing theirs. You must chart your own course and hope for fair winds (and accept the occasional sea-storm).

The seed for this research topic was planted several years ago, before I began my clinical psychology training, whilst speaking to a therapist friend about her work with people who had a diagnosis of non-epileptic attack disorder (NEAD). At the time it was thought that NEAD was a physical display of psychological distress, and I was intrigued by this, the idea that the mind could wield such power over the physical body fascinated me. As I began my training my interest in the subject remained, I was also interested in Adverse Childhood Experiences (ACEs) and the link to physical ill health, to me there seemed to be an obvious relationship between my two interests and I wanted to investigate this in my research.

After meeting with Dr Beckett at the research fair, someone whose knowledge and interest suited me perfectly, she pointed me in the direction of some of the experts in the field of FND, all neurologists. The more I read the more I realised that the idea that only trauma or stress leads to NEAD or other FNDs was both outdated and overdone. Adjusting my viewpoint took a while, even though the DSM had changed the criteria for FND in 2013, the people I knew, such as my old friend who had first introduced me to the existence of NEAD all those years ago, were still adamant it was a purely psychological condition. The debates that followed helped to cement my understanding as I repeated what I had read in the research, namely that it was still up for discussion as to what was the cause of FND.

As I attempted to educate myself with the latest research, I found papers concerned with the patient experience, articles debating the cause, information on diagnostic tests and how to deliver an FND diagnosis. There were a few questionnaire based papers on the neurologist perspective of FND but nothing directed towards the lived experience of the neurologists whose role was so pivotal to the diagnosis of FND. Identifying this gap in the literature allowed me to settle on my research question.

I decided to use IPA as the methodology rather than thematic analysis as it seemed like the most appropriate for my research question. I wanted to deeply understand the meaning that neurologists made of their work with FND and IPA would give me the opportunity to reveal this. Knowing I would need around ten or so participants sounded reasonable, especially as I was introduced to two neurologists who seemed very keen on the project. I felt encouraged when I spoke to them as they assured me they could support me with recruitment. I feel now that I was quite naïve and did not consider that this might not be as serendipitous as it seemed. For example, I decided I would not need to apply for NHS ethics when the time came as I had this route to

recruitment, on reflection, attaining permission to recruit directly through the NHS may have been useful further down the line.

It was around this time that I experienced a delay in my journey and so it was a year later that I finally gained ethical approval. I was already at the end of my training and so I faced the prospect of managing a thesis without the support of my cohort.

This was the beginning of what turned out to be a frustrating process of recruitment, the people that agreed to help were not responding to me. I had placed adverts on the websites of the Association of British Neurologists, the website of the Functional Neurological Society but responses to the calls for participants were few and far between. I felt quite powerless and became acutely aware of the power that neurologists held, how they could shape the experience of those who required their help. I would not be so crass as to say that my experience was anywhere near the same as those awaiting an FND diagnosis, but the experience did encourage me to reflect on the dynamics of power.

The slow pace of recruitment rumbled on, and I was beginning to gather more and more data. Every interview I had was interesting, all the participants were pleasant and gracious towards me, they were clearly passionate about their roles as neurologists. They were undoubtedly very busy people, and I felt grateful that they allowed me to take up some of their precious spare time, the parallel between FND taking up their work hours and now their home hours was not lost on me. Reflecting in action (Schon, 1991) was vital during the interviews, as the participants relaxed into the process their responses seemed to gain authenticity. There were participants who, at the beginning of the interviews expressed empathy for patients with FND and a desire to do all they could to support them, however, as the interviews continued, they began to reveal a level of frustration about the situation, at times the words spoken by a few of the participants were almost cutting in their sharpness. Hearing these opinions voiced was difficult for

me as I reflected on the experiences of the patients in their care, it was these moments that I needed to be the most reflexive and aware of my own views and values and how they could influence my interpretation of what was being said. In contrast to these difficult moments, I experienced some quite poignant moments at the end of the interviews, when I checked in with the participants and asked how it had felt to be interviewed. It seemed they did not expect the question which required some self-reflection on their part, but the majority responded by thanking me for the opportunity to speak about it, one said, "no one ever asks how we feel". It was these responses that really brought home the complexity of the situation, the participants could not be classed as 'good' or 'bad' neurologists, but people whose struggles were overwhelming and mostly unheard.

The difficulty of the analysis and write up process took me by surprise, not necessarily the practicalities of the process itself but in allowing my own authenticity to be unrestricted. I had decided to use IPA (Smith et al., 2009) because I wanted to account for my contribution to the findings, but it felt negative and almost disloyal to the participants I had struggled so hard to find. However, I could not ignore that the more I read the transcriptions the clearer the potential meanings and unconscious bias became to me. The dilemma I felt the most was when considering who I wanted to read the research, I felt that, although publishing in a clinical psychology journal would feel safe and perhaps give me more of a sense of freedom in my writing, it wasn't clinical psychologists who needed to read this. I wanted to bring into awareness what was hidden by holding a mirror up to neurologists, hoping that it would lead to some kind of reflection on their part. But this was easier said than done, in my first draft my supervisor noted I was skirting around the edges, being more descriptive than anything else. Some of it was definitely part of my development as an IPA researcher, but also it was a way to avoid confronting potential unconscious biases and power dynamics without feeling like I had betrayed the trust of my

participants. I wondered if this was the reason for the lack of research into the neurologists lived experience, was it just too difficult to talk about?

Initially working on my SLR felt quite refreshing after the empirical, the methodical steps of a literature search and scoring the papers felt less difficult in many ways. I felt there was a slight parallel to the way my participants had claimed to prefer the logic of neurology, somehow it felt less personal. My review was looking at adult patients' experience of interactions with health care professionals whilst going through the diagnostic process of FND as I believed it complemented my empirical research well. I had initially assumed I would use thematic synthesis for the review. However, once I had gone through the screening l and arrived at the papers I was to include in the review I realised that, whilst they were all qualitative papers, they were relatively heterogeneous in their aims and methodology. After discussion with my supervisor, I decided on using narrative synthesis. It was around this time that the feeling of it being less difficult ended. Creating the narrative from all the data felt quite overwhelming. I had papers from several countries and the stories were often practically identical. Not just to each other but I could imagine the patients of my empirical participants telling the same tale. It feels upsetting that over the past 20 years there has been little change in the reality of the neurology clinics, no matter how the evidence is changing the lag between the two is quite stark. But this only strengthened my resolve to want to publish in a neurology journal and let the results of both papers speak for themselves. I feel some trepidation about neurologists reading it, but I believe I have approached the subject with compassion, the Compassionate Mind Training (Irons & Beaumont, 2017) 'tricky brains' phrase, "it is not their fault, but it is their responsibility' comes to mind.

My overall reflection is that I could have probably made my life easier choosing a different topic with a different population of participants, but if I had this story would still be unheard. I have learned not to expect plain sailing and that sometimes you just must tolerate the discomfort

and do it anyway. I have also discovered that writing a thesis once clinical psychology training is over can be lonely at times, however, it just was not viable for me to have done this any other way.

3.2 Appendix B: Epistemological statement

The following statement outlines the researcher's epistemological and ontological position in relation to this portfolio thesis. Epistemology refers to the philosophy of knowledge, it is concerned with the nature and validity of knowledge and beliefs, and how these have come to be known. Ontology refers to what is out there to be known about, what exists in the real world and what it means for something to exist. There are two dominant positions in ontology, relativism and realism. Relativism understands reality as dependent on the perspective or interpretation of the individual who experiences it, it is subjective and can therefore be different from person to person or culture to culture. Realism posits that reality is independent of human thought, it is objective and there to be discovered, however, it may not be easily observable (Willig, 2008). Positioned between these two stances is critical realism which adopts a realist ontology with a relativist epistemology. This position suggests there is an objective truth that exists independently, however, how it is known is dependent on the cultural and social perspective of the knower (Mingers et al., 2004). For this thesis portfolio the researcher adopts a critical realist approach, this position is compatible with both the SLR and the empirical paper.

To discover how neurologists' make sense of their experiences of making and delivering a diagnosis of FND, the qualitative research method was appropriate. IPA was chosen as the methodology as its main endeavour is to examine how people make sense of their experiences (Smith et al., 2009). It is underpinned by phenomenological and interpretivist epistemologies (which could be described as relativist), meaning it is concerned with how the world is

experienced, and made sense of, by people across time and circumstance. However, it acknowledges that it is not possible to know exactly how people experience their worlds, it must be deduced from their accounts of their experiences, therefore it can only ever be an interpretation of their experiences ([the critical realist ontological position] Willig, 2008). For this process to occur, the researcher is undoubtedly influenced by their own views and beliefs about the world. As they attempt to make sense of the meanings that have been made by participants, they are in fact constructing their own meanings from the information, this is known as double hermeneutics and it is a key element of IPA methodology (Smith et al., 2009). When recognising the influence of the researcher through this hermeneutic process, it is important that they are transparent about their potential biases and perspectives. Therefore, reflexivity and reflection are crucial undertakings when conducting IPA, both of which the researcher committed to throughout the course of completing the thesis (see Appendix X for reflective statement).

The researcher's epistemological stance was also the lens used during the SLR. There has been a historical division of the mind and body in medicine, and because of this, stigma and assumptions are still inaccurately applied to the FND population. This suggests to the researcher that there is a 'truth' to participant's challenging journeys to diagnosis, but this 'truth' can only be accessed via the analysis and synthesis of the accounts of participants' experiences of diagnosis. Considering this, a narrative synthesis (Popay et al., 2006) was conducted of studies which incorporated accounts of participants' lived experiences of the FND diagnostic process. The included studies were heterogeneous in their overall aims, methodologies, and geographical settings, conducting a narrative synthesis provided a way to create a meaningful story from the findings of the studies, regardless of any discrepancies between them.

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3.3 Appendix C: Journal of Neurology guidelines for authors

Contents

Authorship principles

Research Data Policy

After Acceptance

Mistakes to avoid during manuscript preparation

Instructions for Authors

Types of manuscripts and formal requirements

All articles must be written in English.

The following article will be considered for publication and can be submitted via Editorial Manager: Original Communication, Reviews, Short Commentary, Letters to the Editors and Pioneers in Neurology.

Original Communication must not exceed 9,000 words (excluding abstract and keywords, figures, tables, captions and references). Exceptions can be made only with the agreement of the responsible Chief Editor.

Review Articles must not exceed 12,000 words (excluding abstract and keywords, figures, tables, captions and references). Exceptions can be made only with the agreement of the responsible Editor.

Short Commentaries highlight new developments in clinical neuroscience and should not contain more than 6,000 words. Preliminary results of highly innovative studies may be submitted as Short Commentaries.

Letters to the Editors will be considered describing small studies or case reports of special significance and should not contain more than 2,500 words and 15 references. Abstract and key words are not required.

Pioneers in Neurology articles have a limit of 1,000 words, 10 references, and 1 portrait figure. These articles are not obituaries; rather, they focus on the scientific contributions of past pioneers

to the neurological sciences, comprising key biographical information, but foremost, offering originality and a fresh perspective. Please consult previous issues for sample papers.

Neurological Update papers are invited reviews by experts that provide an update in their field of expertise. *Journal of Neurology* does not consider unsolicited submissions of Neurological Update papers.

Journal Club papers are invited to discuss relevant publications in the field of clinical neurology. *Journal of Neurology* does not consider unsolicited submissions of Journal Club papers.

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Editorial procedure

Single-blind peer review

This journal follows a single-blind reviewing procedure.

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Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

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Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

The name(s) of the author(s)

The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country

A clear indication and an active e-mail address of the corresponding author

If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript. The use of an LLM (or other AI-tool) for "AI assisted copy editing" purposes does not need to be declared. In this context, we define the term "AI assisted copy editing" as AI-assisted improvements to human-generated texts for readability and style, and to ensure that the texts are free of errors in grammar, spelling, punctuation and tone. These AI-assisted improvements may include wording and formatting changes to the texts, but do not include generative editorial work and autonomous content creation. In all cases, there must be human accountability for the final version of the text and agreement from the authors that the edits reflect their original work.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

For life science journals only (when applicable)

Trial registration number and date of registration for prospectively registered trials

Trial registration number and date of registration, followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

Competing Interests: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

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Text

Text Formatting

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature’s LaTeX template.

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

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Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

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References

Citation

Reference citations in the text should be identified by numbers in square brackets. Some examples:

1. Negotiation research spans many disciplines [3].

2. This result was later contradicted by Becker and Seligman [5].

3. This effect has been widely studied [1-3, 7].

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

The entries in the list should be numbered consecutively.

If available, please always include DOIs as full DOI links in your reference list (e.g. “https://doi.org/abc”).

Journal article

Gamelin FX, Baquet G, Berthoin S, Thevenet D, Nourry C, Nottin S, Bosquet L (2009) Effect of high intensity intermittent training on heart rate variability in prepubescent children. Eur J Appl Physiol 105:731-738. https://doi.org/10.1007/s00421-008-0955-8

Ideally, the names of all authors should be provided, but the usage of “et al” in long author lists will also be accepted:

Smith J, Jones M Jr, Houghton L et al (1999) Future of health insurance. N Engl J Med 965:325–329

Article by DOI

Slifka MK, Whitton JL (2000) Clinical implications of dysregulated cytokine production. J Mol Med. https://doi.org/10.1007/s001090000086

Book

South J, Blass B (2001) The future of modern genomics. Blackwell, London

Book chapter

Brown B, Aaron M (2001) The politics of nature. In: Smith J (ed) The rise of modern genomics, 3rd edn. Wiley, New York, pp 230-257

Online document

Cartwright J (2007) Big stars have weather too. IOP Publishing PhysicsWeb.

http://physicsweb.org/articles/news/11/6/16/1. Accessed 26 June 2007

Dissertation

Trent JW (1975) Experimental acute renal failure. Dissertation, University of California

Always use the standard abbreviation of a journal's name according to the ISSN List of Title Word Abbreviations, see

ISSN.org LTWA

If you are unsure, please use the full journal title.

Authors preparing their manuscript in LaTeX can use the bibliography style file sn-basic.bst which is included in the Springer Nature Article Template.

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Tables

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

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Artwork and Illustrations Guidelines

Electronic Figure Submission

Supply all figures electronically.

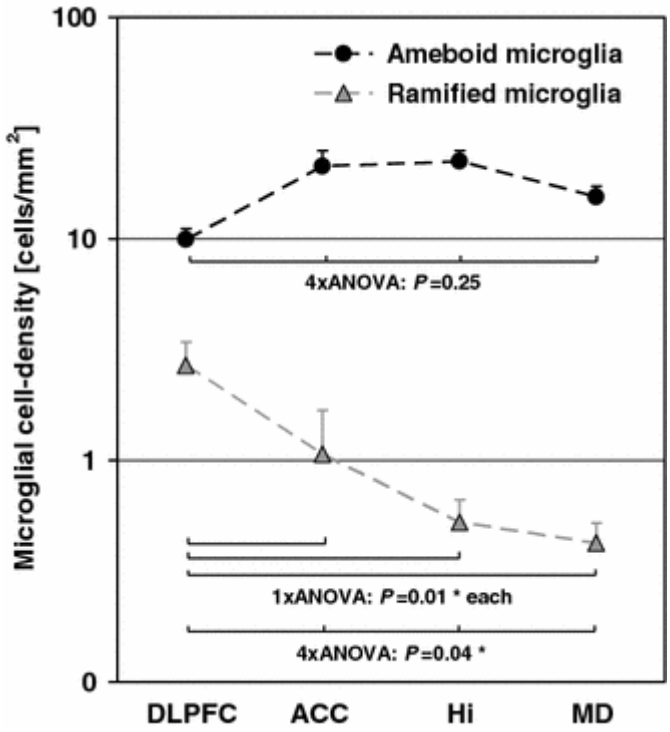
Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



Definition: Black and white graphic with no shading.

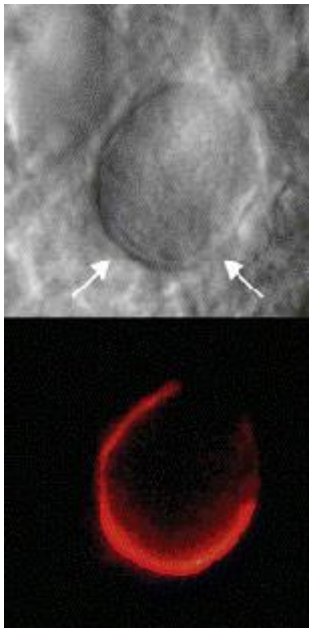
Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.

All lines should be at least 0.1 mm (0.3 pt) wide.

Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.

Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art

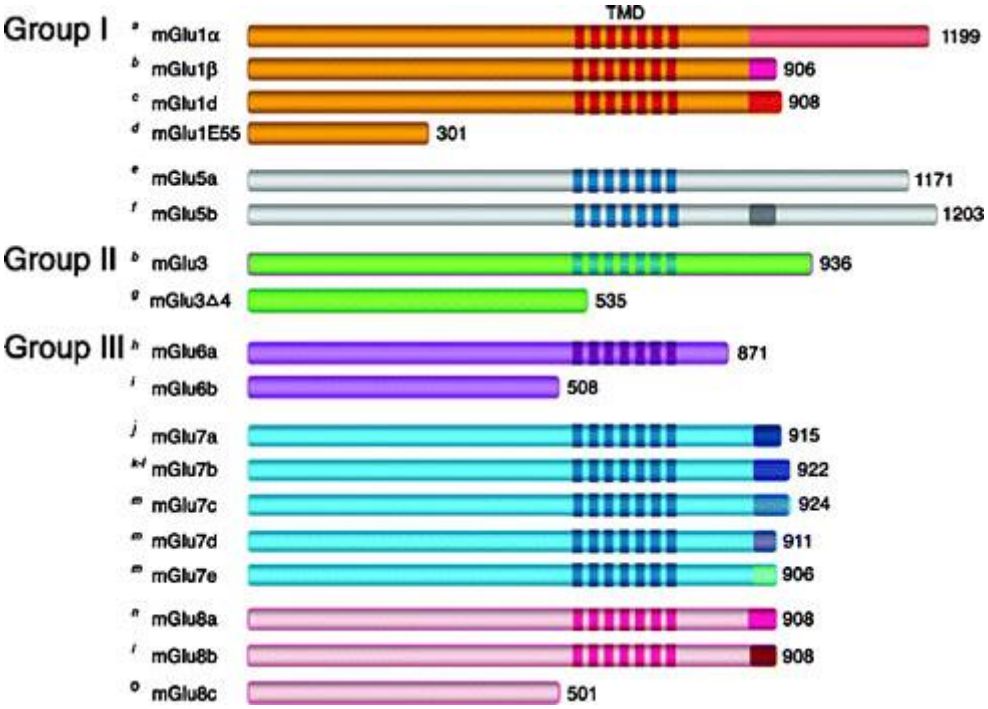


Definition: Photographs, drawings, or paintings with fine shading, etc.

If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.

Halftones should have a minimum resolution of 300 dpi.

Combination Art



Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.

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Integrity of research and reporting

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These statements should be added in a separate section before the reference list. If these statements are not applicable, authors should state: The manuscript does not contain clinical studies or patient data.

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Research involving human participants, their data or biological material

Ethics approval

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

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Ethics approval for retrospective studies

Although retrospective studies are conducted on already available data or biological material (for which formal consent may not be needed or is difficult to obtain) ethics approval may be required dependent on the law and the national ethical guidelines of a country. Authors should check with their institution to make sure they are complying with the specific requirements of their country.

Ethics approval for case studies

Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on **Informed Consent**.

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• All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

• Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

• This research study was conducted retrospectively from data obtained for clinical purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

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Informed consent

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Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written

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Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not have been fully informed, extra care will be taken by the editor and may be referred to the Springer Nature Research Integrity Group.

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Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Consent to participate’ and/or ‘Consent to publish’. Other declarations include Funding, Competing interests, Ethics approval, Consent, Data and/or Code availability and Authors’ contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for **"Consent to participate"**:

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

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The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

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Authorship principles

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Authorship clarified

The Journal and Publisher assume all authors agreed with the content and that all gave explicit consent to submit and that they obtained consent from the responsible authorities at the institute/organization where the work has been carried out, **before** the work is submitted.

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1) made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data; or the creation of new software used in the work;

2) drafted the work or revised it critically for important intellectual content;

3) approved the version to be published; and

4) agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

* Based on/adapted from:

ICMJE, Defining the Role of Authors and Contributors,

Transparency in authors' contributions and responsibilities to promote integrity in scientific publication, McNutt at all, PNAS February 27, 2018

Disclosures and declarations

All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate).

The decision whether such information should be included is not only dependent on the scope of the journal, but also the scope of the article. Work submitted for publication may have implications for public health or general welfare and in those cases it is the responsibility of all authors to include the appropriate disclosures and declarations.

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All authors are requested to make sure that all data and materials as well as software application or custom code support their published claims and comply with field standards. Please note that journals may have individual policies on (sharing) research data in concordance with disciplinary norms and expectations.

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providing transparency on re-use of material and mention any unpublished material (for example manuscripts in press) included in the manuscript in a cover letter to the Editor;

making sure disclosures, declarations and transparency on data statements from all authors are included in the manuscript as appropriate (see above).

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In absence of specific instructions and in research fields where it is possible to describe discrete efforts, the Publisher recommends authors to include contribution statements in the work that specifies the contribution of every author in order to promote transparency. These contributions should be listed at the separate title page.

Examples of such statement(s) are shown below:

• Free text:

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Example: CRediT taxonomy:

• Conceptualization: [full name], …; Methodology: [full name], …; Formal analysis and investigation: [full name], …; Writing - original draft preparation: [full name, …]; Writing - review

and editing: [full name], …; Funding acquisition: [full name], …; Resources: [full name], …; Supervision: [full name],….

For **review articles** where discrete statements are less applicable a statement should be included who had the idea for the article, who performed the literature search and data analysis, and who drafted and/or critically revised the work.

For articles that are based primarily on the **student's dissertation or thesis**, it is recommended that the student is usually listed as principal author:

A Graduate Student's Guide to Determining Authorship Credit and Authorship Order, APA Science Student Council 2006

Affiliation

The primary affiliation for each author should be the institution where the majority of their work was done. If an author has subsequently moved, the current address may additionally be stated. Addresses will not be updated or changed after publication of the article.

Changes to authorship

Authors are strongly advised to ensure the correct author group, the Corresponding Author, and the order of authors at submission. Changes of authorship by adding or deleting authors, and/or changes in Corresponding Author, and/or changes in the sequence of authors are **not** accepted **after acceptance** of a manuscript.

Please note that author names will be published exactly as they appear on the accepted submission!

Please make sure that the names of all authors are present and correctly spelled, and that addresses and affiliations are current.

Adding and/or deleting authors at revision stage are generally not permitted, but in some cases it may be warranted. Reasons for these changes in authorship should be explained. Approval of the

change during revision is at the discretion of the Editor-in-Chief. Please note that journals may have individual policies on adding and/or deleting authors during revision stage.

Author identification

Authors are recommended to use their ORCID ID when submitting an article for consideration or acquire an ORCID ID via the submission process.

Deceased or incapacitated authors

For cases in which a co-author dies or is incapacitated during the writing, submission, or peer-review process, and the co-authors feel it is appropriate to include the author, co-authors should obtain approval from a (legal) representative which could be a direct relative.

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In the case of an authorship dispute during peer review or after acceptance and publication, the Journal will not be in a position to investigate or adjudicate. Authors will be asked to resolve the dispute themselves. If they are unable the Journal reserves the right to withdraw a manuscript from the editorial process or in case of a published paper raise the issue with the authors' institution(s) and abide by its guidelines.

Confidentiality

Authors should treat all communication with the Journal as confidential which includes correspondence with direct representatives from the Journal such as Editors-in-Chief and/or Handling Editors and reviewers' reports unless explicit consent has been received to share information.

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Research Data Policy

This journal operates a type 1 research data policy. The journal encourages authors, where possible and applicable, to deposit data that support the findings of their research in a public

repository. Authors and editors who do not have a preferred repository should consult Springer Nature's list of repositories and research data policy.

List of Repositories

Research Data Policy

General repositories - for all types of research data - such as figshare and Dryad may also be used. Datasets that are assigned digital object identifiers (DOIs) by a data repository may be cited in the reference list. Data citations should include the minimum information recommended by DataCite: authors, title, publisher (repository name), identifier.

DataCite

If the journal that you're submitting to uses double-blind peer review and you are providing reviewers with access to your data (for example via a repository link, supplementary information or data on request), it is strongly suggested that the authorship in the data is also blinded. There are data repositories that can assist with this and/or will create a link to mask the authorship of your data.

Authors who need help understanding our data sharing policies, help finding a suitable data repository, or help organising and sharing research data can access our Author Support portal for additional guidance.

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Upon acceptance, your article will be exported to Production to undergo typesetting. Shortly after this you will receive two e-mails. One contains a request to confirm your affiliation, choose the publishing model for your article, as well as to arrange rights and payment of any associated publication cost. A second e-mail containing a link to your article's proofs will be sent once typesetting is completed.

Article publishing agreement

Depending on the ownership of the journal and its policies, you will either grant the Publisher an exclusive licence to publish the article or will be asked to transfer copyright of the article to the Publisher.

3.4 Appendix D: Ethical approval

UNIVERSITY OF HULL

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Hull, HU6 7RX
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T: +44 (0)1482 463336 | **E:** Maureen.Twiddy@hyms.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Rebecca Waring
Faculty of Health Sciences
University of Hull
Via email

Friday 12th August 2022

Dear Rebecca,

REF FHS460 - Exploring the lived experience of neurologists throughout the process of diagnosing Functional Neurological Disorder

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Maureen Twiddy

Professor Maureen Twiddy
Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

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3.5 Appendix E: Participant information sheet

Participant information sheet

This research is being completed as part of the requirements of the Doctorate in Clinical Psychology course at the University of Hull. The researcher, Beccy Waring, is a Trainee Clinical Psychologist and this study is part of her thesis project.

Title of study

The experiences of Neurologists throughout the process of diagnosing Functional Neurological Disorder and delivering this diagnosis to their patients

We would like to invite you to participate in this research, which explores the experiences of neurologists as they make a diagnosis of functional neurological disorder and then deliver that diagnosis to their patients

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is Functional Neurological Disorder (FND)

FND is a disorder that affects the functioning of the nervous system. In this condition the central nervous system (CNS) does not function correctly, despite the fact it appears there are no physical or organic issues. Instead, the fault lies within the sending, receiving and deciphering of messages within the CNS. FND can cause physical, sensory and cognitive symptoms in any areas of the body that can be affected by other, organic, neurological conditions. The exact cause of FND is not fully known, however, the risk factors that contribute to the development of the condition are considered to include both psychological and physical factors.

What is the purpose of the study?

The aim of the study is to gain insight into the meaning that working with patients throughout the FND diagnostic procedure holds for neurologists, and reflecting on their experience of delivering FND diagnoses to patients. In doing so a better understanding of support needs for neurologists could be gathered, this may be used to inform best practice guidance around the diagnostic disclosure of FND.

What will I be asked to do?

If you agree to take part, then I will contact you to arrange a convenient date and time for an interview. The interview can take place either online or over the telephone. Firstly, I will ask you to confirm that you are in a private, confidential place and can talk freely (If you are not and cannot move to a private space I will suggest postponing the interview and rearranging for a time you can ensure privacy). I will then ask you to answer some short questions about yourself, such as your gender, age, the length of time you have been a practising Neurologist and where you were trained. You will then take part in a semi-structured interview where you will discuss your experience of diagnosing FND.

Your rights

- You do not have to take part
- You can withdraw from the study up to two weeks after the interview date
- All your data will be kept safe and cannot be linked back to you – See confidentiality below
- You have a right to ask questions about the research before and after participating

Confidentiality

Your personal details will remain confidential at all times with the exception of where concern over fitness to practice is raised. In this case, your NHS Trust's safeguarding procedure will be followed. This could entail giving out your details if safeguarding concerns are founded.

What are the possible risks of taking part?

Participating in the study will require your time and this may be inconvenient for you. I will ask you to discuss how you have felt about diagnosing people with FND; some of your cases may have been distressing which might affect your wellbeing. If this is the case I will provide you with details for organisations that may be able to help in the debrief sheet.

As you will be asked about the way you manage FND diagnoses there is a chance that your response will raise concerns about fitness to practice. If this is the case then it may raise a safeguarding concern and the safeguarding procedure will be followed.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, the data you provide will help to build a picture of the way that diagnosing FND, and delivering this diagnosis is managed. The results of the research could inform best practice guidelines for diagnosing FND. These guidelines could assist other Neurologists during the process and may lead to a more positive clinical outcome for FND patients.

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences. If you want to hear about the results of the study then do contact the researcher, Beccy Waring, who will be happy to provide you with a written summary of the research.

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Contact details
- Age
- Years of practise as a Neurologist
- Where you did your medical training

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will destroy the transcripts of the interviews. We will write our reports in a way that no-one can work out that you took part in the study. The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you**.** Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Information Compliance Manager (dataprotection@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What are your choices about how your information is used?

You can withdraw you data from the research up to two weeks after your interview, without giving reason. After this, data analysis will have been begun and it will not be possible to remove it. Withdrawing from the study will not affect you in any way. If you choose to withdraw from the study before this point the data collected will be destroyed.

Where can you find out more about how your information is used?

You can find out more about how we use your information by sending an email to r.oleary-2019@hull.ac.uk

If you have any questions or require more information about this study, please contact me using the following contact details:

Rebecca Waring
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX

E-mail: r.oleary-2019@hull.ac.uk

What if something goes wrong?

If you wish to make a complaint about the study, you can contact the University of Hull using the research supervisor's details below for further advice and information:

Dr Jo Beckett
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482
Email address: j.beckett@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

3.6 Appendix F: Consent form

CONSENT FORM

Title of study: **Exploring the lived experience of neurologists throughout the process of diagnosing Functional Neurological Disorder and delivering this diagnosis to their patients**

Name of Researcher: Rebecca Waring

Please initial box

1. I confirm that I have read the information sheet dated 10/08/2022 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time until the data is analysed (two weeks after the interview has been completed) without giving any reason, without my legal rights being affected. I understand that the data I have provided up to the point of withdrawal will be destroyed. ☐

3. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐

4. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

5. I give permission for the collection and use of my data to answer the research question in this study. ☐

6. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

3.7 Appendix G: Nice Quality assessment tool

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:

2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach?	Defensible Indefensible Not sure	Comments:

• Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		

5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable?	Reliable	Comments:

For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Unreliable Not sure	
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:

9. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:

11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example:	Adequate Inadequate Not sure	Comments:

• How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**		
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity?	Appropriate Inappropriate Not sure/not reported	Comments:

• Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?		
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

3.8 Appendix H: Quality assessment summary table

Study	Is a qualitative approach appropriate?	Is the study clear in what it seeks to do?	How defensible or rigorous is the research design or methodology?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Is the context clearly described?	Were the methods reliable?	Is the data analysis sufficiently rigorous?	Is the data 'rich'?	Is the analysis reliable?	Are the findings convincing?	Are the findings relevant to the aims of the study?	Conclusions?	How clear and coherent is the reporting of the ethics?	Score
Bazydlo & Eccles (2022)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Not sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Carton et al., 2003	Appropriate	Clear	Not sure	Appropriately	Not described	Clear	Reliable	not sure	Not sure/not reported	Reliable	not sure	Relevant	Adequate	Not reported	+
Dickinson et al., 2011	Appropriate	Clear	Defensible	Appropriately	Clearly	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Dosanjh et al., 2020	Appropriate	Clear	Defensible	Appropriately	Clearly	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Fairclough et al., 2014	Appropriate	Clear	Defensible	Appropriately	Clearly	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+
Karterud et al., 2010	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Lowenburger	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	r eliable	Ri gorous	R ich	R eliable	Co nvincing	R elevant	Ad equate	App ropriate	+
Nielsen et al., 2020	Appropriate	Clear	Defensible	Appropriately	Clearly	C lear	R eliable	Ri gorous	R ich	R eliable	Co nvincing	R elevant	Ad equate	App ropriate	+
Pretorius, 2016	Appropriate	Clear	Defensible	Appropriately	Not described	clear	Not sure	not reported	Rich	Not sure	Convincing	Relevant	Adequate	Not reported	+

Pretorius & S, 2015	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Thompson et al., 2009	Appropriate	Clear	Defensible	Appropriately	Cleary	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+
Wyatt et al., 2014	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Not sure	not reported	Rich	Not reported	Convincing	Relevant	Adequate	Appropriate	+

3.9 Appendix I: Data collection form

Data collection form

Review title or ID	
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	

	Descriptions as stated in report/paper		**Location in text or source** *(pg & ¶/fig/table/other)*
Aim of study			
Design			
Qualitative Method			
Ethical approval needed/ obtained for study	☐ ☐ ☐ Yes No Unclear		

Population description *(from which study participants are drawn)*			
Setting *(including location and social context)*			
Inclusion criteria			
Exclusion criteria			
Method of recruitment of participants *(e.g. phone, mail, clinic patients)*			
Informed consent obtained	☐ ☐ ☐ Yes No Unclear		
Age			
Gender			
Race/Ethnicity			

Key Findings			
Key conclusions			
Strengths/Limitations			
Score			

3.10 Appendix J: Questions and prompts

Semi-Structured Interview guide

As a semi-structured, participant led interview, these questions are a guide only and may not all be asked or may not be asked in this order.

Q) I would like you to tell me about your experience of diagnosing FND and delivering this diagnosis to your patients?.

- Could you give me a recent example?

Q) When you think about that example, could you tell me how you felt about delivering the diagnosis?

- Can you tell me what influenced your feelings?

Q) Did you follow any particular processes?

- What guided this process?

Q) Did you expect to be delivering diagnoses of FND during your training?

Q) Tell me about your involvement after a diagnosis has been given?

3.11 Appendix K: Debrief sheet

Debrief sheet and sources of support

Title of study

The experiences of neurologists throughout the process of diagnosing Functional Neurological Disorder and delivering this diagnosis to their patients.

Debrief Sheet

The interview is over, thank you for taking part!

What happens next?

The data collected from you will now be given a code, and no reference to your personal details will be kept with the data. Your data, along with data collected from other participants, will soon be analysed. This will then be reported in a written document to answer the following research questions:

1. What is it like to be a neurologist making and delivering a diagnosis of FND?
2. What meaning do individual neurologists make of the experience of working with patients with FND?

A version of this written report will be submitted for publication in an academic journal. Nothing that could identify you will be included in the results.

Will I find out about the results?

If you want to, yes. If you want us to tell you about the results of the study, please let the researcher know. You can email your request to the email address below. We will then send you a copy of our conclusions when the research is finished.

What if I have questions later on?

You can contact the researcher on the details below directly.

What if I no longer want my data to be in the study?

If you want to take your data out of the study, please contact the researcher (details below). We can remove your answers from the study up until they are analysed, which will be two weeks from today's date.

What if I am upset after taking part in this study?

If you feel worried or upset by any issues raised after taking part in the study, you can seek support from the services listed here:

- **Speak to your supervisor**
    - Your supervisor's role is to support you when required.
- **Speak to your Occupational Health department**
    - Occupational Health are there to help keep you physically and mentally well at work.

Other sources of support that might be helpful:

- **The Samaritans**
    - The Samaritans offer a confidential listening service at any time of day if you want someone to talk to. People sometimes choose to talk to Samaritans if they are upset or have thoughts of hurting themselves.
    - Telephone: 116 123
    - Website: www.samaritans.org
    - Email helpline: jo@samatians.org

- **MIND**
    - Mind is England's leading mental health charity. Mind offers advice and support about all mental health problems.
    - Website: www.mind.org.uk

Thank you again for taking part in this research, your participation is greatly appreciated.

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3.12 Appendix L: FND Hope advert

- Home
- Contact Us
- Login

- ABOUT
- MEMBERSHIP
- FND EDUCATION
- CONFERENCE
- MEMBERS
- RESOURCES
- RESEARCH
- SUPPORT FNDS

This page highlights current research projects in the area of functional neurological disorder (FND). If you want to find out more about any of the studies please follow the links below. If you are researcher and want your project added to the website please complete the Research Project Submission Form.

The Experience of Neurologists as they diagnose FND

Rebecca Waring

FND has been one of the most common reasons for presentation at neurology clinics, estimates suggest that approximately thirty percent of patients attending neurology clinics are patients whose symptoms are 'not at all' or only 'somewhat' explained by disease (Carson et al., 2000). The majority of research into the diagnostic delivery of FND has been focused on the patient experience (Carton, 2003; Monzoni, 2011; Ring, 2005; Thompson, 2009). However, as it is neurologists who make and deliver an FND diagnosis, and with the figures of patients with FND attending neurology clinics so high, it is reasonable to consider how neurologists' experience both making and delivering a diagnosis, which historically was assumed "not regarded as a problem within the territory of neurology" (Stone et al., 2008).

This research wants to learn about the neurologists' experience of working with patients with FND, both in the diagnostic procedure and the delivery of an FND diagnosis. In doing so, a better understanding of support needs for neurologists could be gathered.

The research requires neurologists to take part in an interview for up to one hour, over MS Teams. All information gathered in the study will be fully anonymized.

The research is part of a doctoral thesis by a trainee clinical psychologist.

Project Start Date: April 1, 2022

Project End Date: March 31, 2023

Functional Neurological Disorder Society
555 E. Wells St., Suite 1100, Milwaukee, WI 53202-3823
Phone: (414) 918-9814
E-Mail: info@fndsociety.org

3.13 Appendix M: Recruitment poster

3.14 Appendix N: Example of analysis

	Interviewer Please can we start with you telling me a bit about your experience of working with people with FND? Interviewee So, an open ended question? Interviewer Yeah Interviewee	Is this relief?

Getting it wrong - Being creative	Um, so I am a neurologist, so I see people who come with a symptom, and it could be FND or not..and sometimes the line is obvious and sometimes the line is not, to me at least. So how I feel is, I feel, if the line is blurry, I always feel, it's in my personality to investigate..and you know to make…I know it's not supposed to be an exclusion diagnosis, it's not supposed, you kind of supposed to kind of know that it is and, then confirm. But sometimes, to me it still feels like I'm excluding things and then if nothing's found AND the picture is typical..In terms of what it can look like... It can look like not being able to walk, so like weakness. Sensory symptoms, it can look like non-epileptic attacks, um, so it can have many, it can mimic any sort of neurological conditions, alot of movement disorders as well, and also it could be an overlap, so somebody who already has a neurological condition can have FND on top of it, which then the art is to try and disentangle which is which and try and help on each channel	FND or not the neurologist job is to investigate the symptoms - blurry lines, not yet able to make a clear distinction- difficult to get the words out, I know I should be doing this but I can't - am i good enough at this? - I need to be sure, what would be the worst outcome if she missed it? - comorbid with neurological conditions - the 'art' is to disentangle - art is creative, disentangle, confusing and frustrating