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University of Southampton

Faculty of Environmental Life Sciences

School of Psychology

**An exploration of factors influencing healthcare professionals' perceptions towards
functional neurological disorders.**

Volume 1 of 1

by

Kelly Phipps

Thesis for the degree of Doctorate in Clinical Psychology

June 2020

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Abstract

Faculty of Environmental Life Sciences

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An exploration of factors influencing healthcare professionals' perceptions towards functional neurological disorders.

by

Kelly Phipps

Functional neurological disorders (FND) sit under the umbrella of functional somatic syndromes (FSS), which have been widely recognised as challenging and controversial and are often associated with negative perceptions by health care professionals (HCP). Although recognised as a barrier to care, little is understood about the psychological processes influencing such negative views. Chapter 1 reports a systematic review of the quantitative and qualitative literature, exploring the psychological factors that are underpinning HCP experiences of working with FSS and influencing such perceptions. Narrative synthesis was used to explore 24 papers, 11 qualitative, six quantitative and seven mix methods. This identified eight themes that influenced HCP's negative perceptions of FSS, including perceived knowledge, support, sitting with uncertainty, confidence, doubt, interpersonal difficulties, felt sense of hopelessness and felt sense of incompetence. These findings suggest that negative perceptions towards FSS may be experienced as a defence against these challenges. Limitations were noted including the lack of validated measures and the higher representation of doctors present in the studies, emphasising the need for further research.

Findings from Chapter 1 also noted that the majority of the studies included in the theme of 'doubt', were related to FND. This refers to a set of neurological symptoms, recognised as a neurobiological response to psychological distress and results in unconscious physical symptoms. Often misunderstood, patients frequently attend healthcare services, ensuing unnecessary medical investigations and a high financial impact. Effective communication of this diagnosis can be an important intervention, resulting in positive clinical outcomes. However, one identified barrier to achieving this is HCP's negative perceptions towards FND. The study reported in Chapter 2 aimed to explore perceptions of HCPs working in either mental health settings or emergency departments, to consider factors that may influence perceptions. A cross-sectional survey containing quantitative and qualitative questions that aimed to identify psychological and

professional factors that predict HCPs perceptions towards FND, was distributed to NHS HCP's. Results from 72 participants (20 in ED and 52 in Mental Health), aged 24-60, found younger HCPs, those working in mental health, and those with more training and experience working with FND, held significantly better perceptions. Beyond this, confidence working with complexity was the most significant predictor of positive perceptions. Qualitative findings suggested HCPs felt more education and collaborative working for FND is needed. These findings suggest that developing a training programme for HCP's, providing more information of FND and skills in working with complexity, will support HCP/patient interactions, improve communication of FND and ultimately clinical outcomes.

Table of Contents

Table of Contents	iii
Table of Tables	vi
Table of Figures	vi
Research Thesis: Declaration of Authorship	vii
Acknowledgements	ix
Definitions and Abbreviations	x
Chapter 1 Systematic Review	1
1.1 1.1 What influences healthcare professionals’ perceptions of Functional Somatic Syndromes? A systematic review of the qualitative and quantitative literature.....	1
1.1.1 What is in a name?.....	1
1.1.2 Functional Somatic Syndromes	3
1.1.3 The healthcare professional-patient relationship.....	4
1.1.4 Healthcare professionals’ training and experiences	5
1.1.5 Purpose of review	6
1.2 Method.....	7
1.2.1 Search Strategy.....	7
1.2.2 Eligibility Criteria	9
1.2.3 Screening and Selection	9
1.2.4 Quality Assessment	11
1.2.5 Data Analysis	12
1.3 Results	12
1.3.1 Study Characteristics	30
1.3.2 Themes	30
1.3.2.1 Perceived knowledge	31
1.3.2.2 Doubt.....	32
1.3.2.3 Confidence.....	33
1.3.2.4 Support.....	34
1.3.2.5 Sitting with uncertainty.....	34
1.3.2.6 Felt sense of helplessness	35

Table of Contents and Figures

1.3.2.7	Felt sense of incompetence	36
1.3.2.8	Interpersonal Difficulties.....	37
1.4	Discussion and Critical Review.....	38
1.4.1	Themes.....	39
1.4.1.1	Interpretation of themes	40
1.4.2	Clinical Implications	43
1.4.3	Limitations and Future Considerations.....	44
1.4.4	Conclusion.....	45
Chapter 2	Empirical Paper.....	47
2.1	Factors influencing healthcare professionals' perceptions towards functional neurological disorders	47
2.1.1	Functional Neurological Disorders.....	47
2.1.2	Prevalence.....	48
2.1.3	Treatment	49
2.1.4	Negative perceptions.....	49
2.1.5	Rationale for current study.....	50
2.1.6	Study aims.....	52
2.1.7	Research questions and hypotheses	52
2.2	Method	52
2.2.1	Design.....	52
2.2.2	Measures.....	53
2.2.2.1	Effective Working with Complex Clients Questionnaire (EWCC).....	53
2.2.2.2	Perceived Stress Scale (PSS).....	54
2.2.2.3	Questionnaire on nursing attitudes to patients with functional symptoms in neurology (NAPFS).....	54
2.2.2.4	Free text questions	54
2.2.3	Sampling strategy	54
2.2.4	Exclusion criteria.....	54
2.2.5	Procedure.....	55
2.2.6	Ethical considerations	55

2.2.7	Anticipated sample size.....	55
2.2.8	Statistical analysis.....	56
2.3	Results	56
2.3.1	Demographic characteristics.....	56
2.3.2	Research Question 1: Are there significant differences between specialities and HCP roles in their attitudes towards FND	58
2.3.3	Research Question 2: Does working with complexity and levels of personal stress influence attitudes towards FND?	60
2.3.4	Qualitative interpretation	61
2.3.4.1	Qualitative question 1: What is your understanding of FND?	61
2.3.4.2	Qualitative question 2: Additional comments	63
2.4	Discussion and critical review	65
2.4.1	Interpretation of findings.....	65
2.4.2	Clinical implications.....	68
2.4.2.1	Personal reflections on clinical implications	70
2.4.3	Strengths and limitations	71
2.4.4	Directions for future research.....	72
2.4.5	Conclusion	72
	Appendix A PICOSS Table - Inclusion and exclusion criteria	75
	Appendix B Quality assessment table	77
	Appendix C Data coding table.....	79
	Appendix D Demographic and professional questions	86
	Appendix E Effective Working with Complex Clients Questionnaire (EWCC)	88
	Appendix F Perceived Stress Scale (PSS)	90
	Appendix G Questionnaire on nursing attitudes to patients with functional symptoms in neurology (NAPFS)	91
	Appendix H Recruitment email with poster advert	93
	Appendix I Participant information sheet and consent	95
	Appendix J Debriefing statement	100
	List of References	104

Table of Tables

Table 1.1. Terms used in the search	8
Table 1.2. Summary of data extraction from included studies	13
Table 1.3. Summary of themes.....	31
Table 2.1. Independent variables	53
Table 2.2. Key demographic characteristics for all participants together.....	57
Table 2.3 Summary table of Means, Standard deviations and correlations, with FND attitude scores as the outcome variable.....	59
Table 2.4. Hierarchical model of significantly correlated predictors of attitudes towards FND.	60
Table 2.5. Summary of formulated codes and categories for interpreting understandings of FND	61

Table of Figures

Figure 1.1. PRISMA flowchart (Moher et al., 2009).....	10
Figure 1.2. Diagram representing relationships between themes and negative perceptions of FSS.	39

Research Thesis: Declaration of Authorship

Print name: Kelly Phipps

Title of thesis: An exploration of factors influencing healthcare professionals' perceptions towards functional neurological disorders.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date: 28.5.2020

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Definitions and Abbreviations

Abbreviation	Explanation
CFS	Chronic fatigue syndrome
FND	Functional neurological disorders
FSS	Functional somatic syndromes
HCP	Healthcare professionals
IBS	Irritable bowel syndrome
MUS	Medically unexplained symptoms

Term	Definition
Dissociative Seizures	Also known as non-epileptic attacks [NEADS], pseudoseizures, psychogenic nonepileptic seizures [PNES] and functional seizures. Present similar to an epileptic seizure but are not caused by electrical activity in the brain.
Functional Neurological Disorders	Refers to a set of neurological symptoms, recognised as a neurobiological response to psychological distress and results in unconscious physical symptoms.
Functional Somatic Syndromes	Refers to the cluster of symptoms categorised as the various conditions (i.e. IBS, Fibromyalgia, CFS, FND)
Medically Unexplained Symptoms	Refers to a large spectrum of persistent physical symptoms for which medical investigations do not reveal the presence of any known organic cause

Chapter 1 Systematic Review

1.1 1.1 What influences healthcare professionals' perceptions of Functional Somatic Syndromes? A systematic review of the qualitative and quantitative literature.

"I get so irritated with people who don't believe fibromyalgia is real. For me, and I think for many others, it's really a cyclone of anxiety, depression, PTSD [post-traumatic stress disorder], trauma, and panic disorder, all of which sends the nervous system into overdrive, and then you have nerve pain as a result. People need to be more compassionate. Chronic pain is no joke. And it's every day waking up not knowing how you're going to feel" (Lady Gaga, Singer/songwriter, Vogue, 2018).

Fibromyalgia, irritable bowel syndrome (IBS), chronic fatigue syndrome (CFS) and functional neurological disorders (FND), including dissociative seizures (also known as non-epileptic attacks [NEADS], pseudoseizures, psychogenic nonepileptic seizures [PNES] and functional seizures), represent just a few clinical diagnoses that have confused the medical profession for many years. With a lack of clarity surrounding the physical aetiology, the validity of these conditions has consequentially been questioned, or alternatively healthcare professionals (HCP) are left feeling helpless in a vocation focused on helping (Mayou & Sharpe, 1995; Hartz et al., 2000). This dissonance surrounding these so called functional somatic syndromes (FSS), could perhaps be one of the factors influencing the reported negative stigma that appears to shadow such diagnoses (Looper & Kirmayer, 2004; Rommelfanger et al., 2017).

1.1.1 What is in a name?

Naming this group of conditions has been complex and controversial, feasibly as a reflection of the limited understanding that has ensued them (Isaac & Paauw, 2014). Historically, the overlap between medicine and psychiatry, has led to parallel classification schemes (Sharpe, 2002). Therefore, these conditions have been referred to by a number of diagnostic labels, including, but by no means limited to, psychogenic, somatoform or somatisation disorders, conversion disorder, non-organic symptoms, functional disorders and perhaps more commonly, medically unexplained symptoms (MUS). The term MUS, principally refers to a large spectrum of

Chapter 1: Systematic Review

persistent physical symptoms for which extensive medical investigations do not reveal the presence of any known organic cause (Guo, Kleinstäuber, Johnson & Sundram., 2019; Burton, 2003).

Such diagnoses have been the topic of much debate, not least surrounding the appropriateness of the language used to describe them (Marks & Hunter, 2015). It is argued that careful consideration should be afforded to the labels given, with terms such as 'psycho' and 'pseudo' suggested to be synonymous with 'all in the mind' or 'fraudulent' social constructions (Stone et al., 2003). Equally, the terms 'unexplained' and 'non-organic' have been criticised for their ambiguity, uncertainty and focus on highlighting what symptoms are not, rather than what they are. Such language of exclusion, has the capacity to endorse doubt in the validity of the conditions, significantly amongst medical professionals, those experiencing the symptoms and the rest of the population (Kanaan & Ding, 2017). Furthermore, it is argued that the term reinforces dualistic thinking, viewing symptoms as either physical or psychological, without acknowledgement of psychobiological factors (Rief & Barsky, 2005; Dallochio, Marangi & Tinazzi, 2015).

Creed et al (2010) reasoned that the use of the term MUS, is in itself a barrier to improved care, owing to its lack of acceptability for both clinicians and patients. Therefore, these researchers aimed to identify an acceptable term that would also encourage joint working by medical and psychological disciplines, and so facilitate management of the conditions. To judge potential alternative terms, Creed et al (2010) developed a set of ten criteria to capture the most important aspects. These included: (1) acceptable to patients (2) and HCP; (3) doesn't reinforce unhelpful dualistic thinking; (4) applicable to patients who also have pathologically established disease; (5) suitable as a standalone diagnosis; (6) has a clear core theoretical concept; (7) will assist the prospect of multi-disciplinary (medical and psychological) treatment; (8) has similar meaning across cultures; (9) is neutral in relation to aetiology and pathology and (10) has a satisfactory acronym (Creed et al., 2010, page 6). After reviewing eight separate categories made up of related terms, the category consisting of functional disorder and functional somatic syndromes (FSS), was deemed to be the most acceptable and neutral (Creed et al., 2010; Marks & Hunter, 2015).

The word functional was first used to encompass this dual psychological and physiological meaning in 1831, by Andrew Combes, in relation to nervous diseases (Trimble, 1982). Functional, describes conditions that appear to alter the functioning of the organ, without any physical structural change. This is often referred to metaphorically by neurologists, like a 'problem with the functioning of the software on a computer', as opposed to 'physical damage to the hardware'

(Stone, 2014). Several studies looking at clinician and layperson preferences across MUS have found 'functional' to be one of the most acceptable terms (Ding & Kanaan, 2017; Marks & Hunter, 2015). Therefore, this review uses the terms functional symptoms to refer to the physical symptoms and functional somatic syndromes (FSS) to refer to the cluster of symptoms categorised as the various conditions (Mayou & Farmer, 2002; Guo et al., 2019).

1.1.2 Functional Somatic Syndromes

A further argument underpinning FSS, considers whether grouping these related but distinct disorders under the same label is appropriate, or whether they are simply different manifestations of a single underlying syndrome. This latter point was put forward by Wessely, Nimnuan and Sharpe (1999), whom after reviewing the literature concluded that such a significant overlap was present amongst the syndromes that the similarities outweigh the differences, potentially contributing to diagnostic confusion. In a recent evaluation of said commonalities, Guo et al (2019) supported this notion, remarking that traditionally research and management of FSS has been confined to the corresponding speciality (i.e. fibromyalgia within rheumatology, IBS within gastroenterology, dissociative seizures within neurology etc.). While this has advanced our understanding in each specific area, it poses a risk of missing information regarding the shared mechanisms underlying all FSS, that would otherwise enhance our overall understanding.

In response to the evaluation by Guo et al (2019), Tack (2019) argues that the differences between different functional syndromes should not be ignored. He highlights evidence of biological differences and differences in responses to treatment approaches, as key indicators these conditions should all be treated as distinct (Abbi & Natelson, 2012; Evengard et al., 1998). Likening it to the evolution of cancer research, this opposing stance judges that on the contrary, combining functional conditions into one diagnostic label would obstruct research into the underlying pathology of the distinct conditions. Tack (2019) argues that if one of the main difficulties facing clinicians is diagnostic confusion, due to overlap of symptoms and lack of clarity, then creating one large classification for the syndromes will further complicate the problem. Furthermore, longitudinal studies have suggested that some functional diagnoses are later revised following evidence of organic pathology. Although the likelihood of this happening has been found to be relatively small (Eikelboom, Tak, Roest & Rosmalen, 2016) it also raises questions as to the impact on patients who are caught up in such a homogenous label (Tack, 2019).

However, this review considers that the argument put forward by Guo et al (2019) can be interpreted as the need to take a more holistic view, by considering functional syndromes as a

spectrum, and at an individual, clinical cohort and organisational (healthcare system) level. The fact that these conditions do share a number of fundamental factors seems apparent and while these don't necessarily mean they should be deemed as one condition, understanding these similarities could hold the key to better healthcare journeys for patients and clinicians. In addition to shared aetiological mechanisms, cognitive factors, comorbidity and perceived symptom burden, studies have found that FSS also share common barriers between the clinician and the patient (Guo et al., 2019). In a systematic review, Murray, Toussaint, Althaus and Löwe, (2016) found several factors that contributed to these interactional difficulties when diagnosing FSS in primary care, such as communication and consultation behaviour, a predominance of the biomedical model, both patient and clinicians beliefs that primary care is an inappropriate setting and practitioners attitudes towards patients with FSS.

1.1.3 The healthcare professional-patient relationship

Although functional symptoms traditionally sit somewhere between the disciplines of medicine and psychiatry, due to the nature of the presentations, patients will initially seek a physical health investigation. Reports of negative HCP experiences, by patients with a diagnosis of FSS have peppered the literature to date. Studies reflecting patients' accounts of interactions with medical professionals have reported that patients are left feeling invalidated, that their symptoms were doubted and not being taken seriously, as well as feeling in limbo, dumped and confused (Rawlings & Reuber, 2016; Thompson, Isaac, Rowse, Tooth & Reuber, 2009; Nettleton, Watt, O'Malley, & Duffey, 2005). This has been answered with reports that HCP's find FSS patients, frustrating, challenging and difficult (Hanssen & Rosmalen, 2019; Rief, 2007; Maatz, Wainwright, Russell, Macnaughton & Yiannakou, 2016), consequently giving rise to a conflicted HCP-patient relationship.

Speculation as to the reasons behind these reported experiences include assumed fundamental differences in aetiological beliefs (physical versus psychological), prompting some clinician's conviction that patients will be resistant to a psychological explanation for their symptoms (Whitehead, Kandler & Reuber, 2013). Evidence to suggest patients disagree with a psychological explanation, acknowledges that some patients feel psychological factors could only play a small role in their symptomatic experiences (Stone, Binzer & Sharpe, 2004; Nettleton, 2006). However, further evidence suggests that it is the objective language used in diagnostic consultations that may cause patients to experience offence and a high degree of uncertainty, playing a vital role in the diagnostic resistance observed (Ding & Kanaan, 2016; Weiland et al., 2012). It is claimed that more detailed explanations around the psychobiological relationship, can support the acceptance of a non-dualistic explanation and leave patients feeling validated

(Robson & Lian, 2015; Clements, Sharpe, Simkin, Borrill & Hawton, 1997). Some researchers suggest that a clear and consistent rationale of the diagnosis, can in itself be an effective intervention (Stone, Carson & Hallett, 2016; Payne & Brooks, 2016; Payne, 2015).

Acknowledging the dissatisfaction experienced by both parties during medical consultations, Peters et al (2008) conducted thematic analysis of in-depth interviews looking at patients' experiences of general practitioners (GP's) attempts to reattribute functional symptoms. They found that patients presented their problems and needs as a lot more complex than the unidimensional or perceived simplistic response they received from their GP; with such a contrast insufficiently reducing patient concerns. The study also found that patients often accepted or even developed their own psychosocial models to explain their symptoms, yet would elect to withhold this from the GP in the consultation. Peters et al (2008) concluded that, as well as being aware of the time constraints of the consultations, this was again due to patients feeling GP's had a less sophisticated idea of their problems and were dualistic in their thinking; therefore, they didn't want to risk the symptoms being completely attributed to psychological causes. This echoed the findings of Nettleton, Watt, O'Malley and Duffey (2005), who also concluded that patients' felt marginalised from medicine and were more concerned with securing some kind of support, be it medical or social. This suggests the tasks for HCP's is not to change illness beliefs but to understand patients' distress and develop validating and empowering explanations using psychobiological models (Salmon, Peters & Stanley, 1999; Weiland et al., 2012).

1.1.4 Healthcare professionals' training and experiences

There have been a number of initiatives developed in recent years, to support HCP's in delivering psychoeducational interventions for FSS (Wiseman, Mousa, Howlett & Reuber, 2016; Hastings et al., 2016; Morriss & Gask, 2002); however, these are nearly always post-qualification and have relatively poor uptake (Salmon et al., 2007). Although FSS are becoming ever more prevalent in healthcare settings (Nimnuan, Hotopfn & Wessely, 2001; Jadhakhan, Lindner, Blakemore & Guthrie, 2019) and incur substantial costs that have been found to exceed those of other patient groups (Burton, McGorm, Richardson, Weller & Sharpe, 2012; Barsky, Orav & Bates, 2005), teaching of these conditions is still absent or limited in medical and psychological clinical training (Howman, Walters, Rosenthal, Good, & Buszewicz, 2012; Shattock, Williamson, Caldwell, Anderson & Peters, 2013). In a study considering this phenomenon, Joyce et al (2018) identified three main barriers to UK educators including functional symptoms in the undergraduate medical curriculum. The first of these adopted the commonly occurring theme that functional symptoms are too complex for explicit teaching, highlighting the lack of clarity and understanding of the conditions as a barrier to being able to teach about them, compounded by the belief that

Chapter 1: Systematic Review

functional symptoms do not fit into the biomedical model that dominates medical training. Secondly, it was felt functional symptoms are a marginal medical issue and that educational time should be focused on life-threatening conditions. Finally, the study found negative attitudes by tutors towards functional symptoms and that these can have a significant impact on students learning and own attitudes (Joyce et al., 2018). This supported findings by Shattock et al (2013), that medical students reported their negative attitudes to be influenced by observing senior clinicians speaking to and about these patients; in addition to their lack of knowledge and uncertainty causing them to feel frustrated, powerless, incompetent and devalued (Shattock et al., 2013). To date there is a gap in the literature considering this within the educational systems for clinical psychologists.

These findings suggest that there are a number of factors underpinning HCP's widely acknowledged negative attitudes towards patients with FSS. For example, the word 'difficult' is used ubiquitously in relation to FSS, but it is unclear what this means. Aiming to unpack this expression using a qualitative design, Maatz et al. (2016) found that 'difficult' tended to refer to doctor's own perspectives and experiences and was rarely used to describe a patient characteristic. These experiences included difficulties in communicating, diagnosing and managing the conditions, as well as the difficult emotional responses elicited within the doctor, such as helplessness, guilt, concern, distress and an undermining of their expertise (Maatz et al., 2016). This may explain why patients demand for emotional support has been found to positively relate to frequency of criticism noted in consultations (Salmon et al., 2007). The literature has also highlighted difficulties with limited guidelines or service provision available for many FSS, adding an additional layer of complexity and 'difficulty' for HCP's to negotiate (Maatz et al., 2016; Olde Hartman et al., 2017).

1.1.5 Purpose of review

Functional somatic syndromes have been widely acknowledged and experienced as controversial and confusing, with patients reporting feeling marginalised and HCP's confirming negative perceptions. Yet to date, no systematic review has been conducted that draws together all the psychological factors that are underpinning HCP experiences of working with FSS as a whole.

Rawlings and Reuber (2018) have recently conducted a narrative synthesis exploring HCP's perceptions of dissociative seizures, a functional neurological condition and subsequently FSS. Exploring 30 studies (15 with quantitative data, seven with qualitative data, and eight with both), this study concluded five concepts relating to the attitudes and perceptions of HCP's towards

functional seizures, including (1) demonstrated uncertainty, (2) confirmation of strong dualistic beliefs, (3) that patients were considered challenging and frustrating by HCP's, (4) contested clinical responsibility for treatment of these patients and (5) patients viewed as less severe than those with epilepsy. However, these findings are specific to a single functional condition in one specialist area and while they support understanding in this area, they have only begun to touch on the psychological processes that may be influencing such beliefs. This review recognises that all FSS experience HCP-patient difficulties and therefore in order to expand this understanding, it aims to identify and appraise the literature exploring HCP's perceptions towards all FSS, including IBS, CFS, Fibromyalgia and functional symptoms under the umbrella term MUS. Using narrative synthesis, this review will consider the psychological processes that may be underpinning such perceptions, so that services might be better equipped to support their staff and patients on their clinical journey.

1.2 Method

1.2.1 Search Strategy

In order to explore the current literature base of FSS, initial scoping searches were conducted using Google Scholar and Web of Science, which revealed a number of empirical papers exploring HCP perceptions into the different FSS. To confirm a systematic review addressing this research question was not already in progress, the reviewer consulted PROSPERO, the database of systematic review protocols. A recent systematic review considering HCP perceptions of dissociative seizures was highlighted in these searches (Rawlings & Reuber, 2018; described in the previous section); therefore, to avoid duplication, a decision was made to exclude any papers recently analysed in this paper from the current review.

A systematic search of the literature was conducted in October 2019, to identify relevant empirical papers to be reviewed. The scoping searches aided the identification of meaningful keywords for the development of the search strategy, this was then verified by the research librarian at the University of Southampton. These keywords were focused around the three components of the research question, 'diagnosis', 'perception' and 'healthcare professional' and combined using the Boolean 'AND', to concentrate the search.

The following databases were used: Web of Science, PubMed, PsychInfo, CINAHL (Plus with Full Text), PsychArticles, MEDLINE and The Cochrane Library, using the search strategy stated in Table 1.1. Where permitted, the searches were narrowed by publication type (peer reviewed

Chapter 1: Sytematic Review

journal), language (English) and, given the wide range of functional syndromes, a twenty-year period was selected (1999 to present). The search was repeated in each database until it was felt the all of the relevant literature was obtained (n=348). These papers were then combined with other papers already known to the researcher (n=15).

Table 1.1. Terms used in the search

Concept	Area of search	Search terms
1# Diagnosis	Title (TI)	("conversion disorder" OR somati*ation OR "Medically unexplained symptoms" OR MUS OR "somatic symptom disorder" OR "somatoform disorders" OR "functional neurological disorder*" OR "functional movement" OR FND OR FNS OR "medically unexplained neurological" OR "functional cognitive" OR "Motor functional neurological disorder OR "Functional cognitive disorder" OR "Dissociative amnesia" OR fibromyalgia OR "irritable bowel syndrome" OR "chronic fatigue" OR "functional somatic symptoms" OR "Functional seizures" OR psychogenic OR "dissociative seizures" OR PNES OR NEAD*)
2# Perception	Title (TI)	(perception* OR perspective* OR attitude* OR opinion* OR experience* OR view* OR reflect* OR belief* OR Believe* OR stereotype* OR bias* OR Stigma* OR communicat* OR "doctor-patient communication" OR manage* OR Understand*)
3# Healthcare professional	Title (TI)	("health care" OR Healthcare OR "healthcare professional*" OR HCP OR practitioner OR Doctor* OR psychologist* OR Nurse OR "general practitioner" OR psychiatrist OR Neurologist OR NHS OR "health service" OR physiotherapist* OR OT OR "Occupational therapist*" OR Multidisciplinary OR "Mental health")

1.2.2 Eligibility Criteria

The inclusion criteria were developed using a PICOSS table (Population, Intervention, Comparator, Outcomes, Study design, Setting; Boland, Cherry & Dickson, 2017; Appendix A). To be included, the studies had to be (a) published in English, (b) published in a peer reviewed journal, (c) published between 1999 and October 2019, (d) participants were HCP, (e) participants were working with an adult population, (f) the study focused on a FSS, (g) the study reported on factors that may influence perceptions. Papers were excluded if (a) it had previously been reviewed in Rawlings and Reuber (2018), (b) was a secondary data analysis, (c) focused on organic conditions, (d) did not report on factors influencing perceptions, e.g. only discussed diagnosis and treatment.

1.2.3 Screening and Selection

To ensure a systematic approach was taken to screening and exclusion of papers from the review, the PRISMA guidelines were followed (Moher, Liberati, Tetzlaff & Altman, 2009). The process is reported in Figure 1.

Following the systematic search of the databases, the titles of the 348 empirical papers identified and the 15 identified through other sources, were screened for relevance to the research question. The remaining 134 studies were imported into EndNote reference management software, where duplicates were removed. Using the inclusion criteria, the abstracts of 85 empirical papers were screened by the reviewer, leaving a total of 44 empirical papers to be read in full and assessed for eligibility, resulting in a total of 18 studies. The reviewer then conducted a citation chaining hand search of these papers, eliciting a further six and therefore a total of 24 empirical papers for inclusion in the review. Overall, 11 studies collected qualitative data, six studies collected quantitative data and seven studies collected both. Any papers that presented with ambiguity were discussed with the reviewer's academic supervisor to limit subjectivity.

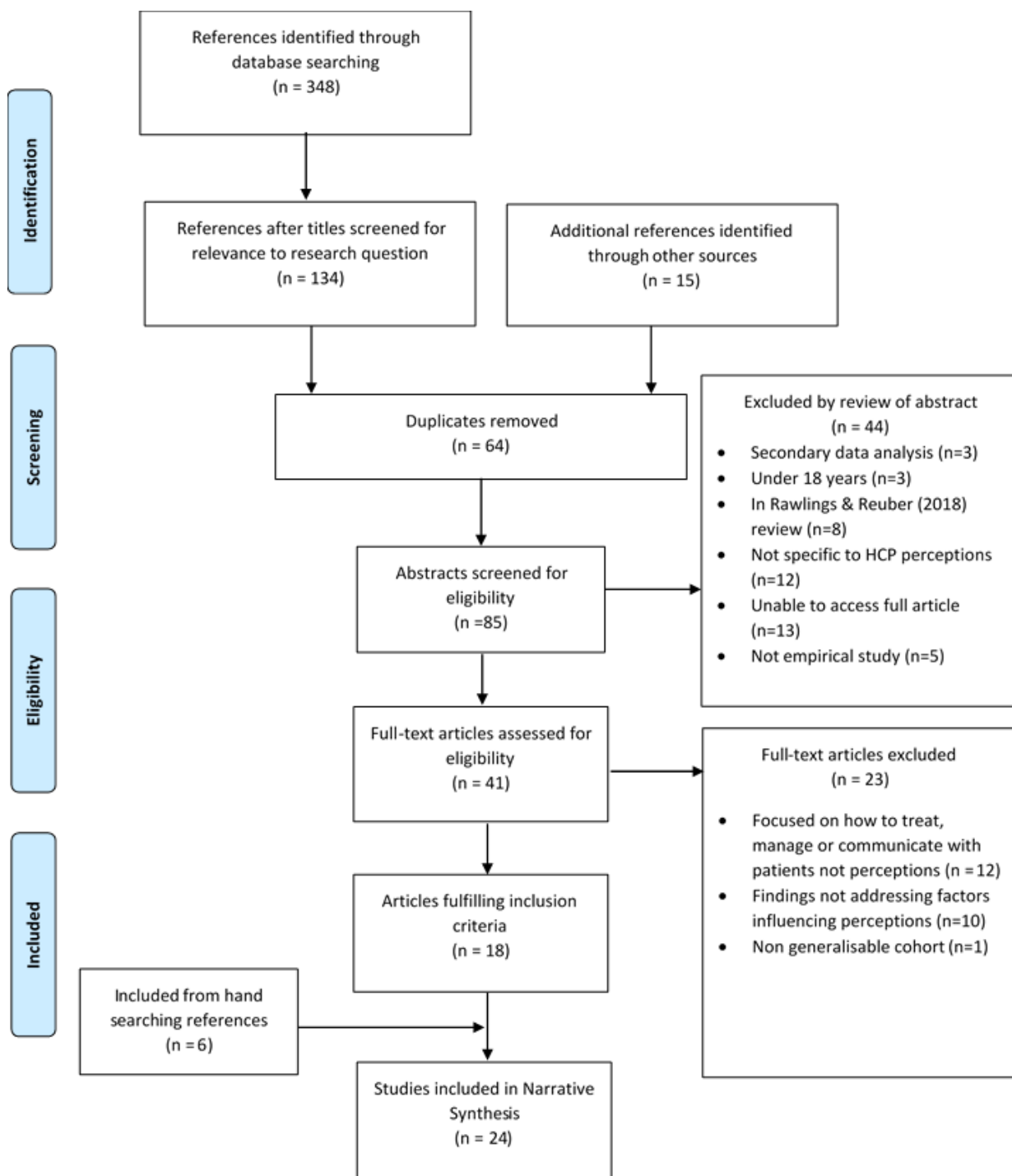


Figure 1.1. PRISMA flowchart (Moher et al., 2009)

1.2.4 Quality Assessment

Given the variety of methodological designs, through the combination of qualitative and quantitative literature included for review, the Mixed Methods Appraisal Tool (MMAP) was selected to conduct the methodological quality assessment (Hong et al., 2018). The MMAP consists of two screening questions, followed by five questions specific to the study's methodology; however, the tool discourages calculating an overall score and instead suggests a detailed presentation of the quality of the studies (see Appendix B for quality assessment table). The quality assessment took place alongside data extraction, as it was felt greater familiarity with the data would support the assessment (Boland et al., 2017). Although this process is subjective, the reviewer studied the papers on two separate occasions in an attempt to ensure consistency and any ambiguity was discussed with the academic supervisor.

Given the research question was specifically targeting participants views and experiences, a number of study designs included in the review were quantitative descriptive research designs, in the form of a survey (n=11). This would be considered an appropriate quantitative methodological design to capture participants perceptions using a sufficient sample size; however, all but three of the questionnaires used in these studies were purposefully designed by the researchers and therefore, without reliability and validity. The exception to this rule, involved the inclusion of an expert review by co-investigators, to declare face validity for a questionnaire (Lehn, Bullock-Saxton, Newcombe, Carson & Stone, 2019). Also the use of the Brief Illness Perception Questionnaire (Pastor, López-Roig, Johnston, Gracia, & Daza, 2012) which has been found to have good psychometric properties (Broadbent et al., 2015) and a validated questionnaire used to assess GP's attitudes and knowledge of CFS, although the paper is unclear which questionnaire this is (Bowen, Pheby, Charlett & McNulty, 2005). This methodological approach, is also at risk of non-response bias due to the way participants were recruited and their reasons for participating. Finally, five of these 11 studies (Lehn et al., 2019; Edwards et al., 2012; Kanaan, Armstrong & Wessely, 2011; Cranford & King, 2011; Ahern, Stone & Sharpe, 2009) included some free text questions which were qualitatively interpreted by the researchers, classifying them as mixed methods studies. In all five cases, the assessed quality of the qualitative section was low.

Overall, there was varied methodological quality observed amongst the included studies. However, it was felt that this was due to the nature of the designs required to assess perceptions of an under-represented topic, with few validated measures available. Therefore, the studies were considered to bring value to the review and not excluded on quality assessment.

1.2.5 Data Analysis

The data was extracted using a narrative synthesis approach of the qualitative and quantitative literature and recorded through units of meaning, using the thematic analysis technique (see Appendix C for coding table). This was considered an appropriate technique due to the quantitative literature being predominantly survey research (Popay et al., 2006). While quotes are not usually included in narrative synthesis systematic reviews, the reviewer chose to illustrate the themes using quotes of the data extracted from the results and discussion sections of the empirical papers. This was due to the complexity of this particular field and to provide the reader with an insight into the nuances of 'labels' and saliency of choice of language within this marginalised area. It is also hoped this will provide some transparency into the theme development that is often difficult to achieve in an inductive approach (Popay et al., 2006).

1.3 Results

The data extracted from the empirical papers were recorded in a data extraction table, so that key study characteristics and findings relevant to the research question could be evaluated. For the purpose of comprehensive study referencing, without compromising the flow of results, a numerical referencing system for all relevant studies to be referenced will be used in the results section only (the study identification numbers are listed in Table 1.2.). The studies are listed in date order, date order, facilitating exploration of the progression of perceptions over time.

Table 1.2. Summary of data extraction from included studies

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
1	Yogarajah et al (2019) Dissociative Seizures	Functional seizures: An evaluation of the attitudes of general practitioners local to a tertiary neuroscience service in London	To explore the attitudes toward, and the terminology, clinical features, and management of patients with functional seizures	General practitioners (GP)	N = 120 12.3% response rate. 65.5% female 75.7% younger than 55 89.2% seen patients with FS	Design: Quantitative descriptive Online survey Country: UK Setting: All GP's within catchment of Atkinson Morley Regional Neuroscience Centre in London. One city in UK	3 authors with a specific expertise in area, designed an 11-item questionnaire exploring: <ul style="list-style-type: none"> terms used attitudes toward terminology clinical features, management 	<ul style="list-style-type: none"> 75% used "pseudoseizures", 76% used "nonepileptic events/attacks/seizures". Around half of GPs (53.3%) agreed that, or did not know whether, patients had voluntary control over their functional seizures. rates of incorrect or absent knowledge about functional seizures among GPs were still approximately 20% 50% of GPs expressed an interest in managing 48% reported a lack of confidence in dealing with their queries. 98.3% and 62.5% of respondents felt that neurology and psychiatry, respectively, should be involved in some way in the diagnosis more GPs reported that psychiatry (82.5%) should be involved at some level in the management of these patients compared to neurology (48.4%) 60.8% of GPs felt that neurology and psychiatry together should be responsible for the diagnosis majority (45%) felt that general practice together with psychiatry should be responsible for the management although 96.7% of GPs reported feeling comfortable referring patients to neurology, only 50% felt comfortable referring to psychiatry. 72.3% reported feeling adequately supported by neurology, only 39.5% reported feeling adequately supported by psychiatry in managing

Chapter 1: Sytematic Review

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
2	Lehn et al (2019). Functional Neurological Disorders (FND)	Survey of the perceptions of health practitioners regarding Functional Neurological Disorders in Australia.	To better understand education needs within the professions with the ultimate goal of developing appropriate resources for professional dissemination for improved care of this patient group.	Health professionals involved in the care of FND. Including: neurology, psychiatry, psychology, general practice, nursing and physiotherapy	N = 538 74.3% female, M age 43.4 79 neurologists, 35 psychiatrists, 81 psychologists, 195 physiotherapists, 70 neuroscience nurses 56 general practitioners	Design: Mixed methods - Quantitative descriptive with free text questions Online survey Mixed methods. Online survey with free text questions. Country: Australia Setting: N/A	Questionnaire designed for the study. The questionnaire then underwent expert review by Co-investigators to assure content and face validity.	<ul style="list-style-type: none"> More than 75% of GPs would actively welcome a dedicated diagnostic and management service for these patients. <p><u>Survey:</u></p> <ul style="list-style-type: none"> Neurologists, nurses and general practitioners reported less clinical interest and greater negative attitudes and negative experiences Negative attitudes were significantly related to increasing age ($r = -0.13, p = .004$) and more years of practice ($r = -0.10, p = .02$), For neurologists and nurses, a greater negative attitude was related to finding it more difficult to help patients with FND ($p < .01$). Most health professionals did not think they received adequate education about FND and self-perceived knowledge was low in most groups. Increased patient contact and greater knowledge of FND, rather than years in practice, were related to more confidence in diagnosing FND as well as explaining the diagnosis. Discrepancy between perceived knowledge and confidence, not found in other neurological conditions. Could be due to tendency not to take conditions seriously. 10% of respondents were unable to agree that the symptoms of FND were 'real' <p><u>Free text interpretations:</u></p> <ul style="list-style-type: none"> Participants voiced the need for more training in this area Concerns about time constraints were frequently mentioned – more time for consultation would make it easier

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								<ul style="list-style-type: none"> Pointed out the need for multi-disciplinary management Several complained about having patients referred without the diagnosis having been explained
3	Jorden et al (2019) Dissociative Seizures	Exploring psychiatrists' perspectives of working with patients with dissociative seizures in the UK healthcare system as part of the CODES trial: a qualitative study.	Gain an understanding of UK-based psychiatrists' experiences of the DS patient group.	Psychiatrists	N = 10 Selected from 29 psychiatrists involved in CODES RCT to encompass the geographical distribution and range of experience	Design: Qualitative Thematic analysis was used to identify key themes and subthemes Country: UK Setting: psychiatrists were working in Liaison or Neuropsychiatry services in England	Semi structured interviews on psychiatrists' perspectives of working with patients with dissociative seizures	<ul style="list-style-type: none"> HCPs ill-equipped to deal with DS - Psychiatrists thought other Healthcare Professionals' uncertain and unprepared to work with FND The need for experience - in order to diagnose and treat DS, the clinician needed to have a significant level of experience with the disorder and that treatment should be undertaken in a specialist setting Avoidance - viewed as a key area of difficulty for the DS patient group Complex interpersonal relationships - Identified challenges such as patient avoidance, interpersonal relationships
4	Bradley et al (2018) Irritable Bowel Syndrome (IBS)	General practitioners' perceptions of irritable bowel syndrome: a Q-methodological study	Aimed to elucidate the ways in which GPs perceive IBS	GP's	N = 33 Just over half female. Median age 40-50	Design: Mixed methods Q-methodology. Part 1, form of factor analysis. Part 2, some participants (n=10) invited for	Statements used were based on the 58 statements from patients' study (Stenner et al. 2013). A further eight statements were constructed following	<ul style="list-style-type: none"> Conception of IBS as largely a psychological disorder, but not unequivocally so. Such clinicians (GPs) readily admit uncertainty that surrounds IBS There was an element of discord regarding the extent to which psychological or other incompletely understood pathological processes account for IBS symptoms.

Chapter 1: Sytematic Review

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						10-minute open ended interview to elaborate on responses. Country: UK Setting: One city in UK	literature review. Total of 66 statements	<ul style="list-style-type: none"> Suggested degrees of uncertainty and discomfort around the aetiology of IBS
5	Warner et al (2017) Medically Unexplained Symptoms (MUS)	How do hospital doctors manage patients with medically unexplained symptoms: a qualitative study of physicians	Aimed to explore the ways in which doctors working in secondary care approach and manage such patients.	Doctors	N = 20 11 consultants and 9 specialty trainees	Design: Qualitative study - in-depth interviews Thematic analysis. Country: UK Setting: Three hospitals in the North Thames area. One city in UK	In-depth interviews on how doctors working in secondary care approach and manage patients with MUS	<ul style="list-style-type: none"> The doctor's level of experience appeared to be a more important factor in their investigation and management strategies than their medical specialty Investigations were often ordered without a clear rationale (quotes suggest reassurance) Little training Doctors described learning from their own experience and from senior role models. Organisational barriers were identified Doctors' perceptions of their role when dealing with MUS varied considerably Some participants who found managing patients with MUS exhausting described them as very time-consuming. Several felt unsatisfied or frustrated at times when they felt unable to treat patients effectively.
6	Sirri et al (2017)	Medically unexplained symptoms and general practitioners: a	To assess GPs' clinical experience with MUS and its relationship	GP's	N = 347 80.1% response rate	Design: Quantitative descriptive.	Questionnaire designed for the study exploring:	<ul style="list-style-type: none"> Spent 'much' or 'very much' time and energy for MUS Fear of neglecting a medical disease

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	Medically Unexplained Symptoms (MUS)	comprehensive survey about their attitudes, experiences and management strategies	with their gender, age and length of practice.			structured questionnaire survey Country: Italy Setting: Italian National Health System	Demographic features, perceived clinical workload due to MUS, Cognitive and emotional responses elicited, Management strategies, perceived usefulness of psychological interventions and GPs' sources of education.	<ul style="list-style-type: none"> Psychological interventions as 'much' or 'very much' useful for MUS. Only a third of GPs were well informed about the role of psychologists in MUS
7	Hughes et al (2016) Fibromyalgia	Nurse Practitioners' Education, Awareness, and Therapeutic Approaches for the Management of Fibromyalgia	Aimed to evaluate nurse practitioners' education and awareness of fibromyalgia and to evaluate nurse practitioners' practices for the management of fibromyalgia.	Nurse practitioners	N=66 27% response rate Female = 65 Average age=49	Design: Quantitative descriptive. Online survey Country: USA Setting: online	Survey developed by the Medical Outcomes Specialists from Pfizer, Inc. Exploring demographics, education, awareness and treatment. No validity and reliability studies have been completed	<ul style="list-style-type: none"> Difficulty diagnosing fibromyalgia Worried about labelling their patients Most had to self-educate about fibromyalgia and found diagnosis to be difficult. Majority were not fully confident in treating fibromyalgia.
8	Howman et al (2016) Medically Unexplained Symptoms (MUS)	"You kind of want to fix it don't you?" Exploring general practice trainees' experiences of managing patients with medically	Aimed to explore GP trainees' clinical and educational experiences of managing people presenting with MUS.	Trainee GP's	N = 80 completed baseline questionnaires 76% response rate N=15	Design: Mixed methods Part 1. Written questionnaire with some free text questions Part 2. Invitation to semi-structured interview.	Attitudinal questionnaire was based on a questionnaire piloted and used by Rosendal et al.(2005). Free text questions added and number of	<u>Survey</u> <ul style="list-style-type: none"> The GP trainee responses were mixed and relatively neutral in tone. Most GP trainees did not feel well prepared for managing people with MUS. The majority of GP trainees said they had some MUS teaching at undergraduate level, mainly within mental health lecture. Only 15% stated they had postgraduate teaching and this was

Chapter 1: Sytematic Review

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			unexplained symptoms.		Completed the semi structured interviews	<p>Country: UK</p> <p>Setting: Survey at educational session about MUS</p> <p>Interviews at GP trainees place of work</p>	<p>questions reduced for accessibility.</p> <p>No validity and reliability studies have been completed</p>	<p>usually a discussion with their GP trainer or during a Psychiatry post.</p> <p><u>Free text interpretations</u></p> <ul style="list-style-type: none"> • GP trainees felt under-prepared for managing people with MUS. • Several GP trainees reiterated the lack of formal teaching • GP trainees noted difficulties in following up patients so they could find out whether they had organic pathology or not. <p><u>Qualitative interviews</u></p> <ul style="list-style-type: none"> • GP Trainees reported a range of feelings towards MUS patients, from negative to more positive, with uncertainty, fear of misdiagnosis and a sense of impotence identified as key explanations for the negative emotions experienced. • Most GP trainees described consultations with patients with MUS as challenging, often provoking emotions of anxiety, frustration, unease, feeling overwhelmed and sometimes anger. • Difficulty dealing with uncertainty appeared to underpin much of the unease described by GP trainees • Several GP Trainees described a sense of dissatisfaction or failure at their inability to make a diagnosis or alleviate a patient's symptoms. • GP Trainees who appeared to cope better with managing patients with MUS seemed more able to operate outside the biomedical model and to

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								<p>have more realistic goals than fixing or curing the patient.</p> <ul style="list-style-type: none"> Over half GP trainees cited concerns about damaging the doctor/patient relationship if suggesting a referral for help with psychological difficulties.
9	Yon et al (2015) Medically Unexplained Symptoms (MUS)	Junior doctors' experiences of managing patients with medically unexplained symptoms: a qualitative study	Aimed to explore junior doctors' familiarity with MUS, identify gaps in their knowledge and to explore their views and recommendations for postgraduate teaching about MUS	Junior doctors	N=22 Newly-qualified doctors undertaking the 2-year UK Foundation Training Programme (FY1/FY2)	Design: Qualitative in-depth interviews analysed using the framework method. Country: UK Setting: three North Thames London hospitals within the UK.	in-depth interviews exploring Junior doctors' experiences of managing patients with MUS	<ul style="list-style-type: none"> Expressed feelings of anxiety, frustration and a self-perceived lack of competency in this area Spoke of over-investigating patients or avoiding patient contact altogether due to the challenging nature of MUS and difficulty in managing the accompanying uncertainty. The uncertainty associated with MUS seemed linked to a feeling of incompetence, particularly as they were more accustomed to dealing with cases involving clear organic pathology. Negative attitudes of some senior clinicians and potential role models Described feeling unprepared and unsure what they as doctors could offer in terms of on-going management. Described challenging group of individuals who are often perceived as 'impossible to help' Junior doctors appeared unclear about their role in patient management, and spoke about avoiding conversations or ordering multiple tests because of this uncertainty
10	Shattock et al (2013) Medically Unexplained	'They've just got symptoms without science': Medical	Aimed to examine medical trainees' beliefs and influences about MUS.	Medical trainees	N=43 Third (n = 27) and fourth year	Design: Qualitative Semi-structured interviews analysed using an	Semi structured interviews exploring the range of beliefs held by trainees towards MUS	<ul style="list-style-type: none"> Medical trainees unanimously reported having never had any formal teaching about MUS Understanding of MUS arose from experiential learning within clinical placements where medical students learnt from health professionals that

Chapter 1: Sytematic Review

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	Symptoms (MUS)	trainees' acquisition of negative attitudes towards patients with medically unexplained symptoms.			students (n = 9) and seven medical students who were taking an intercalated degree	iterative approach. Country: UK Setting: medical school in the Northwest of England	and the influences operating upon them	<p>such presentations were problematic and, in some cases, illegitimate medical presentations</p> <ul style="list-style-type: none"> Reaching a diagnosis for MUS was viewed as challenging by medical trainees. MUS was a diagnosis by exclusion and should only be made as a last resort Medical trainees identified feeling frustrated and powerless when working with these patients. Many reported feelings of hopelessness, uncertain how to help Many medical trainees believed that being unable to offer treatment emphasised their incompetence as doctors and devalued their skill. Medical trainees reported experiencing a lack of confidence due to being unable to explain why MUS occur Medical trainees reported having experienced frustration towards the patients. Some claimed that patients had unrealistic expectations of their doctors, which further intensified the difficulty in communicating the limited amount of care that could be offered in practice Medical trainees described frequently hearing views that denied the existence of patients' symptoms and, in some cases, that patients were mentally ill
11	Pastor et al. (2012). Fibromyalgia	Clinical self-efficacy and illness beliefs in ambiguous chronic pain conditions: General	Aimed to identify General Practitioners' beliefs about Fibromyalgia, in terms of mental representation and clinical self-efficacy,	GP's	N= 208 Female = 64% M = 45.4 years	Design: Quantitative descriptive Cross-sectional questionnaires	Brief Illness Perception Questionnaire	<ul style="list-style-type: none"> Fibromyalgia were seen to be psychological Three components of the GPs' mental representations, 'Controllability', 'Illness Severity' and 'Emotional Representation' They consider they have low personal or treatment control over FM. Report having low understanding of it.

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		practitioners' management of fibromyalgia	and to study their relationships with patient management.			<p>Country: Spain</p> <p>Setting: Fibromyalgia workshops and medical conferences</p>	<p>Researchers designed questionnaires assessing: Socio-demographic, clinical experience variables, Clinical self-efficacy in managing FM. Patient management variables and satisfaction in managing FM</p>	<ul style="list-style-type: none"> • Self-efficacy for dealing with FM as only moderate • Satisfaction in managing FM patients was also moderate but lower for technical than for interpersonal aspects of management. These results support previous findings that physicians are unhappy with the care they provide. • More tests were ordered by GPs with greater experience of working with FM patients and who saw the condition as more severe.
12	Edwards et al (2012) Functional Neurological Disorders (FND)	Physiotherapists and patients with functional (psychogenic) motor symptoms: a survey of attitudes and interest.	Aimed to explore exposure to and attitudes towards patients with FMS among neurophysiotherapists.	Physiotherapists	N = 702 Response rate = 61% Female = 91%	<p>Design: Mixed Methods</p> <p>Quantitative descriptive online survey with free text questions.</p> <p>Country: UK</p> <p>Setting: Online survey</p>	<p>Purpose-designed questionnaire, including demographics, experience, terminology, exposure, interest and knowledge, practical care and free text questions.</p>	<p><u>Survey</u></p> <ul style="list-style-type: none"> • Majority of physiotherapists (52%) used the term 'medically unexplained symptoms' with patients • Most physiotherapists (68%) preferred to use the word 'functional' when discussing patients • had low self-judged knowledge. • Most respondents felt physiotherapy had more to offer patients with FMS • felt poorly supported by referring neurologists and by inadequate service structures. • Some harbour concerns about feigning in a substantial proportion of patients. <p><u>Free text questions – 25% response rate</u></p> <ul style="list-style-type: none"> • Indicated dissatisfaction with current service structures, particularly with neurological and psychological support patients often appeared to be 'dumped' on physiotherapy services without a clear diagnosis and explanation of symptoms being given, and without adequate support for

Chapter 1: Sytematic Review

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13	Monzoni et al (2011) Functional Neurological Disorders (FND)	How do neurologists discuss functional symptoms with their patients: A conversation analytic study	Aimed to describe some of the interactional and linguistic resources doctors use when they deliver the diagnosis of a functional disorder	Neurologists	N= 20 consultations undertaken by N=3 neurologists	Design: Qualitative Conversation Analysis (CA) Country: UK Setting: two neuroscience centres (Sheffield Teaching Hospitals NHS Foundation Trust and Southern General Hospital, Glasgow)	Neurologists regular consultations were recorded and analysed.	<p>treating neurophysiotherapists from other relevant professionals, especially neurologists.</p> <ul style="list-style-type: none"> Excessive Formulation Effort (FE) from the outset shows that doctors treat these consultations as particularly delicate The unusual displays of accounting activity, whether in their discussion of test results or physical examination findings, reflect doctors' defensiveness about the messages they are trying to convey, and that, from their own point of view, they are communicating an unwelcome diagnosis. Formulation Effort and accounting activities were sometimes linked to objective interactional problems Doctors also seemed to engage in these practices for no clear interactional reasons, suggesting a degree of defensiveness or prior concern about the consultation
14	Kanaan et al (2011) Functional Neurological Disorders (FND)	Neurologists' understanding and management of conversion disorder	Aimed to explore the attitudes of neurologists to the nature of conversion and its management.	Neurologists	N=349 Male = 82%	Design: Mixed methods Quantitative descriptive Postal survey Country: UK Setting: N/A	33 questions, largely multiple choice but with some free text, covering demographics, details of the clinician's practice, their understanding and management of Conversion disorder. The neurologists were asked to give an	<ul style="list-style-type: none"> Neurologists would rather remain non-committal as to the motivations or consciousness of their patients' behaviour. Most of the respondents saw feigning as entangled with conversion disorder Those who favoured models in terms of feigning were older. Younger, female neurologists preferred psychological models, believed conversion would one day be understood neurologically and found communicating with their conversion patients easier than it had been in the past.

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							example of a memorable case and a qualitative rating was made.	
15	Cranford et al., (2011) Fibromyalgia	Nurse Practitioner Students' Perceptions of Fibromyalgia Pain and Quality of Life	The purpose of this research was to explore future nurse practitioners' perceptions of fibromyalgia pain, quality of life (QOL), and their preparedness to treat these issues.	Student nurse practitioners	N= 21 Response rate = 70% Female = 95% Senior NP students = 95%	Design: Mixed methods Quantitative descriptive survey, consisting of both quantitative and qualitative questions along with a QOL Model diagram Country: USA Setting: University	Investigator developed survey. The questionnaire was adapted from a non-published questionnaire King previously used to inquire about nurses' perceptions of pain and quality of life in relation to patients with cancer (C.R. King, personal communication, September 3, 2008).	<ul style="list-style-type: none"> • Acknowledged the importance of controlling FMS pain and QOL issues • they lacked confidence in treating FMS pain • NP students believed FMS pain affects all aspects of QOL. • Reported learning about the diagnosis primarily through practice experiences.
16	Kanaan et al (2009). Functional Neurological Disorders (FND)	In the psychiatrist's chair: how neurologists understand conversion disorder	Aimed to explore how today's neurologists understand conversion	Neurologists	N=22 Male = 15 Median age = 45	Design: Qualitative In depth interviews Country: UK Setting: Not stated	In depth interviews on how neurologists understand conversion disorder	<ul style="list-style-type: none"> • Endorsed psychological models but did not understand their patients in such terms. • Distinguished conversion from other unexplained conditions Clinically by its severity and inconsistency. • Many did not see this as clearly distinct from feigning • They did not feel that this was their problem to resolve.

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17	Ahern et al (2009) Functional Neurological Disorders (FND)	Attitudes of Neuroscience Nurses Toward Patients with Conversion Symptoms	To study the attitudes of neuroscience nurses towards FND	Neurology nurses	N=68	Design: Mixed methods: Quantitative descriptive - Online survey with free text questions. Country: UK Setting: Single centre	55-Item Questionnaire, Illustrating Attitudes of Nurses Toward Patients with Conversion/Functional Symptoms and open text questions	<ul style="list-style-type: none"> • They saw themselves as 'agnostic' regarding non-neuropathological explanations. • 16% disagreed that conversion symptoms were "real;" • 46% thought the patients were "manipulative;" • 34% disagreed that neurology was "an appropriate place" for these patients. • Levels of self-perceived knowledge were low. • Negative attitudes toward patients with functional symptoms were correlated with lower nursing grade
18	Ali et al (2008) Medically Unexplained Symptoms (MUS)	Attitudes of general practitioners towards cause and management of patients with medically unexplained symptoms; Capital health district, Kuwait.	To survey the attitudes of general practitioners towards management of medically unexplained symptoms in the Capital health region in Kuwait	GP's	N= 114 Response rate = 77.6% Male = 41.2% Mean age = 38.7	Design: Quantitative descriptive Country: Kuwait Setting: primary health care centres under the Capital health region, Kuwait	Investigator developed survey Included 6 sections: (1) sociodemographic, (2) attitudes towards patients with MUS, (3) GP role in managing, (4) best setting for managing, (5) attitudes towards somatisation as a helpful diagnosis, (6) view on availability of effective treatment.	<ul style="list-style-type: none"> • Agreed on the difficulty they encounter when managing patients with MUS. • In this study, more than half of the GP's reported their worries of missing physical illness among MUS patients that may be a reflection of the concern of missing diagnosis in the face of increasing medical litigation • More than half (57%) agreed that these patients have undiagnosed physical illness. • GP's agreed on the contribution of personality factors to the development of somatoform disorders • 80% agreed that primary care is the most appropriate setting for management of patients • 55.3% felt that there were effective treatments for somatization.

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19	Salmon et al (2007) Medically Unexplained Symptoms (MUS)	Why do General Practitioners Decline Training to Improve Management of Medically Unexplained Symptoms?	Aimed to explore how GPs' attitudes to patients with MUS might inhibit their participation with training to improve management.	GP's	N= 33 Who had declined or accepted training in reattribution techniques in the context of a research trial	Design: Qualitative Interviews Country: UK Setting: In GP's practices	Interviews including discussion of: (1) GPs' views of the training that was offered; (2) their reasons for agreeing or not feeling able to participate; and (3) their own experience of patients with MUS.	<ul style="list-style-type: none"> Practitioners devalued their psychological skills. The cognitive dissonance that arises when practitioners say that patients cannot or should not be helped, but then try to help the patient, may further compound GPs' discomfort.
20	Ringsburg et al (2006) Medically Unexplained Symptoms (MUS)	Coping with Patients with Medically Unexplained Symptoms: Work-related Strategies of Physicians in Primary Health Care.	Aimed to elucidate primary health care physicians' perceptions of patients with medically unexplained symptoms, focusing on stressing situations, emotional reactions and coping strategies.	GP's	N= 27 16 = Female 11 = Male	Design: Qualitative focus-group Phenomenography approach used. Country: Sweden Setting: Five primary health care centres, strategically selected to represent rural areas and towns	Focus group discussions aiming to explore perceptions of patients with medically unexplained symptoms, focusing on stressing situations, emotional reactions and coping strategies	<ul style="list-style-type: none"> Six particularly stressful situations in the doctor-patient encounter as experienced by the GPs were identified: GP's reported a fear of missing a serious diagnosis, which they coped with by Taking tests, making referrals and having an alternative diagnosis in mind GP's reported MUS patients to be time consuming and can turn up in emergency appointments, which they coped with by booking a new appointment, preparing mentally and Showing a negative attitude The GPs reflected on the responsibility associated with issuing certificates for sick-leave and early retirement pensions and described how difficult it is to assess a person's working ability The GPs stated that some patients were more demanding than others. These were the patients who 'know everything about their disease'. The GPs described that they occasionally felt questioned by these patients and found

Chapter 1: Sytematic Review

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
								<p>themselves being pushed into negotiations to perform various investigations, which they coped with using positive affirmations, referring on, showing authority and reflecting over transference.</p> <ul style="list-style-type: none"> • GP's had feelings of unease and disharmony. 'Getting stuck' was described as being caught up in something that was impossible to solve, which they coped by meeting more regularly, bouncing it back to the patient and seeking emotional support from colleagues • GPs reflected on their role as medical doctors in relation to society. As a consequence, feelings of insufficiency occasionally developed when they could not help to cure these patients, which they coped with by Reflecting on whose demands are involved and sharing responsibility.
21	Bowen et al (2005) Chronic Fatigue Syndrome (CFS)	Chronic Fatigue Syndrome: a survey of GPs' attitudes and knowledge	Aimed to obtain baseline data and identify the factors associated with GPs' attitudes to and knowledge of CFS/ME	GP's	N=811 77% response rate	Design: Quantitative descriptive – postal survey County: UK	A validated questionnaire asking about: agreement with nine statements about CFS/ME	<ul style="list-style-type: none"> • 48% of GP's did not feel confident with diagnosis of CFS • 41% did not feel confident in treatment of CFS • only 12% enjoyed working with CFS/ME patients. • GP's who accepted CFS/ME as a clinical entity were around three times more positive about diagnostic confidence and around 2.5 times more positive about enjoying working with CFS/ME patients than those who did not accept CFS/ME as a recognisable clinical entity (28%) • Three other key factors that were significantly, positively associated with GPs' attitudes were knowing someone socially with CFS/ME, being male and seeing more patients with the condition in the last year

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
22	Woivalin et al (2004) Medically Unexplained Symptoms (MUS)	Medically unexplained symptoms: perceptions of physicians in primary health care	To explore GPs' perceptions and ways of managing patients with medically unexplained symptoms (MUS).	GP's	N=27 Female = 16 Male = 11	Design: Qualitative Focus groups with open and semi-structure interviews. Country: Sweden Setting: 5 centres of primary health care selected to represent rural Sweden.	Focus groups exploring perceptions and management of MUS	<ul style="list-style-type: none"> • There was a constant fear of missing a condition that could be treated medically. • Expressed an eagerness to find explanations that could be of help in their understanding of these patients. • GPs reported occasional frustration and powerlessness • The tendency to dichotomize medical practice into a biomedical and a psychosocial perspective leads many doctors to dismiss parts of their knowledge and may then result in feelings of distress, insecurity and incompetence
23	Åsbring et al (2003) Chronic Fatigue Syndrome (CFS) & Fibromyalgia	Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia.	The aim of this study was to investigate: (1) How physicians describe and categorise patients with CFS and fibromyalgia; (2) What the character of CFS and fibromyalgia, with regard to diagnosing, treatment and medical knowledge/aetiology, mean to the physicians in encounters with patients; and (3) Which strategies physicians describe	Doctors	N=26 12 = Female 14 = Male Mean age 50yrs	Design: Qualitative semi-structured interviews. Country: Sweden Setting: Doctors place of work	Interviews on themes of (1) own and other physicians' perception of the condition, the diagnosis and its status, (2) description of the patient group, (3) perception of the patients' strategies in managing their problems, seeking care and handling the physicians and (4) the role of the physician, own feelings and approach to the patients.	<ul style="list-style-type: none"> • Physicians expressed from a natural science approach, a scepticism for conditions characterised by a lack of objective measurable values that would make it possible to establish the cause of the condition • Scepticism was expressed by physicians regarding especially CFS, but also fibromyalgia. • According to the physicians there was a discrepancy between how persons with CFS and fibromyalgia represented themselves in the encounter with the physician and how a sick person, according to the physician's assessment, is expected to look and behave. • Physicians felt there is a discrepancy between the ideal role of the physician and reality in the everyday work in interaction with these patients.

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
			that they use in the encounter with these patients.					<p>This may lead to the professional role being questioned.</p> <ul style="list-style-type: none"> • Feelings of frustration, helplessness and failure can be a consequence of the discrepancy between 'ideal and reality roles of the physician', experienced by the physicians. • For the physicians the encounter with the patients with CFS and fibromyalgia may lead to a questioning of their own professional role. • A further consequence of the discrepancy that may arise between ideal and reality is an expressed need for knowledge about how to manage these patients. Many of the physicians pointed out gaps in medical training. • The need for support and supervision in working with patients with a complicated problem was also mentioned, such as help from colleagues and other staff. • A common view was that it was not desirable to have too many of these (CFS & Fibromyalgia) patients, as it could prove difficult to put up with them psychologically.
24	Wileman et al (2002) Medically Unexplained Symptoms (MUS)	Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study	Aimed to explore GPs' attitudes to the management of patients that present with medically unexplained symptoms in primary care.	GP's	N= 15 6= Female 11=Male	Design: Qualitative semi-structured interviews. Country: UK Setting: N/A	Interviews exploring GPs' attitudes to the management of patients that present with MUS	<ul style="list-style-type: none"> • Negative attributions dominated GPs' accounts of patients with these symptoms. Interviewees described how they seemed to dominate the day even though small in number. • GP's reported the sense that patients possessed real power, and could dominate and direct the course of the consultation. • GPs construed that personal gains derived from the sick role (notably attention from others) encouraged and amplified its presentation

<u>Numerical reference system</u>	<u>Author, Year & Condition</u>	<u>Title</u>	<u>Aims</u>	<u>Sample</u>	<u>Sample size & Characteristics</u>	<u>Study design & Characteristics</u>	<u>Measures</u>	<u>Key Findings</u>
								<ul style="list-style-type: none"> • The central problem that GPs faced, therefore, was the extent to which they had little power to influence patients' understandings of their illness, whilst patients were perceived to have much greater power to direct and control the course of events. • Patients were described as 'frustrating' or 'heartsink'. Exploration of such feelings revealed a spectrum of emotions from inadequacy to the resentment and fear of such patients who could dominate and manipulate the course of the consultation • Patients were seen by GPs as being able to gain authority by undermining the opinion of the doctor or lacking trust in the doctor's abilities. This is frustrating for the doctor and potentially harmful to the outcome of the consultation.

1.3.1 Study Characteristics

Although the parameters for this search were set to obtain studies published within the past 20 years (1999-2019), the oldest paper selected for review was published 17 years ago, in 2002. Of the 24 empirical papers reviewed, 17 were published in the last decade (2009-2019), leaving only seven published in the seven years prior to that (2002-2008). Out of the 24 papers, 11 studies used a qualitative methodology in order to elicit HCP's perceptions towards FSS. Semi-structured or in-depth interviews were used in eight of these studies^{3,5,9,10,16,19,23,24} and two studies used focus groups^{20,22}. The remaining qualitative study recorded the consultations of three neurologists and interpreted these using conversation analysis¹³. A quantitative descriptive approach was used in 11 of the empirical papers, in the form of online or postal surveys. Of these 11, six focused only on quantitative data^{1,6,7,11,18,21}, while the remaining five also included free text questions to enable a richer understanding of the data; therefore, categorising them as mixed methods^{2,12,14,15,17}. The final two empirical papers used more comprehensive mixed methods designs; a Q-methodological design when exploring GP's perceptions of IBS⁴ and a study of two parts, consisting of a quantitative descriptive survey, followed by qualitative interviews of a subsequent sample⁸.

The empirical papers reviewed included a range of FSS including, FND (n=6)^{2,12,13,14,16,17}, dissociative seizures as a distinct condition (n=2)^{1,3}, IBS (n=1)⁴, CFS (n=1)²¹, fibromyalgia (n=3)^{7,11,15}, one study included both CFS and fibromyalgia²³ and ten studies considered all functional symptoms under the umbrella term MUS^{5,6,8,9,10,18,19,20,22,24}. There were also a vast range of HPCs, including psychiatrists (n=1)³, neurologists (n=3)^{13,14,16}, neurology nurses (n=1)¹⁷, junior doctors/doctors (n=3)^{5,9,23}, medical trainees (n=2)¹⁰, student/nurse practitioners (n=2)^{7,15}, physiotherapists (n=1)¹², a mix of HCP (n=1)², trainee GP's (n=1)⁸ and GP's (n=10)^{1,4,6,11,18,19,20,21,22,24}. The most common focus was GP's perceptions of MUS (n=7)^{6,8,18,19,20,22,24}. The sample sizes reported in the empirical papers varied with the quantitative descriptive studies reporting samples of n=21 to n=811 and the qualitative studies ranging from n=10 to n=43. The studies included in the review also took place in various geographical locations, such as Spain¹¹, Kuwait¹⁸, Australia² and Italy⁶. Two studies took place in the USA^{7,15} three in Sweden^{20,22,23} and the remaining 15 studies all took place in the UK^{1,3,4,5,8,9,10,12,13,14,16,17,19,21,24}.

1.3.2 Themes

Following narrative synthesis data analysis, eight themes were identified (Table 1.3)

Table 1.3. Summary of themes

Themes	Description
1. Perceived knowledge	Clinician's reported sense of knowledge or lack of knowledge, surrounding the condition.
2. Doubt	Indication that the clinician doubts validity of the condition or questions patients control of the symptoms.
3. Confidence	Clinicians reported sense of their ability to diagnose, manage or treat patients with the condition and concerns with making mistakes.
4. Support	The reported levels of support or need for more support, either from other disciplines, the organisation or governing body guidance.
5. Sitting with uncertainty	The felt sense of sitting with the doubt and ambiguity surrounding the condition itself, diagnoses, management, treatment pathways.
6. Felt sense of helplessness	Clinicians belief that they have little control and are unable to do anything to help these patients and the felt consequence of that.
7. Felt sense of incompetence	Clinician's experiences resulting in an internalised criticism for not fulfilling their 'role'. Feelings of incompetence, stupidity, ineffectiveness.
8. Interpersonal difficulties	Clinicians reported challenges with interacting and communicating with these patients and the clinician's emotional experience from interaction.

1.3.2.1 Perceived knowledge

Perceived knowledge of functional somatic syndromes presented as a reoccurring theme throughout the literature assessed. Of the 24 empirical papers studied in this review, half found reports of low self-perceived knowledge and understanding of FSS, amongst most HCP's

1,2,5,7,8,10,11,12,15,17,22,23

"GP's report having low understanding of fibromyalgia"^[11]

"Physiotherapists had low self-judged knowledge of FND"^[12]

Chapter 1: Systematic Review

This often appeared to be attributed to the lack of formal training offered during their clinical qualifications. For example, in a study by Howman et al⁸ the majority of GP trainees reported some teaching on MUS at undergraduate level, however only 15% described education during their postgraduate training, which was often categorised as a conversation with their trainer on a psychiatry placement. This theme was also evident amongst the empirical papers^{2,5,8,10,15,23}, along with an expressed need to know more.

“Most health professionals did not think they received adequate education about FND and self-perceived knowledge was low in most groups”^[2]

“A further consequence of the discrepancy that may arise between ideal and reality is an expressed need for knowledge about how to manage these patients (chronic fatigue syndrome and fibromyalgia). Many of the physicians pointed out gaps in medical training”^[23]

In the absence of formal training, six studies highlighted that their knowledge had been self-taught, gained through experience or working with colleagues^{2,3,5,7,10,15}.

“Most Nurse Practitioners’ had to self-educate about fibromyalgia and found diagnosis to be difficult”^[7]

“Understanding of MUS arose from experiential learning within clinical placements where medical students learnt from health professionals that such presentations were problematic and, in some cases, illegitimate medical presentations”^[10]

1.3.2.2 Doubt

Doubt was classified by the indication the HCP held doubts over the validity of the condition.

“According to the physicians there was a discrepancy between how persons with CFS and fibromyalgia represented themselves in the encounter with the physician and how a sick person, according to the physician’s assessment, is expected to look and behave”^[23]

“GPs construed that personal gains derived from the sick role (notably attention from others) encouraged and amplified its presentation (MUS)”^[24]

Out of the empirical papers assessed in this review, ten were found to reference doubt in the validity of the conditions^{1,2,10,12,14,16,17,18,23,24} of which six studies were examining the perceptions of functional neurological disorders, including dissociative seizures^{1,2,12,14,16,17}. Such as Karaan et al¹⁴ who noted that most neurologists saw feigning as entangled with conversion

disorder (now known as FND), although acknowledged that those who took this view tended to be older.

“Around half of GPs (53.3%) agreed that, or did not know whether, patients had voluntary control over their functional seizures”^[1]

“Some physiotherapists harbour concerns about feigning in a substantial proportion of patients”^[12]

“Many psychiatrists did not see conversion disorder as clearly distinct from feigning”^[16]

1.3.2.3 Confidence

The most predominant theme, referenced in 16 of the 24 studies reviewed^{1,2,3,5,6,7,8,10,11,12,15,18,19,20,21,22}, was HCP confidence in diagnosing, managing and treating FSS. This appeared, on at least one level, to be a consequence of the theme of knowledge; for example, Shattock et al¹⁰ stated that medical trainees reported experiencing a lack of confidence due to being unable to explain why MUS occur.

“48% GP’s reported a lack of confidence in dealing with their queries (dissociative seizure patients)”^[1]

“Increased patient contact and greater knowledge of FND, rather than years in practice, were related to more confidence in diagnosing FND as well as explaining the diagnosis in HCP”^[2]

A further factor influencing HCP confidence was fear of misdiagnosis, with a number of studies referencing clinicians’ concerns of missing a serious, medically treatable, condition^{6,8,18,20,22}.

“In this study, more than half of the GP’s reported their worries of missing physical illness among MUS patients that may be a reflection of the concern of missing diagnosis in the face of increasing medical litigation”^[18]

“GP Trainees reported a range of feelings towards MUS patients, from negative to more positive, with fear of misdiagnosis identified as one key explanation for the negative emotions experienced”^[9]

Chapter 1: Sytematic Review

This perhaps has also given rise to a fundamental lack of confidence in the HCP perceptions of their own ability. This was highlighted by Salmon et al ¹⁹ who found GPs declined training to improve their skills in working with MUS due to devaluing their own psychological skills.

“GP’s Self-efficacy for dealing with FM was only moderate” ^[11]

1.3.2.4 Support

The theme of support encapsulated HCP’s feeling unsupported by either the organisation or their colleagues as well as the feeling of requiring more support and was identified in five studies ^{1,2,5,12,23}. This theme was predominately found in the most recent empirical papers; for example, Warner et al ⁵ established that doctors felt there were organisational barriers preventing effective management of patients with MUS, including limited time, lack of continuity and limited management options.

“Physiotherapists indicated dissatisfaction with current service structures, particularly with neurological and psychological support” ^[12]

“More than 75% of GPs would actively welcome a dedicated diagnostic and management service for these patients” ^[1]

In addition to conclusions suggesting that HCP’s feel unsupported, the studies also highlighted a desire by HCP’s to be more supported, through a multidisciplinary approach ^{1,2,23}.

“Many participants (HCPs) pointed out the need for multi-disciplinary management and several complained about having patients referred without the diagnosis having been explained, ‘Doctors/neurologists often avoid making such diagnoses and explaining to patients about their symptoms, which makes following treatment and education extremely difficult’” ^[2]

“The need for support and supervision in working with patients with a complicated problem was also mentioned, such as help from colleagues and other staff” ^[23]

1.3.2.5 Sitting with uncertainty

Uncertainty, classified as the discomfort of sitting with ambiguity, was noted in five of the 24 studies ^{3,4,5,8,9}, all of which were published in the last five years (2015-2019). This theme captures the uncertainty experienced in each area of a HCP’s work with these patients, i.e. uncertainty regarding knowledge of the condition itself in order to adequately explain to the patient and colleagues, uncertainty surrounding the diagnosis and management of the conditions

and uncertainty in regards to the options available for treatment, in terms of treatment pathways open to these patients.

“GP’s suggested degrees of uncertainty and discomfort around the aetiology of IBS” [4]

“HCPs ill-equipped to deal with DS (dissociative seizures) - Psychiatrists thought other Healthcare Professionals’ uncertain and unprepared to work with FND” [3]

In addition, several studies noted HCP’s uncertainty of their own role in caring for their patients and how ultimately sitting with this uncomfortable feeling often transferred into negative feelings towards the patients ^{5,8,9}. This was encapsulated in a qualitative study by Yon et al ⁹ who found that junior doctors felt unprepared and unsure of what they could offer patients with MUS, as well as feeling unclear as to their role in patient management, resulting in attempts to avoid these patients.

“Junior doctors spoke of over-investigating patients or avoiding patient contact altogether due to the challenging nature of MUS and difficulty in managing the accompanying uncertainty” [9]

“GP Trainees reported a range of feelings towards MUS patients, from negative to more positive, with uncertainty, identified as one key explanation for the negative emotions experienced” [8]

1.3.2.6 Felt sense of helplessness

A further theme established within the data extraction was a felt sense of helplessness, categorised by HCP belief that they have little control when caring for these patients and are unable to do anything to help, this elicits a feeling of helplessness which is experienced as uncomfortable. This concept was referenced in nine of the 24 empirical studies reviewed ^{2,5,9,10,11,19,20,22,23}.

“Medical trainees identified feeling frustrated and powerless when working with these patients. Many reported feelings of hopelessness, uncertain how to help” [10]

“GP’s consider they have low personal or treatment control over fibromyalgia” [11]

These reports of helplessness were often linked with negative concepts such as ‘difficult’ or ‘challenging’, suggesting a relationship between this uncomfortable emotion and overarching negative perception that has come to be recognised towards this patient group.

Chapter 1: Systematic Review

“Junior doctors’ described MUS as challenging group of individuals who are often perceived as ‘impossible to help’” [9]

“For neurologists and nurses, a greater negative attitude was related to finding it more difficult to help patients with FND ($p < .01$)” [2]

Furthermore, the concept of helplessness becomes a direct contradiction to the identity of those within the healthcare profession, whose dominant role is perceived as helping and fixing the problem. This dissonance may also play a distinct role in the negative attitudes that are then perceived to be projected by HCP’s.

“The cognitive dissonance that arises when practitioners say that patients cannot or should not be helped, but then try to help the patient, may further compound GPs’ discomfort” [19]

“Feelings of frustration, helplessness and failure can be a consequence of the discrepancy between ‘ideal and reality roles of the physician’, experienced by the physicians” [23]

“GP’s had feelings of unease and disharmony. ‘Getting stuck’ was described as being caught up in something that was impossible to solve, which they coped with by meeting more regularly, bouncing it back to the patient and seeking emotional support from colleagues” [20]

1.3.2.7 Felt sense of incompetence

An additional psychological process noted from the studies reviewed was clinicians felt sense of incompetence. This differs from the previous theme of helplessness, as it addresses the clinicians internalising their experienced challenges, resulting in self-criticism and feelings of incompetence, stupidity, and ineffectiveness. Of the 24 studies reviewed, eight referenced this theme ^{8,9,10,11,20,22,23,24}, of which all were medical doctors: five were GP’s ^{8,11,20,22,24} and the remaining three were specialist physicians ²³, junior doctors ⁹ and medical trainees ¹⁰.

“Junior doctors’ expressed feelings of anxiety, frustration and a self-perceived lack of competency in this area” [9]

“Many medical trainees believed that being unable to offer treatment emphasised their incompetence as doctors and devalued their skill” [10]

“The tendency to dichotomize medical practice into a biomedical and a psychosocial perspective leads many doctors to dismiss parts of their knowledge and may then result in feelings of distress, insecurity and incompetence” [22]

This appeared to also be influenced by HCP's beliefs that they are not fulfilling their 'role', which has been afforded them by our cultural expectations.

"GP's reflected on their role as medical doctors in relation to society. As a consequence, feelings of insufficiency occasionally developed when they could not help to cure these patients, which they coped with by reflecting on whose demands are involved and sharing responsibility" [20]

"Physicians felt there is a discrepancy between the ideal role of the physician and reality in the everyday work in interaction with these patients. This may lead to the professional role being questioned" [23]

1.3.2.8 Interpersonal Difficulties

Interpersonal difficulties were categorised as the challenges experienced by the clinician in engaging and communicating with this patient group and the consequential emotional experience linked to that interaction. Of the studies reviewed, 11 highlighted interpersonal challenges expressed by HCP's ^{2,3,5,6,8,10,13,17,18,20,24}. This was described both in practical terms, such as the additional time and effort that was required by HCP's when working with these patients and the emotional responses this elicited.

"Some hospital doctors found managing patients with MUS exhausting and described them as very time-consuming" [5]

"GP's reported MUS patients to be time consuming and can turn up in emergency appointments, which GP's coped with by booking a new appointment, preparing mentally and showing a negative attitude" [20]

"GP's spent 'much' or 'very much' time and energy for MUS" [6]

An additional concept lying within this theme appeared to be a sense that the patient was attempting to control the interaction and therefore influence the HCP, in direct opposition to the usual clinical interaction whereby an HCP may be positioned as the lead and identify as such.

"GP's reported the sense that patients possessed real power, and could dominate and direct the course of the consultation (MUS)" [24]

"46% of Neuroscience Nurses thought the patients were "manipulative" [17]

"GP's agreed on the contribution of personality factors to the development of somatoform disorders" [18]

One study that specifically explored doctor/patient interaction used conversational analysis to analyse twenty outpatient appointments conducted by three neurologists for patients with FND. Monzoni et al.¹³ found when explaining the diagnosis and recommending psychological help, the doctors' communication behaviours could be characterised by high levels of two features; formulation effort and extensive accounting activities. Formulation effort was explained as a feature of verbal communication consisting of behaviours such as, silences, repetitions, self-corrections, syllable stretching, self-interruptions and cut offs. An example of extensive accounting behaviours would be going to the extra effort of explaining how the diagnosis was reached. This study concluded that doctors engage with these patients with a sense of defensiveness and expectation that the interaction will be experienced as difficult.

“Formulation Effort and accounting activities were sometimes linked to objective interactional problems (neurologists)”^[13]

1.4 Discussion and Critical Review

This systematic review aimed to identify and appraise the literature exploring HCP's perceptions towards FSS (including IBS, CFS, Fibromyalgia and MUS), and identify the psychological processes that may be underpinning such perceptions.

The majority of studies were published in the last decade, proposing a recent growth in the academic interest in this field, consequently suggesting there may be a growing clinical conflict that makes this an area seen to benefit from academic impact (Chew-Graham et al., 2017). The high number of UK studies is an interesting observation, prompting the question as to whether the organisational structure of the British National Healthcare Service (NHS) is giving rise to more tensions in this area, i.e. free healthcare supporting prevalence of patient visits and/or organisational service demands and budgets, fuelling disputed clinical responsibility for the treatment of this cohort.

Regardless of the suggestion to adjust language and adopt terms such as functional, MUS was the most commonly investigated term. This suggests that this is still considered the most familiar label to gain an understanding of HCP's perceptions of functional symptoms (even in more recent studies). The most predominant profession examined were GP's, including trainees. This may be due to the perceived level of patient exposure experienced by GP's in their position as a gatekeeper to care. However, this over-representation of GP's could also be due to a recruitment bias; as GP's based in surgeries could be considered more accessible and able to

participate in studies, than medical professionals working on busy wards. This may also account for the lack of representation of healthcare assistants and nurses, who may find it difficult to access a computer or may be less motivated by service evaluation, to participate in research.

1.4.1 Themes

This review identified eight themes that are believed to play a fundamental role, in the predominately negative perceptions identified within the empirical papers reviewed. These included; perceived knowledge, doubt, confidence, support, sitting with uncertainty, felt sense of helplessness, felt sense of incompetence and interpersonal difficulties. Each of the themes, although distinct psychological processes, all appeared fundamental to one another and therefore intrinsically linked. One possible way these are linked is presented in Figure 1.2, where the belief of insufficient knowledge reveals feelings of being unsupported, which can lead to the absence of certainty. This is then associated with reduced confidence, promoting doubt and creating more space for interpersonal difficulties. This is an experience that leads to feelings of hopelessness that gives rise to feelings of incompetence. All of these beliefs and experiences can become projected onto FSS in the form of negative perceptions and/or attitudes.

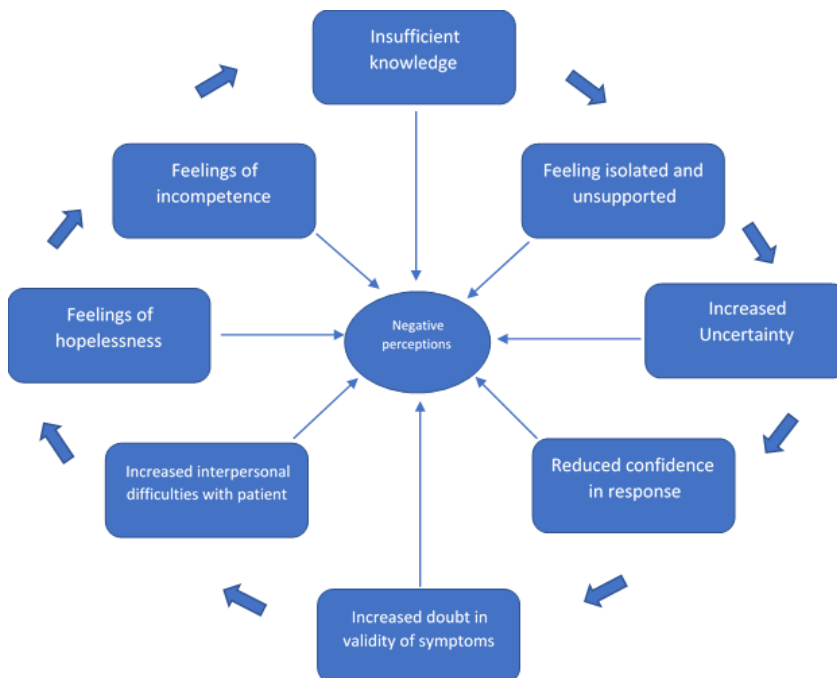


Figure 1.2. Diagram representing relationships between themes and negative perceptions of FSS.

1.4.1.1 Interpretation of themes

The first theme identified that insufficient **knowledge** contributes to negative perceptions of FSS. Having limited accessible knowledge is a potentially difficult position for HCP's reliant on science to support clinical decision making (Grutters, van Asselt, Chalkidou & Joore, 2015). Therefore, there is a dependence on knowledge for confidence and certainty within health care (Wallace, 2005). This review found that from their experiences working in the clinical setting, HCP's felt that more education was needed. Yet, Joyce et al (2018) concluded that a medical prequalification sample and their tutors considered FSS less of an educational priority. This may highlight a lack of awareness and perceived clinical responsibility of FSS by the wider medical community, that potentially does not become realised until post qualification, when faced with the need to support functional patients. It is also curious to note that Howman et al (2016) found that education was categorised as a conversation on one placement, which questions the subjective interpretation of 'education' and may suggest that perhaps a higher number of HCP's feel under educated than has been reported.

The theme of **support**, though not as commonly referenced as other themes, emphasised an important underpinning factor that HCP's feel unsupported by the organisational structure within which they work; for example, not having the appropriate services available to refer patients or not having the capacity to meet these patient's specific treatment needs. It also highlighted that clinicians also do not feel supported by their colleagues, suggesting a sense of sole responsibility when making clinical judgements for this complicated patient group, which ultimately invites positions of isolation and negative affect. This was highlighted through an apparent desire for a multidisciplinary approach, which has also been embraced within the literature as an effective approach to the management and treatment of MUS (Van der Feltz-Cornelis, Hoedeman, Keuter & Swinkels, 2012). Interdisciplinary approaches have been shown to achieve positive outcomes in discrete FSS such as fibromyalgia (Sarzi-Puttini, 2011) and dissociative seizures (Libbon et al., 2019; Gasparini et al., 2019), and more recently attention has turned to new service models which aim to establish interdisciplinary approaches for high intensity service users presenting with functional symptoms (Bestall et al., 2017).

Feeling uncertain was a reoccurring concept within the data, with reference to uncertainty surrounding aetiology, treatment plans and HCP's own clinical role. All of which were acknowledged to impact on negative perceptions towards FSS. In this review, **uncertainty** is understood as the metacognitive process that causes HCP's discomfort. The links between uncertainty and anxiety have been widely documented within the literature and conclude that sitting with uncertainty can be difficult to tolerate (Shihata, McEvoy & Mullan, 2017). This review

suggests that the intolerance of uncertainty within the medical culture leads to a feeling of discomfort, influenced by expectations of their role which promotes responses such as, reduced confidence and negative psychological responses towards the cause of the uncertainty, FSS.

The theme of **confidence** in relation to how to diagnose, manage and treat FSS appeared in over half the studies in this review, making it the most prominent theme. This theme differs from the theme of uncertainty, as the focus is on confidence in taking action or decision making as opposed to the feeling of tolerating uncertainty. The three concepts within this theme were confidence in knowledge of FSS, HCP's perceptions of their own ability and fear of misdiagnosis causing clinicians to miss a more serious underlying physical condition. This apprehension implies clinicians do not feel comfortable making the decisions associated with clinical responsibility for FSS patients. Ali et al (2008) found that concern of missing a diagnosis was influenced by a fear of medical litigation, which can be understood within modern culture of liability. Bolton and Goldsmith (2018) considered the impact of complaints from patients with FND on the clinicians responsible for their care and found that these complaints were often more difficult to resolve than in other areas. This study also noted that this process often meant that the clinicians became the 'second victim', which had a consequential impact on patient care (Bolton & Goldsmith, 2018). Fear of such consequences, may impact on HCP's confidence and influence generalised negative perceptions towards FSS.

Despite the progressive development of awareness of FSS in the past two decades, acknowledged by shifts in diagnostic classifications (American Psychiatric Association Division of Research, 2013; World Health Organization, 1992; Gureje, 2015) and emerging literature aiming to contribute to our understanding (Milán-Tomás, Persyko, del Campo, Shapiro & Farcnik, 2018; Afari et al., 2014), there still appears to be some **doubt** in the validity of such presentations amongst some in the clinical profession. Notably of the ten studies in this review that referenced doubt, six were in relation to FND. While it is important to consider that a third of included studies focused on FND, this may suggest that there are higher levels of HCP's disbelieving the validity of their patient's symptoms when they are neurological in nature. This may have been influenced by earlier research reporting that factitious disorder with neurological symptoms may be more prevalent than is generally assumed (Bauer & Boegner, 1996). Furthermore, Nicholson, Stone and Kanaan (2011), note significant challenges in distinguishing between FND and factitious disorder, due to the similar clinical features and suggest that this may influence conclusions that they are not distinct. Such clinical challenges may impact on perceptions of FSS.

It is reasonable to suggest that psychological processes such as uncertainty, lack of confidence and doubt would create a difficult basis for HCP-patient **interpersonal interactions**. In

Chapter 1: Sytematic Review

several empirical papers, HCP's referred to perceived challenges they experienced when engaging with patients diagnosed with FSS. This was partly attributed to the time and effort consumed by these conditions in comparison to other clinical cohorts, with some studies explicitly noting that clinician's put additional energy into their consultations with the FSS cohort (Monzoni et al., 2011). This review suggests that the additional mental energy exerted by HCP's, a population already prone to burnout (Grace & VanHeuvelen, 2019), may contribute to reduced tolerance towards FSS and the reported tendency to avoid these patients (Jorden et al., 2019). An additional factor within this theme was the observation by HCP's that their patient held more power within the interpersonal interaction, attempting to manipulate or direct the consultations (Ahern et al., 2009; Wileman et al., 2002). Studies exploring why HCP's feel pressurised by MUS patients found that these patients did not explicitly seek somatic interventions from their doctors; however, they did seek more emotional support and explanations (Ring, Dowrick, Humphris & Salmon, 2004; Salmon, Ring, Dowrick & Humphris, 2005). This suggests that HCP's find it challenging coping with the emotion placed on them by their patients as well as tolerating the uncertainty brought up through patients' quest for an explanation. The discomfort described by HCP's in this interaction could relate to the psychodynamic model of transference/countertransference, which suggests that through countertransference the HCP's emotional response can either mirror the patients experience or produce the opposite affect (Cowan, Welton & Kay, 2016). These difficult emotions elicited through working with FSS, could contribute to the negative perceptions identified.

This review identified themes suggesting HCP's felt they held little control in being able to effectively treat FSS. This theme was conceptualised as a ***felt sense of helplessness***, which identified language within the extracted data such as, 'powerlessness', 'impossible', 'hopelessness' and 'failure'. This theme suggests that when working with FSS, HCP's experience an external locus of control that contributes to a learned helplessness, producing negative affect (April, Dharani & Peters, 2012; Khajeddin, Hakim Shoushtari & Hajebi, 2006; Seligman, 1972). This experience appears to once again create a cognitive dissonance between both the self-attributed and social constructions of what is expected of a clinical professional and what, in reality, is possible. This review suggests that the anticipation of this experience triggers a generalised negative perception of working with FSS.

The final theme discovered within this review considered how this negative affect was found to be internalised by HCP's, resulting in self-criticism. This theme, categorised as feeling of incompetence, highlighted that HCP's often felt questioned by FSS patients, leading them to a process of questioning themselves and their ability. Notably all of the studies found to reference a ***felt sense of incompetence***, used a sample of medical doctors (including trainees). In a qualitative study exploring this construct, Crowe and Brugha (2018) found that for doctors, competence was

associated with being emotionally tough, thus hiding emotional vulnerability, struggles and uncertainty. Often achieving this expression of competence came at the cost of self-care and emotional wellbeing. The findings of the current study suggest that the lack of clear aetiology for FSS, to fit with their differential diagnosis training, leaves doctors dismissing their knowledge, feeling incompetent and devaluing their skills, creating a dissonance between the norms, values, and assumptions of medical culture (Crowe & Brugha, 2018). Therefore, negative perceptions towards FSS may serve as a defence for clinicians, attributing the 'blame' to FSS in order to protect themselves.

1.4.2 Clinical Implications

These findings raise significant clinical implications as they suggest that HCP's don't feel appropriately equipped to support patients experiencing FSS. Limited access to education regarding current knowledge and recommended management of FSS, in addition to many HCP's self-educating in this area (Warner et al., 2017; Pastor et al., 2012), implies a risk to the quality and consistency of patient care. It also suggests that HCP's educational curriculum should be reconsidered; however, due to negative perceptions already imbedded within the professional system (Joyce et al, 2018), to achieve impact this may need to be targeted at a cultural level. Finset (2018), proposes that one way to support the inclusion of functional symptoms into the medical curriculum would be to drop the medical tendency to look for a single explanation and instead encourage better integration of the biopsychosocial model at an undergraduate level. By encouraging a contemporary culture to the medical model that incorporates biological, social and environmental factors along with individual perception, it would create a foundation onto which functional symptoms could be more easily understood (Engel, 1977; Finset, 2018).

There was some indication that reduced confidence in diagnosing FSS caused clinicians to order more clinical investigations (Ringsburg et al., 2006; Warner et al., 2017), with financial implications. It has been acknowledged within the literature that the communication behaviours displayed by HCP's and their perceived knowledge can influence the uncertainty experienced by patients (Brashers, Hsieh, E., Neidig & Reynolds, 2006); this is of particular note within this cohort as it could contribute to the pattern of patients seeking additional medical investigations and the high number of functional symptoms amongst frequent attenders in secondary health care (Reid, Wessely, Crayford & Hotopf, 2001; Jadhakhan et al., 2019). It is also interesting to consider that of all the FSS, FND has the most visible symptoms and yet this review has found a higher association with doubt. This prevalence of clinicians' doubt in the validity of patients' symptoms has been found to impact on patients own negative beliefs about their condition, which can in itself be a

predictor of poor clinical outcome. (Thompson et al., 2009; Sharpe et al., 2010; Sharpe et al., 2011).

Yet currently there are few of these specialist multidisciplinary services in place providing specialist knowledge and support, potentially attributing to HCP's position of uncertainty with how to manage FSS. Simpkin and Schwartzstein (2016) suggest that while the medical community is acutely aware that uncertainty inevitably exists, it appears to have developed a culture whereby it isn't acknowledged or even accepted, potentially giving rise to the high levels of burnout witnessed within the profession (Crowe & Brugha, 2018). Although it is important to acknowledge that the samples in the included studies were skewed towards medical doctors, this finding still presents significant implications. Perfectionism in doctors is widely documented as a trait within their profession; however, perfectionism has also been associated with perceived stress, burnout and psychopathological symptoms such as anxiety, depression and somatic symptoms (Craiovan, 2014; Peters & King, 2012; Swider & Zimmerman, 2010). Therefore, the perceived demands placed on them by their patients, coupled with a personal sense of failure in treating FSS, could have implications for doctor's own wellbeing and contribute to staff sickness rates. However, doctors may not have a safe base in order to express these difficulties and process their internal experience. Reflecting on the themes of uncertainty, hopelessness, incompetence and the challenges of holding the emotional demands of patients, psychological supervision for doctors could provide an opportunity to support clinicians with the challenges of working with the complexities of FSS. These provisions could promote more positive perceptions of FSS in healthcare settings.

1.4.3 Limitations and Future Considerations

The varied methodological quality of the studies included and interpreted is a limitation of this review. This was predominantly due to the number of quantitative descriptive studies and the consequential limitations of these, such as levels of non-response bias associated with an anonymous survey methodology (e.g. participants decision to respond due to personal relationship with the topic) and the lack of validated measures used within the included studies. This could suggest that the inclusion of flawed raw data may have compromised the overall findings and interpreted results (Egger, Dickersin & Smith, 2001). However, it is worth noting that a number of the studies that presented as low quality, were those that included a small qualitative element in the form of free text questions, designed to support the quantitative data not necessarily for full qualitative analysis. These were by definition mixed methods studies and assessed as such, impacting on the overall methodological quality of the study. Furthermore, due to the lack of empirical research in this area, robust validated measures are not easily accessible

and therefore excluding such studies could also misrepresent the findings; this highlights the need for future research in this area. This review found an overrepresentation of medical doctors in the empirical studies selected, which suggests a reflection of the current literature. This presents a gap in the literature considering other HCP's, such as nurses, occupational therapists, physiotherapists, and healthcare support workers all of whom may spend considerable time caring for patients with FSS, with different levels of clinical responsibility. Furthermore, there were no mental health professionals represented in this review. Considering that psychological therapies have been identified as an appropriate treatment pathway for many FSS, this identifies a need for future research.

A further methodological limitation relates to the review not utilising a second reviewer to support the selection of empirical papers for review and the identification of themes. This was due to a lack of available resources within the time constraints of this review. An element of personal interpretation and therefore risk of possible biased interpretations, may be expected within the realms of a narrative synthesis systematic review and countering this with additional reviewers would have benefited the strength of these findings. While the reviewer did seek a second opinion from an academic supervisor in relation to these stated issues, this still presents a limitation of this review.

1.4.4 Conclusion

This review aimed to take the literature a step further by providing explanations as to why HCPs may experience negative perceptions towards FSS, so that we can begin to think about influencing change. Following exploration of qualitative and quantitative literature, it found eight themes that relate to the psychological processes underpinning the negative perceptions experienced by HCP's towards FSS. These include perceived knowledge, support, sitting with uncertainty, confidence, doubt, interpersonal difficulties, felt sense of hopelessness and felt sense of incompetence, which were all found to elicit negative affect for HCP's, which this review suggests translates into negative perceptions towards FSS as a defence against this affect. Limitations were noted including the lack of validated measures and the higher representation of doctors present in the study, emphasising the need for further research.

This review concludes that in order to change healthcare experiences of FSS, what is needed is a shared understanding and joined up working. Yet what appears to be experienced is isolated uncertainty and reluctance, presenting as defensive negative perceptions of these patients. This negativity has been acknowledged for a number of years and one solution has been to rename the symptoms in a bid to reduce stigma. However, from a social constructionist

Chapter 1: Sytematic Review

standpoint, it is the lived experiences that attribute meaning to language; therefore, this review argues that it is these underlying processes that influence stigma towards FSS. Renaming the symptoms is essentially a short-term fix as the negative experiences, and therefore perceptions, will inevitably follow. In order to influence real change, services need to reconsider the way in which they work with these patients, factoring in increased knowledge for healthcare professionals, in addition to psychological and structural support.

Chapter 2 Empirical Paper

2.1 Factors influencing healthcare professionals' perceptions towards functional neurological disorders

2.1.1 Functional Neurological Disorders

Functional neurological disorders (FND) refers to a set of neurological symptoms, such as altered voluntary motor, sensory and cognitive symptoms that are present without a known neurological cause. Instead these conditions are generally understood as a problem with the 'functioning' of the central nervous system (CNS), rather than structural changes or disease. The first recordings of these symptoms date back to the second millennium BC. Then known as hysteria, it was historically considered a condition only to afflict women, as a consequence of uterine dysfunction (Stone, Hewett, Carson, Warlow & Sharpe, 2008; Tasca, Rapetti, Carta & Fadda, 2012). While it has continued to be studied throughout history, the symptoms were only redefined as conversion disorder as recently as the 1980s with the DSM III and ICD 10; as a consideration of psychological distress being 'converted' into physical symptoms. Since then much debate has continued to surround the understanding of the conditions aetiology and consequently disputes over the most appropriate terminology to use. In a systematic review of the current terminology of conversion disorder, Ding and Kanaan (2017) highlight the variety of terms that have been developed to describe the condition. Reporting these range from those attempting to attribute aetiological understanding, such as 'dissociative' and 'stress', to those that avoid aetiology, such as 'non-epileptic' or 'medically unexplained'. There is also the contrast between the language used by neurologists, including 'functional' or 'non-organic' and psychiatrists with 'conversion' or 'psychosomatic'. Their review found that the term 'functional' meets most of the criteria for an appropriate label as well as being the most preferred by clinicians and the public (Ding & Kanaan, 2017). Functional neurological disorders (FND) became an official term in DSM-5 replacing the psychiatry classified conversion disorder (American Psychiatric Association, 2013) and more recently the ICD-11 also re-defined these symptoms as dissociative neurological symptom disorder, in recognition of the mechanism behind 'conversion' being a dissociation of awareness from bodily symptoms (World Health Organization, 2018; Canna & Seligman, 2020). However, the term FND has become widely used and accepted both among patients and professionals and therefore will be used throughout this study.

Since the early psychodynamic explanation of functional presentations through the work of Pierre Janet, Sigmund Freud and Joseph Breuer (Tasca et al., 2012), the aetiological understanding of FND has made slow progress and remained controversial. However, the last two decades has seen a revival in the scientific interest in the field and the technological development of functional magnetic resonance imaging (fMRI) has provided researchers with neurobiological evidence of the symptoms being an unconscious response (Aybek & Vuilleumier, 2016; Carson et al., 2012; Nahab, Kundu, Maurer, Shen & Hallett, 2017). Developments in this area have also established poor integration of emotion processing, executive control and motor networks in the brain (Reuber & Brown, 2017), which is thought to be an associated consequence of trauma (Gray, Calderbank, Adewusi, Hughes & Reuber, 2020; Ludwig et al., 2018; Reuber, 2018). In a review of proposed aetiological models, Fobian and Elliot (2019), reiterate this relationship between trauma and neurological processes, in addition to offering further predisposing factors such as psychiatric symptoms and illness exposure. They also present a mechanism for action and reinforcing factors, including sick role and secondary gain. However, further research is required as this body of thinking is still in its infancy and yet to show significant impact on clinical understanding.

2.1.2 Prevalence

The symptoms of FND present similarly to those that can be attributed to a physical neurobiological origin, which often poses difficulties for healthcare professionals (HCP). These include motor weakness and slowness (presenting as paralysis or stroke like symptoms), excessive movement (tics, tremors), axial disturbances (gait, posture), speech disorders (stuttering, effortful, foreign accent), paroxysmal attacks (seizures, appearing similar to epilepsy) and sensory manifestations (visual deficits, dizziness); of which pain (fibromyalgia, migraine) has been found to be a common comorbidity, although not included with in the FND classification (Espay et al., 2018). Research has indicated that FND is amongst one of the most common presentations seen within neurology clinics, with community incidence rates reported at 4-12 per 100,000 population per annum (Stone et al., 2010; Carson & Lehn, 2016). Furthermore, these individuals are reported to experience more distress, disability and social isolation than individuals with an organic aetiology (Carson & Lehn, 2016; Canna & Seligman, 2020). Patients frequently present to emergency departments (ED) as high intensity service users (Cock & Edwards, 2018; Anderson, Nakhate, Stephen & Perez, 2019), which often leads to unnecessary medical investigations and inpatient stays, ensuing a high financial impact (Carson et al., 2011; Scotland, Healthcare Improvement, 2012).

2.1.3 Treatment

While the prevalence rates of FND are having a significant impact on healthcare services, at present the quality of medical care for this cohort is variable (Scotland, Healthcare Improvement, 2012). There are currently no NICE guidelines on how to diagnose and treat FND, influencing local and regional inconsistencies. Additionally, there is contested responsibility among clinical disciplines (i.e. neurology, psychiatry, psychology), unclear treatment pathways and a lack of local funded services (FNDAction, 2018; Rawlings & Reuber, 2018). All of which creates challenges for HCP's in offering effective treatment, potentially causing further stress to an already burnt out healthcare system (Wilkinson, 2015). Although, some encouraging outcomes have been established through psychological therapies such as cognitive behavioural therapy and acceptance and commitment therapy (Wilkinson et al., 2020; Kamil, Qureshi & Patel, 2019; Barrett-Naylor, Gresswell & Dawson, 2018), the way in which the diagnosis of FND is communicated to the patient, has itself been found to have a central role in the treatment of the condition (Stone, Carson and Hallett, 2016). Clear explanations, communication protocols and brief manualised psycho-educational interventions can reduce dissociative seizures (also known as psychogenic non-epileptic seizures [PNES], non-epileptic attack disorder [NEAD] and functional seizures) and reduce the use of emergency services, irrespective of whether the seizures continue (McKenzie, Oto, Russell, Pelosi & Duncan, 2010; Mayor et al., 2012; Mayor et al., 2013). Stone et al (2016) suggest that if the clinician explains the rationale for the diagnosis, makes space for discussion on how the symptoms may arise, emphasises potential for reversibility and takes the patient seriously, then on its own an explanation has the potential as a therapeutic intervention. This approach can also be an important facilitator for engagement in other therapeutic treatments and consequent outcomes (Wilkinson et al., 2020). This highlights the importance of a clear and consistent communication of FND diagnosis from all HCPs in contact with this patient group, to ensure good clinical outcome.

2.1.4 Negative perceptions

While the clear communication of an FND diagnosis appears to be a simple and financially viable clinical intervention, it is not always effectively implemented. One of the identified barriers to this is reported negative attitudes held by HCPs towards patients with FND (Stone et al., 2016). Research on patients' experiences suggests that throughout their clinical journey many patients with FND have negative encounters with HCPs, with reports of feeling ignored, doubted, confused and uncertain (Rawlings & Reuber, 2016; Karterud, Risør & Haavet, 2015; Dickinson, Looper & Groleau, 2011). Such experiences have been found to impact on patients own negative beliefs of their condition, which can in itself be a predictor of poor outcome (Sharpe et al., 2010; Sharpe et

al., 2011). These experiences have been validated through research considering HCPs perspectives of FND finding terms such as ‘challenging’ and ‘frustrating’ often used to describe this patient group, along with reports that doctors and neurologists find this cohort the most difficult to help compared to other patients (Rawlings & Reuber, 2018; Carson, Stone, Warlow & Sharpe, 2004). Several studies exploring HCPs attitudes towards FND have found that lack of education or limited self-perceived knowledge is often associated with negativity (Du Toit & Pretorius, 2017; Edwards, Stone & Nielsen, 2012; Hingray et al., 2018) A number of HCPs are reported to experience doubt over the validity of the symptoms, considering that patients with this presentation may be feigning (Kanaan & Ding, 2017; also found in the systematic review in Chapter 1). In addition to doubt, Ahern, Stone and Sharpe (2009) found that neuroscience nurses also held beliefs that FND “patients were manipulative” and that the “neurology service wasn’t appropriate for these patients”. Subsequently, in 2012, Sahaya, Dholakia, Lardizabal and Sahota found that 48% of nurses felt dissociative seizures were ‘fake’ or that patients had control over their symptoms. Even despite current advances of aetiological recognition in the field, a recent study evaluating 120 London general practitioners (GPs) attitudes towards dissociative seizures found that still over 50% doubted that they were involuntary (Yogarajah et al., 2019). Interestingly, some differences in negative perceptions between different clinical disciplines have been found. In a large-scale survey, Lehn, Bullock-Saxton, Newcombe, Carson and Stone (2019) concluded that neurologists, nurses, and GPs had less clinical interest and greater negative attitudes for patients with FND than psychiatrists, psychologists and physiotherapists. This is significant when considering the clinicians found to feel more negatively are the ones most likely to have increased contact with patients in the first instance and/or be the gateway to therapeutic interventions. For example, Carter et al (2018) found that after receiving a diagnosis of dissociative seizures, the majority of patients are discharged from neurological services without the opportunity for psychological intervention (unlike those diagnosed with epilepsy).

2.1.5 Rationale for current study

The current literature would suggest that there are negative perceptions towards patients with FND and that these can impact on the type of care these patients receive; however, few studies consider what psychological processes may be driving these perceptions in order to identify opportunities for change. The findings from chapter one of this review, suggest that difficult interpersonal interactions can play a role in the challenges described by HCP’s when working with these patients, perhaps contributing to greater personal stress levels and reduced tolerance towards functional conditions (Chapter 1; Monzoni et al., 2011). Rawlings and Reuber (2018) conducted a systematic review to begin to explore HCPs perceptions of dissociative

seizures in more detail. These researchers identified five themes, including (1) uncertainty around the diagnosis and treatment, (2) consideration that the symptoms are largely due to psychological factors, (3) contested responsibility for treatment, (4) views patients are challenging and frustrating and (5) that the condition is less severe and disabling than epilepsy. Their review begins to contemplate factors relating to negative perceptions of HCPs such as working with uncertainty and the suggestion that care of these patients should fall to someone else. However, it only evaluates dissociative seizures (not all FND), and the reviewers note that the limited number of qualitative studies assessing perceptions available within the literature, may limit the findings. Furthermore, the majority of papers examined in their review only considered staff perceptions coming from the specialties of neurology and psychiatry, both being disciplines which have taken a leading role with FND in recent years. Few studies incorporated views of HCPs working in ED, yet ED is often where patients will first present with their symptoms. Furthermore, in a qualitative study considering the experiences of patients with dissociative seizures, doctors in ED were frequently identified in participants' descriptions of their 'single worst' health care interaction relating to their condition (Robson & Lian, 2017). Rawlings and Reuber (2018) also observed the limited representation of non-medical and mental health practitioners in the available research. This is a significant gap in the literature, when considering the emerging evidence supporting the shift towards psychological interventions for FND.

To date the majority of the literature in this area is focused primarily on dissociative seizures, with fewer studies investigating perceptions towards the global diagnosis of FND incorporating all of the presentations within it (including motor, sensory and cognitive symptoms). As dissociative seizures are distinct in their presentation, are more easily quantified, and potentially cause more acute disruption (i.e. explicit episodes, calls to emergency services) these findings cannot be assumed to generalise to all FND presentations; therefore, more research is needed considering views towards FND more broadly. While the current study was in progress, Lehn et al (2019) published a large-scale survey of HCPs perceptions towards FND in Australia. Their study aimed to establish knowledge and support needs for a wider range of HCP who come in contact with FND patients and included non-medical and mental health staff. It is also the first study to begin to incorporate the views of these professional groups within the context of FND and therefore more research is needed in this area to build on these findings. Given their study was carried out in Australia, which has a different healthcare system to the UK, their findings cannot necessarily be generalised to the UK health system, and so research is needed to explore this in the UK, specifically, in relation to the National Health Service (NHS).

2.1.6 Study aims

The current study aims to address these gaps in the literature, seeking to identify whether psychological factors (confidence working with complex clients and personal stress) and professional factors (experience working with FND, training, professional role, banding and specialty area) predict HCPs perceptions towards FND. Data will be collected from UK NHS-based settings, to explore whether there are differences between different professional roles, such as ED staff and mental health staff, and if so how do they contribute to and expand our understanding within the literature.

2.1.7 Research questions and hypotheses

Research question 1: Are there significant differences between different specialities and HCP roles in their perceptions towards FND?

Hypothesis 1: It is predicted that there will be differences in perceptions towards FND, between different HCP types (e.g. nurse/consultant) and speciality areas (ED/mental health). It is hypothesised that mental health professionals will have better perceptions than ED staff.

Research question 2: Does working with complexity and levels of personal stress influence perceptions towards FND?

Hypothesis 2: It is hypothesised staff's confidence to work effectively with complex clients and perceived personal stress levels will be associated with more negative perceptions towards FND (controlling for demographic factors and professional factors).

2.2 Method

2.2.1 Design

The current study implemented a cross-sectional design, using self-reporting measures to measure the influence of HCPs perceived confidence in working with complexity and perceived stress, on attitudes and beliefs towards patients with FND.

The independent variables explored included psychological factors, professional factors and demographic factors (see Table 2.1). The primary outcome variable were attitudes towards FND. The survey also included two free text qualitative questions to provide opportunity for a richer

understanding of HCP attitudes towards FND, in addition to providing participants a space to share experiences with the researcher.

Table 2.1. Independent variables

Independent variables	
Psychological factors	Confidence in effective working with complex clients Staff personal experiences of stress
Professional factors	Amount of experience working with FND Level of training on FND Staff's grade/banding Professional job role Specialty area/department of work
Demographic factors	Age Gender Ethnicity

2.2.2 Measures

Three self-report measures and two free text questions were included in the online survey. When designing the survey, attention was paid to creating a balance between making the survey short and accessible for busy NHS staff, particularly HCP's working in ED, while also gleaning quality information. Demographic and professional factors are described in Table 2.1 (See Appendix D for survey questions), whilst the three self-report measure are detailed below.

2.2.2.1 Effective Working with Complex Clients Questionnaire (EWCC)

The first psychological factor, working with complexity, was measured using the EWCC (Appendix E). The EWCC is a 13-item self-report questionnaire used to assess staff confidence in working with a complex client group. Although this measure has not yet been validated it has been used in studies exploring staff's attitudes towards homeless clients (Maguire, 2005b). It is scored on a scale of one to five, where one equals 'not at all' and five equals 'extremely'. It has five reverse scored items.

2.2.2.2 Perceived Stress Scale (PSS)

The second psychological factor, was measured using the PSS; a 10-item self-report questionnaire (Appendix F) was used to measure personal stress. This measure has been found to have good Internal consistency reliability, factorial validity, and hypothesis validity in the working population (Lee, 2012). It is scored on a scale of zero to four, where zero equals 'never' and four equals 'very often'. It has four reverse scored items.

2.2.2.3 Questionnaire on nursing attitudes to patients with functional symptoms in neurology (NAPFS)

The primary outcome measure of HCP perceptions towards FND was measured using the 20-item version of the nursing attitudes to patients with functional symptoms in neurology questionnaire (NAPFS). This disorder specific measure, developed by Ahern et al (2009) considers attitudes towards functional symptoms and encompasses stigma (Appendix G). The questionnaire has a high level of response consistency. It is scored on a scale of zero to four, where zero equals 'strongly agree' and four equals 'strongly disagree'. It has nine reverse scored items.

2.2.2.4 Free text questions

Two free text questions were included in the survey. These were (a) 'What is your current understanding of Functional neurological disorder?' (b) 'Please include anything you feel is important about your experiences with functional neurological conditions'. These were incorporated to glean qualitative information in order to better understand participants responses.

2.2.3 Sampling strategy

Participants were recruited using opportunity sampling from one NHS England Trust and two NHS Wales Health Boards. The sample consisted of all adults, aged 24-60, who worked for the NHS within ED or mental health specialities. All participants professional roles had direct clinical contact. Recruitment in England took place over four months (December 2019 – March 2020) and in Wales over three months (January 2020 – March 2020), due to the differing timescales of local ethical approval.

2.2.4 Exclusion criteria

Any professional who was not directly involved in patient care (i.e. domestic staff).

2.2.5 Procedure

Participants were recruited from mental health and ED settings within NHS trusts in Hampshire and South Wales. NHS teams were contacted directly to outline the purpose of the study and obtain consent to disseminate the survey amongst their team. The researcher offered to attend team meetings to introduce the study before sending out the online survey link, this was only taken up by one community psychology team and one liaison psychiatry team. The remainder of services opted for the information to be provided to one member of the team for them to circulate on the researcher's behalf. An email with the iSurvey link was circulated to all participating teams, with details of what their participation would entail and how they would be compensated for their time (entered into a draw for Amazon vouchers). This also included a poster making participants aware of the study (Appendix H).

On entering the survey, participants were asked to provide their consent to take part in the study and were made aware that they had the right to withdraw from the study at any time during the completion of the questionnaire (Appendix I). On completion they were provided with a debrief sheet and contact details of the researcher (Appendix J). They were also given the opportunity to give their email address to be entered into the prize draw (this data was kept separately from the questionnaire responses to ensure anonymity and meet data protection policies). Given the busy environment and nature of the participant's jobs, this method of recruitment was selected in order to provide convenience to participants, reduce participant burden, increase the likelihood of honest reflective responses, ensure anonymity and increase the number of participants willing to engage.

2.2.6 Ethical considerations

This study obtained full ethical approval from the University of Southampton's Ethics and Research Governance Committee (ERGO ID: 48573), before receiving full ethical approval from the NHS Health Research Authority (IRAS: 262006). Within NHS England and NHS Wales, three participant identification centres (PIC) were identified for data collection and capacity and capability approval was obtained from the three relevant research and development offices.

2.2.7 Anticipated sample size

Power was estimated using G-power, version 3.1.9.2 (Faul, Erdfelder, Lang & Buchner, 2007). Assuming a medium ES ($p^2 = 0.13$), an a-priori power analysis to test a linear multiple regression (random model), allowing for up to 10 predictors, identified at least 140 participants were needed; to test a two tailed hypothesis, with power $>.08$ and a significance level $<.05$.

As a data reduction method, only predictors that were sufficiently correlated (aiming for a medium effect size) planned to be included in the regression, thus potentially reducing the number of predictors included.

2.2.8 Statistical analysis

All data was recoded ready for analysis. An exploration of the data was conducted to check for sources of bias using descriptive statistics, concluding the assumptions of linearity and independence were met. Due to the sample being slightly under powered, limitations with the Kolmogorov-Smirnov and Shapiro-Wilk tests of normality were considered. Therefore, a visual inspection of the histograms was chosen over these tests (Wilkinson, 1999; Field, 2018; Appendix K), which verified all variables were sufficiently normally distributed. Internal consistency was checked using Cronbach's alpha with a cut-off point of 0.7 (Field, 2018). Good internal consistency was found for the EWCC ($\alpha=.81$), PSS ($\alpha=.84$) and NAPFS ($\alpha=.83$).

Various professional roles completed the survey. The data was sorted to combine similar posts where the participant had opted to specify their job title in the 'other' section. For example, 'staff nurse' in ED was combined with 'physical health nurse (ED)'. Smaller sample groups were combined with similar professional roles where considered possible, to create a sample large enough to analyse. For example, the two assistant psychologists were combined with trainee clinical psychologists and CBT therapists were combined with mental health practitioners. The community mental health and acute mental health groups were combined in order to create a large enough sample size for analysis. Following this, these groups were further combined with liaison psychiatry in order to compare mental health and ED specialties directly. In relation to training, a higher number of participants had received no formal training on FND. The majority of participants who had received training completed half a day training with only six participants completing more than half a day's training on FND. Therefore, groups were combined into 'no training' and 'some training', which included half a day to over five days training.

2.3 Results

2.3.1 Demographic characteristics

A total of 159 people accessed the survey and it was completed by 72 participants (recruitment had to be closed early due to the covid19 pandemic). No participants were excluded from the study. Although the sample size did not meet the intended power calculation, this number is comparable to literature in this area (Ahern et al., 2009) and therefore was still deemed

to add value to the evidence base. The majority of participants were female (83.3%), British (77.8%) and working within a mental health specialty (72.2%). Key demographic and professional characteristics are displayed in Tables 2.2 and 2.3 respectively.

Table 2.2. Key demographic characteristics for all participants together

Variable	N (%)
Age (Mean, SD)	37.02, 9.87
Gender	
Male	12 (16.7%)
Female	60 (83.3%)
Ethnicity	
African	2 (2.8%)
Any other Asian background	4 (5.6%)
Any other ethnic group	2 (2.8%)
Any other white background	4 (5.6%)
British	56 (77.8%)
Caribbean	1 (1.4%)
Chinese	1 (1.4%)
Do not state	1 (1.4%)
Pakistani	1 (1.4%)
Professional grade	
Band 3	2 (2.8%)
Band 4	2 (2.8%)
Band 5	20 (27.8%)
Band 6	25 (34.7%)
Band 7	9 (12.5%)
Band 8	11 (15.3%)
Band 9	1 (1.4%)
Doctor	2 (2.8%)
Specialty/Department	
Emergency Department	20 (27.8%)
Community Mental Health	17 (23.6%)
Acute Mental Health	4 (5.6%)
Liaison Psychiatry	20 (27.8%)
Other areas	14 (19.4%)
Professional role	
HCA	1 (1.4%)
Physical Health Nurse (ED)	14 (9.4%)
Junior Doctor	1 (1.4%)
Consultant	2 (2.8%)
Clinical Psychologist	13 (18.1%)
Assistant Psychologist	2 (2.8%)
Trainee Clinical Psychologist	11 (15.3%)
Allied Health Professionals (Physiotherapists and OTs)	3 (4.2%)
Mental Health Nurse	15 (20.8%)
Mental Health Practitioner & CBT therapists	6 (8.3%)
Training	
No training	50 (69.4%)
Half a day	15 (20.8%)
1 day	1 (1.4%)
Less than 5 days	4 (5.6%)
More than 5 days	1 (1.4%)
Experience	
No contact	17 (23.6%)
Limited	43 (59.7%)
Moderate	10 (13.9%)
Very experienced	1 (1.4%)

2.3.2 Research Question 1: Are there significant differences between specialities and HCP roles in their attitudes towards FND

Independent sample t-tests, one-way ANOVA's and correlations were run to answer research question one. All results are presented in Tables 2.3 and 2.4.

Exploration of demographic factors showed that female participants had a significantly better FND attitude scores, $t(15.10) = -2.82, p=0.13$, than male participants, representing a large effect size of $d = -1.46$ (all Means and Standard deviations are reported in Table 2.3). No significant ethnic differences in attitude scores were found, $t(29.93) = -.891, p=.380$, with a small effect size of $d = -0.32$. However, age was significantly correlated with FND attitude scores, with younger participants having more positive FND attitudes scores than older participants, $r=-.322, p=.008$.

Exploration of professional factors showed a significant difference in FND attitudes across speciality: $F(2,57) = 4.33, p= .018, \omega = 0.16$ (indicating a large effect size), with Bonferroni follow-up tests (this follow up test was chosen because it is the most conservative control of type 1 error), showing that participants working in mental health settings had significantly better FND attitude scores than those working in ED settings (Mean Difference 6.61, Std Error 2.34, $p= .020$). Significant differences were also found between professional roles: $F(4,56) = 4.07, p= .006, \omega = 0.10$ (indicating a medium effect size), with Gabriel's follow-up analysis (this follow up test is recommended to control for type 1 error when sample sizes are unequal), showing that on average clinical psychologists held significantly better FND attitude scores, $F(4,56) = 4.07, p= .006, \omega = 0.10$ (indicating a medium effect size) than physical health nurses (Mean Difference -10.2, Std Error 2.93, $p=.010$). Finally comparison of the combined mental health and physical health areas found that HCPs working in mental health had significantly better FND attitude scores, $t(24.78) = 3.02, p = .006$, than HCPs working in physical health, representing a large effect size of 1.21. While FND attitudes were not significantly correlated with professional banding, those who had experienced some formal training on FND held significantly better FND attitude scores, $t(44.51) = 2.35, p = 0.23$) than those who had no formal training. Additionally, there was a significant relationship between more positive FND attitude scores and having more experience working with FND, $r=.371, p=.001$.

Table 2.3 Summary table of Means, Standard deviations and correlations, with FND attitude scores as the outcome variable.

Variable	Mean	SD	Correlation	Significance
Age (N=62)	37.02	9.87	-.322	.008
Ethnicity British (N=55)	51.76	8.49	.095	.433
Not British (N=16)	49.94	6.81	-	
Gender Female (N=59)	52.58	7.61	.336	.004
Male (N=12)	45.33	8.21	-	
Professional role Physical Health nurse (N=14)	46.50	9.19	-.298	.012
Clinical Psychologist (N=13)	56.69	5.19	.313	.008
Mental health nurse (N=15)	49.87	8.59	-.095	.429
Trainee & assistant Psychologists (N=13)	54.38	6.90	.178	.138
MH practitioners & CBT therapists (N=6)	47.50	6.57	-.145	.228
Speciality Emergency Department (N=19)	46.11	9.52	-.393	.001
Mental Health combined (N=21)	52.71	5.92	.109	.364
Liaison Psychiatry (N=20)	51.25	6.42	-.008	.948
Area Physical Health (N=19)	46.11	9.52	.393	.001
Mental Health (N=52)	53.27	6.69		
Professional grade (N=71)	6.71	1.39	.148	.219
Training Some training (N=21)	54.52	6.95		
No training (N=50)	50.02	8.20	-.255	.032
Experience (N=71)	1.95	.612	.371	.001
EWCC (N=67)	40.37	6.46	.479	.000
PSS (N=71)	16.03	16.02	-.144	.229

2.3.3 Research Question 2: Does working with complexity and levels of personal stress influence attitudes towards FND?

Correlation and multiple regression were used to determine univariate and multivariate predictors of staff attitudes. As previously stated, only predictors that were significantly correlated with NAPFS scores in the univariate analyses were included as predictors in the regression. In order to include the categorical variables (professional role and specialty) in a linear model, they were first converted into dummy variables (Field, 2018). All results are presented in Tables 2.3. and 2.4.

Correlations revealed that participants with better attitude scores towards FND also have significantly greater confidence in working with complexity. However, perceived personal stress was not significantly correlated and not deemed to influence perceptions. Variables significantly correlated with the NAPFS score (age, gender, clinical psychologists, working in ED and mental health settings, training, experience) were included in a multiple linear regression model, to explore the ability of this model to predict attitude scores towards FND. A hierarchical model was carried out to see whether confidence in working with complexity (while controlling for demographic and professional factors in separate blocks) predicted attitudes towards FND. When all other variables are controlled for, the results show that overall, this model was significant ($R^2 = .45$, $F(7,54) = 6.36$, $p < .001$), with younger age, more experience working with FND, and greater confidence working with complexity associated with better attitudes of FND. This final model accounted for 45% of the variance in attitudes towards FND.

Table 2.4. Hierarchical model of significantly correlated predictors of attitudes towards FND

	b	SE B	β	P	Part correlations	sr^2
Step 1						
Age	-.22	.10	-.28	.026	-.278	.08
Gender	4.3	2.65	.20	.109	.198	.04
Step 2						
Age	-.30	.09	-.38	.001	-.369	.14
Gender	4.89	2.31	.23	.039	.222	.05
Clinical psychologist	3.98	2.09	.21	.062	.200	.04
ED Vs Mental health	4.87	2.12	.27	.025	.242	.06
Experience	3.13	1.44	.25	.034	.228	.05
Training	-.44	1.88	-.03	.814	-.025	.00
Step 3						
Age	-.26	.08	-.35	.002	-.321	.10
Gender	3.47	2.30	.16	.137	.152	.02
Clinical psychologist	2.81	2.06	.15	.178	.137	.02
ED V Mental health	3.84	2.08	.21	.070	.186	.03
Experience	2.80	1.39	.22	.049	.203	.04
Training	.53	1.85	.03	.777	.029	.00
EWCC	.34	.14	.29	.021	.240	.06

Note. $sr^2 = .02$ (small effect size), $sr^2 = .13$ (medium effect size), $sr^2 = .26$ (large effect size)

2.3.4 Qualitative interpretation

Participants also had the opportunity to share their own comments in the free text questions. Content analysis was used to interpret the participants responses to the free text questions. The researcher made themselves familiar with the data and formulated codes, these were then grouped into categories and the frequencies recorded. Due to the results of the t-test identifying significant differences between ED and mental health staff (research question 1), frequencies were calculated separately to explore this further in the qualitative data. Overall, the sample of 72 participants includes 20 ED staff and 52 mental health staff.

2.3.4.1 Qualitative question 1: What is your understanding of FND?

Participants responses were coded into categories that described their interpretation of FND. These are presented in Table 2.5.

Table 2.5. Summary of formulated codes and categories for interpreting understandings of FND

Category	Code	Frequency	MH	ED
No Response	Participant did not provide a response.	7	2	5
Little to none	Declared limited/no knowledge.	16	10	6
Presentation	Describing symptoms/conditions.	8	6	2
Neurological functioning	Acknowledgement of functional neurological/CNS changes not structural.	8	4	4
Dualistic thinking (mind not body)	Psychological or non-medical cause with no further clarification	10	7	3
Connection between mind and body	Examples of non-dualistic thinking and acknowledgement of mind and body as one.	18	18	0
Misnomers	Misinterpreted question (e.g. as experience) or provided unclear/incorrect explanation.	5	5	0

Note. MH = Mental health, ED = Emergency department

Out of 72 participants, 16 declared little to no knowledge of FND. Further to this, seven of the participants who did provide an explanation, also displayed some uncertainty in their answer.

“No specific understanding of FND, but I would hazard a guess it is a condition that affects emotional and psychological functioning” [Advanced Clinical Practitioner, ED].

Chapter 2

Eight participants offered an explanation of FND presentations, suggesting some knowledge of the specific conditions that fall under the FND diagnosis.

"I have two clients with this diagnosis and they present very differently. In both clients there is a significant loss of control in movement. Symptoms include pain, burning and numbness in limbs; falls and poor balance with restricted mobility; poor grip. Also, severe and multiple seizures which can vary in presentation" [Mental health nurse, Community mental health].

There were examples of dualistic thinking both in terms of fully psychological explanations (n=5) and non-medical explanations (n=5) with no further clarification.

"Non-organic cause, no medical or surgical intervention required for treatment, disorders of psychological origin" [Junior doctor, Liaison psychiatry].

Eight participants understood FND as physical symptoms caused by the functioning of the central nervous system as opposed to structural changes in the brain.

"The brain of a patient with functional neurological disorder is structurally normal, but functions incorrectly" [Clinical psychologist, Acute mental health].

Additionally, 18 participants made the connection between mind and body when describing their understanding of FND, all of whom worked within a mental health setting.

"That it is sometimes referred to as medically unexplained symptoms. That they are often triggered by a traumatic event and that the symptoms being experienced by the individual are very real to them. Individuals diagnosed with FND often experience anxiety and depression" [Occupational therapist technical instructor, Liaison psychiatry]

"It is caused by a person's mental health affecting their physical health. This is often because the person bottles up their feelings/emotions and this builds up; eventually the brain can't cope with this anymore and causes a physical problem, such as a pseudo-seizure or pain or paralysis without a physical cause" [Student mental health nurse, Liaison psychiatry].

Five participants either misinterpreted the question or provided an inaccurate definition.

2.3.4.2 Qualitative question 2: Additional comments

A total of 47 out of 72 participants offered additional comments that they felt were important in relation to their experiences with FND. Of these, 17 participants reported that they had limited knowledge or experience of working with FND, the majority of whom worked within a mental health setting (n=14). These are presented in Table 2.7.

Table 2.7. Summary of formulated codes and categories for additional comments

Category	Code	Frequency	MH	ED
No Response	Participant did not provide a response.	25	11	14
Limited knowledge/ experience	Little experience working directly with FND or knowledge about the condition	17	14	3
Organisation/service limitations	Acknowledgment of organisational factors that further impact on patients' experiences, such as limitations to service structures and the need for more joint up working (MDT)	11	11	0
Validation and formulation	Value in patient centred approach. Validating patients' experiences and supporting them to understand.	11	9	2
More education needed	Highlighting need/requesting more education/training. Or Knowledge self-taught/colleagues	10	10	0
Experiences - Positives/ Challenges	Experiences both positives and challenges Including more time required, feelings and dilemmas	8	8	0
Trauma/ Psychological approach	Working psychologically with patient. Within context of trauma	5	5	0
Negative attitudes	Acknowledged negative attitudes amongst some staff	6	6	0

Note. MH = Mental health, ED = Emergency department

A total of 11 participants acknowledged organisational factors that further impact on patients' experiences, such as limitations to service structures and the need for more joined up multidisciplinary working.

"As I understand it FND should be a diagnosis of exclusion, however I do not think that possible explanations are always excluded/or if they are that the medics reasoning for diagnosing a functional condition is not sufficiently explained. Siloed departments in

hospitals often mean that different teams do not join up in patient care. It feels important that doctors remain involved/oversee this patient group rather than purely hand over to psychologists - requires an MDT approach. A recent patient who was informed that she may have had a functional seizure found the experience very frustrating and invalidating as no explanation was given regarding how this diagnosis was decided upon. She would have benefited from a conversation around the differential diagnosis” [Clinical psychologist, Health psychology]

“No services to sign post to” [Mental health nurse, Liaison psychiatry]

A further 11 participants commented that they felt it was important to take the time to understand and validate the experience of each individual patient. Furthermore, noting that a valuable role of HCP’s is to support patients in understanding their symptoms.

“I have often felt that my role has been really important in helping patients/clients to understand how it is possible to have physical symptoms without an 'organic' cause, in advocating for patients with other professionals, and in enabling patients to cope with their symptoms whilst they last” [Clinical psychologist, Health psychology]

Ten participants highlighted a need or requested more education on FND, three of which noted that their own understanding was self-taught or informal conversations with colleagues.

“There is a massive need for education in this area. I have learnt as I have worked with these two clients and have read up independently” [Mental health nurse, Community mental health]

Eight HCPs commented on their own personal experiences of working with FND. Two participants experienced FND as a “challenging” to work with and two noted that these patients require more time than other patients. Three participants also commented on positive experiences of working with this patient’s group, such as finding the work “rewarding”.

“...If patient's difficulties, however, are at such an extent that they cannot tolerate psychology sessions or talking about their difficulties without dissociating then I can feel quite hopeless and inadequate...” [Clinical psychologist, Community mental health]

Six participants acknowledged that there were negative perceptions towards FND within the healthcare system, all of whom worked in mental health. Five of the six participants were based in a hospital environment, i.e. liaison psychiatry or health psychology. Some comments inferred negative perceptions lay within physical health settings.

“Often are high intensity users, and therefore can be frustrating when explaining cause of pain cannot be found, different techniques used to explain - positives that nothing is wrong with any of their organs or blood work, which means managing this would require a different from conventional approach. Sometimes, and understandably, explanation of this to patients with FND is met with frustration, the stress therefore comes from managing expectations and frustrations. Unfortunately, there are patients who malingering and these are often clumped together with FND which is not the same thing, but staff approach is like that of those trying to take advantage of the system. Training and more education of FND is important to change attitudes and hopefully help manage patients that come through the front door” [Junior doctor, Liaison psychiatry]

“Limited experience. I have thought that the patient and all the staff involved assessing the patient experience some negative feelings, frustration is common. Patients have commented that no one is doing anything for them and staff say that there is nothing to fix. Lose lose situation” [Mental health nurse, Liaison psychiatry]

“The patient I assessed felt that the General Hospital nursing staff were unwilling to give her and time and attention and thus when she was able to speak freely with a mental health nurse she left feeling listened to, validated and understood which is a large part of what she wanted to feel” [Mental health nurse, Liaison psychiatry]

2.4 Discussion and critical review

The present study aimed to improve knowledge of perceptions towards FND, through exploring and comparing the FND attitude scores of HCPs working in the underrepresented areas of ED and mental health specialties. Specifically, it intended to identify whether demographic factors (age, gender, ethnicity) professional factors (experience working with FND, training, professional role, professional grade and specialty area) and/or psychological factors (confidence working with complex clients and perceived personal stress) predict HCPs perceptions towards FND.

2.4.1 Interpretation of findings

In support of the first hypothesis, this study found significant differences between ED and mental health HCP specialties, with mental health HCP’s displaying more positive perceptions of FND. Further to this, significant differences were also displayed between the different HCP roles;

Chapter 2

with clinical psychologists declaring significantly more positive perceptions of FND. While there are limited studies looking at perceptions towards FND within these samples, these findings support comparable research (Lehn et al., 2019; Yogarajah et al., 2019). Differences in opinion were also highlighted within the qualitative data, as the initial question drew out some responses of both ED and mental health HCPs, suggesting a dualistic response to beliefs i.e. symptoms are psychological not physical (either/or opposed to both/and). Previous research suggests that beliefs such as these, in relation to other functional conditions, are often associated with the consideration that these symptoms are not a medical matter or a legitimate use of healthcare services, creating a barrier to care (Murray, Toussaint, Althaus & Löwe, 2016). Therefore, perhaps better perceptions were recorded by mental health specialties as they considered themselves better placed to hold the responsibility for FND patients. Nevertheless, a number of participants did define FND as a problem with the functioning of neurological systems and acknowledged a relationship between psychological distress and the biological functioning of the central nervous system, resulting in physical symptoms. Of note, all participants who highlighted a connection between body and mind worked within a mental health setting, found to be a predictor of positive perceptions of FND in this study. Further research is needed to directly examine the relationship between dualistic and integrated aetiological beliefs and FND perceptions.

While ethnicity was found to have no bearing in this sample, further analysis observed that demographic factors of younger age and female gender were significant predictors of positive FND perceptions. The association between these two variables and better perceptions of FND is also supported by previous studies (Lehn et al., 2019; Kanaan et al., 2011). However, it is important to note that a higher proportion of mental health professionals were female, so this could be a contributing factor. One explanation for the positive influence of younger age could be the impact of the revolutionary call for a biopsychosocial approach to the medical model (Engel, 1977), filtering into modern medical training (Ayers & De Visser, 2010). Familiarity with this model provides a helpful framework for which FND can be understood. In terms of additional professional factors, this study found that even some training can improve perceptions of FND amongst HCP's and experience working with the condition was also a predictor of positive perceptions (Klinke et al., 2019). Again, this contributes to findings by Lehn et al (2019), who found that more training and experience was positively related to confidence in diagnosing and explaining FND. The current study found no suggestion that HCP's professional grade influences their perceptions towards FND, suggesting that where available, training and experience is accessible across professional grades. Exploration of psychological factors found that perceived personal stress doesn't predict perceptions as hypothesised. However, when considering the high levels of HCP burnout documented across the literature (Grace & VanHeuvelen, 2019), this can be

considered a positive finding. This is because it implies that perceptions towards FND are not transient or variable on how staff are feeling. Therefore, this suggests that training and experience in FND has the potential to influence lasting change.

The main finding of the regression analysis was that after controlling for demographic and professional factors, confidence working with complexity was the most significant predictor of FND perceptions. This confirms part of the second hypothesis, and suggests that once complexity is brought in, regardless of being a psychologist or working in mental health, it is the ability to cope with complexity that is the key influencer of perceptions towards FND. The qualitative data found that participants commonly reported little understanding and/or knowledge of FND or acknowledged uncertainty while providing their definition of FND. This may be a reflection of the uncertainty that surrounds this diagnosis historically, within the literature and clinically. The subtlety of the language captured in the qualitative data, portrays a limited sense of confidence, which may be observed in the EWCC scores and subsequently FND attitudes scores. Interestingly Lehn et al (2019) found that across all HCP groups surveyed were HCP who reported high confidence of communicating about FND, while also reporting poor knowledge of FND; interpreted as possibly not taking the condition seriously. A similar discrepancy was found within the present study, a high frequency of participants qualitatively reported limited knowledge of FND, while quantitatively some also reported more confidence working with complex clients, associated with more positive perceptions of FND. This finding and that of better FND perceptions by mental health specialities, suggests that confidence in one's ability to work with complexity may be more significant than knowledge of the condition itself. It is possible that this reflects the expectation of longer and complex engagement with clients within a mental health setting as opposed to the fast pace and quick 'fix' culture placed upon ED. Working with complex presentations is a key skill incorporated into clinical psychologists training, which could explain the significantly better attitudes recorded by clinical psychologists within this study.

The quantitative data in this study also reflected the findings of chapter one, with participants calling for more education of FND and a joined-up multidisciplinary approach to care (Warner et al., 2017; Howman et al., 2016; Yogarajah et al., 2019; Edwards et al., 2012). There was also acknowledgment of how these limitations impacted on patients' experiences, causing them to "languish" across multiple services and feel unheard. There was a sense that validating and taking time to make sense of the patient's experiences with them was received as extremely valuable, supporting the notion that clear communication can itself be an effective intervention (Stone et al., 2016; McKenzie et al., 2010; Mayor et al., 2013). Interestingly, only mental health staff reported both some challenges working with this cohort but also that the work could be rewarding. Some also reflected that trauma was a predominant presentation with these patients,

supporting the evidence in the field (Myers et al., 2019). Further to this, several participants recognised negative perceptions amongst HCP's in general, with some indication that this conflict was more predominant in physical health settings. These reflections were all from HCP's working in mental health, including mental health nurses, clinical psychologists and a junior doctor working in liaison psychiatry, suggesting this mental versus physical health divide may also be experienced by HCP's working in each domain.

2.4.2 Clinical implications

The present study has found that HCP's working across mental health settings held significantly better perceptions towards FND than HCP's working in the physical health setting of ED. This has clinical implications for the treatment of FND, as HCP's in ED will often be the first interaction that some patients have with the healthcare system following onset of symptoms or the interactions experienced by patients when in the most acute distress. Negative views of their condition held by the clinicians in charge of their care, risks difficult and invalidating experiences for patients, which have been found to negatively impact on effective communication of the FND diagnosis and clinical outcome (Sharpe et al., 2011; Stone et al., 2016).

The difference between physical and mental health was also observed within the qualitative data, that indicated the presence of dualistic aetiological beliefs, in both mental health and ED HCPs. Until recently, it was widely acknowledged that symptoms of FND were caused by psychological factors (Demartini, D'Agostino & Gambini, 2016; Garcin, 2018), therefore these perceptions could be considered relatively justified. However, due to the lack of empirical evidence suggesting such a causal relationship, psychological factors have now been removed from diagnostic criteria (World Health Organization, 2018; American Psychiatric Association, 2013). Furthermore, fMRI studies have found the symptoms to be linked to genuine brain dysfunction, relating to emotional dysregulation (Garcin, 2018). As a reflection of these changes, FND is now considered a rule-in diagnosis, based on neurological examination and semiotics. The move to incorporate this approach clinically has considered the challenges faced by HCP's working in ED settings. In 2019, Anderson et al, published guidance to the assessment and acute management of FND within ED, highlighting that ED HCP's are important contributors to the interdisciplinary approach to treating FND. Anderson et al (2019) also emphasise that it is the responsibility of the clinician to effectively communicate their suspected diagnosis, in a way that facilitates patients understanding (Stone et al., 2016). The present study's finding that mental health HCP's acknowledgment of psychobiological factors (categories of neurological functioning and connection between body and mind) implies that this more progressive understanding of FND has started to filter into clinical settings. However, the recency of this research suggests it may

still take time and in order to support this dissemination, more education and opportunities for continuing professional development (CPD) are required.

The call for more education on FND appears to be a consistent finding within the research in this area (Yogarajah et al., 2019; Jordan et al., 2019; Hingray et al., 2018; Chapter 1). While the perceptions of one's own knowledge could be considered subjective, what this appears to highlight is a willingness and curiosity of HCP's to know more. The present study found that even having had some training has a positive influence on perceptions of FND, demonstrating the clinical benefit of investing in training and education in this area. Additionally, more reported experience with FND was also associated with more positive perceptions. It is possible that a number of HCP's within ED may have worked with FND without realising it, and therefore without training do not have the knowledge or awareness to deliver optimum treatment. While this in itself has its own clinical implications, with a risk to patients receiving inappropriate treatment (for example, thrombolytic therapy for suspected stroke), it also suggests that education of FND may support HCP's confidence in their experience working with the condition. However, a key finding of the current study is that improving perceptions of FND, and therefore improving clinical outcomes, is not just about training in FND itself, but about focusing this training on the broader mindset of working with complexity. When considering parallel difficulties within other marginalised groups, Maguire, Grellier and Clayton (2017) found that training focused on increasing skills and competencies, indicated increased confidence working with complexity and reduced negative perceptions. Therefore, to be more effective, training on FND also needs to incorporate developing confidence in working with complex clients.

In addition to more education in FND, the qualitative data in this study also found that HCP's had a strong sense of what is needed clinically to improve their ability to work with FND. Calling for more service provision, HCP's acknowledged the need for more joined up working in this area and a multidisciplinary approach to care. In support of this request, research evaluating the effectiveness of a multidisciplinary approach to FND treatment has found positive clinical results (Gasparini et al., 2019; Jacob et al., 2018; Whiting, Riashi & Perry, 2019). Additionally, Kline et al (2019) found that having knowledgeable interdisciplinary healthcare professionals and reinforced dynamic collaboration could lead to a higher quality of inpatient care for FND patients, improving competent care and reducing stigma (Kline et al., 2019). This suggests that in order to better support both patients and HCP's working with FND, changes need to be implemented at an organisational level to establish better service provision. The positive findings for this approach to treatment, may also see a financial return for such investment, with care being centralised and less use of emergency services (Wortman et al., 2018; Libbon et al., 2019; Joint Commissioning Panel for Mental Health, 2017). Furthermore, early investigations into integrating physical and

mental health care for all medically unexplained symptoms, have found a positive impact of embedding psychology provision within ED (Griffiths & Nolan, 2018; Griffiths, Curvis & Cunningham, 2018). Considering the current study's identification of positive perceptions by clinical psychologists towards FND, this presents positive clinical implications for the direction of future provision.

2.4.2.1 Personal reflections on clinical implications

While conducting this research, I undertook my final specialist placement in the area of functional symptoms. This placement involved working within a new directly commissioned NHS service that provides psychological provision to ED for individuals experiencing distressing physical symptoms that cannot be attributed to any known physical cause. Through this work, I have developed my own reflections of the structural challenges in translating such research findings into clinical care.

It is my consideration that these findings suggest that there is an appetite amongst some HCP's to be thinking differently about bridging the gap between physical and mental health. I have observed that alongside the current surge in the literature there is a sense of discourses beginning to change within services, with a shift in tensions to the structural barriers in achieving such change. There is a sense of an acknowledgement of the problem but without the willingness or capacity to take ownership of it. Without specifically commissioned services, this appears to be driven by financial budgets, which fosters a culture of siloed departments, creating a barrier for joined up working. This structure drives the experience of the patient being one in which they are bounced between departments that contest responsibility for care.

Alternatively, when services are commissioned, this may still be without the flexibility to work differently in order to successfully reach this clinical cohort. For example, there may be a focus on measuring standardised outputs, rather than meaningful outcomes that may take time to translate into change. There can also be an inability to engage patients in a more adaptable way, such as focusing on outpatient clinics rather than in-reach to ED. I have observed colleagues frustrated at a number of perceived barriers for HCP's who attempt to implement changes with the hope of benefiting both patients and the healthcare system. This is in addition to colleagues expressing an associated learned helplessness from their own experiences trying. Without the facilities and resources to encourage innovation and nurture joined up working, it can become an impossible task, with failure reinforcing the negative beliefs surrounding FND. One colleague used the following metaphor to describe her experiences *"It is like I am walking forward with my FND flag and everyone is behind me, excited and on board. Then after a while I turn around and I*

realise that I am the only one still walking, and so the task begins again", Clinical Neuropsychiatrist.

2.4.3 Strengths and limitations

A strength of this study was collecting data from mental health and ED HCPs, two underrepresented samples that may play significant roles in the clinical journey of a patient experiencing FND. This therefore supports information as to where future educational efforts need to be targeted, such as working with complexity. Furthermore, recruiting from two nations within the UK provides more generalisability for the findings. The number and quality of qualitative responses also contributed further value to this study, as they provided deeper insight, reflecting nuances and caveats in the language used by HCP's. This study adds to a limited evidence base, considering perceptions towards the overarching diagnosis of FND. Furthermore, this is one of the few studies to explicitly measure psychological factors that may contribute to perceptions experienced and suggest a specific construct as a predictor of developed perceptions.

Despite this, the present study is not without its limitations. Being a survey, much like other studies in this area, it is open to responder bias; suggesting individuals who hold an interest in this area are more likely to participate. Anecdotal feedback received from HCPs when advertising the study, suggested that some participants were unsure whether to take part because they had never heard of FND. This further highlights the challenges of limited education on FND, affording opportunity for HCPs to engage with patients experiencing FND and develop perceptions in the absence of any prior prospects for knowledge.

A further limitation of this study was that due to being a marginalised field, there were limited measures available to measure the constructs within this study. Additionally, participant recruitment only took place over three to four months (depending on locality), due to the research governance and NHS ethical processes taking 11 months to complete and impacting on the submission deadline. Furthermore, the final weeks of recruitment were impacted by the COVID-19 pandemic, particularly within ED settings. Considering the natural challenges in accessing a busy NHS sample, this study would have benefitted from a longer recruitment period. Moreover, the researcher was not made aware that there were two different NHS trusts operating within one NHS England general hospital. This meant that the trust that was responsible for physical health staff was not included in the NHS ethics application and only mental health HCP could be recruited from this site, further limiting recruitment. Consequently, all of the ED sample were recruited within South Wales. This may also account for the higher frequency of mental health HCP in the sample.

Additionally, the majority of the ED sample was made up of ED nurses; therefore, results relating to ED nurses need to be considered with caution as they cannot be generalised to other disciplines working in ED. The study also had a high proportion of psychologists (qualified clinical psychologists, trainee clinical psychologists and assistant psychologists). The study had hoped to recruit a more diverse ED sample including healthcare assistants and doctors. This may have been limited by using an online survey and the limited access to computers in ED settings, in addition to the researcher not attending the departments to introduce and support the research as offered.

2.4.4 Directions for future research

The current study found that, training, experience and confidence working with complexity were the key influencers in developing positive perceptions towards FND. Therefore, future research could focus on developing a training program that incorporates skills in working with complexity. The effectiveness of delivering this training to NHS staff working in ED and mental health settings could then be measured to establish the impact it has on perceptions of FND. Furthermore, this current study found positive effects of female gender and working in mental health, on perceptions of FND. However, it also noted that a higher proportion of mental health staff were female, suggesting a potential overlap in predictors. Future research with a larger sample size could explore the effects of this overlap in more detail, to further investigate factors underpinning HCP's perceptions of FND.

Another area for future research stems from the qualitative findings, which implied a divide between aetiological debates (physical versus mental). These differences in opinion were expressed through the subtlety of the language used to describe FND, i.e. 'disorders of psychological origin'. In 2020, Canna and Seligman remarked that cultural meaning is pivotal in the development of FND. Therefore, the language used to describe FND and its causes could influence how HCPs view patients. For example, this is not physical, therefore there is nothing wrong or there is a level of control over the symptoms, perhaps suggesting the patient is manipulative. Future research could build on this, to consider the impact of such language on perceptions of FND and therefore on the HCP-patient relationship and clinical outcomes.

2.4.5 Conclusion

To date the majority of literature considering staff perceptions of FND includes GPs, neurologists and psychiatrists (see Chapter 1). However, patients regularly attend ED following the onset of symptoms, and following recent advances in the research attributing these physical symptoms to a trauma response, more patients are being seen within mental health services. Yet

perceptions in these areas are largely unrepresented. Furthermore, previous research has established that in the first instance clear communication of FND diagnosis by HCP's, can have positive implications on clinical outcomes. While research in this area has noted HCP's negative perceptions towards FND potentially being a barrier to care, few studies have looked to establish the psychological factors that may influence such perceptions. The current study aimed to explore perceptions of HCP's working in mental health and ED settings and explore the factors that influence such perceptions. It found that there were significant differences in the direction of perceptions towards FND. Those working as clinical psychologists held more positive perceptions than HCP's working in ED. Furthermore, confidence working with complex clients was found to be the most significant predictor of positive perceptions of FND. Qualitatively, HCP's acknowledged limitations in current service provision and a lack of perceived knowledge of FND, with a curiosity to know more. It is hoped that these findings will inform future FND training to incorporate key skills that improve confidence working with complexity. Such training may have the ability to influence change in perceptions towards FND and consequently improve communications and have a positive impact on clinical outcomes of FND.

Appendix A PICOSS Table - Inclusion and exclusion criteria

Factor	Inclusion criteria	Exclusion criteria
Focus	<p>Any study focusing on healthcare professionals' attitudes, beliefs or perceptions of medically unexplained symptoms (MUS). Including but not limited to conversion disorder/functional neurological disorder (FND), movement disorders, paralysis or weakness, sensory difficulties, cognitive issues, irritable bowel syndrome, chronic fatigue and fibromyalgia.</p> <p>Any study exploring attitudes towards dissociative seizures [non-epileptic attacks/NES/NEAD] post 2017.</p> <p>Any study that provides insight into the processes underpinning such perceptions (i.e. experiences of working with).</p>	<p>Any studies exploring organic conditions (including epilepsy, stroke, dementia etc.).</p> <p>Any PNES studies included in Rawlings review</p>
Population	<p>Healthcare professionals caring for adults.</p> <p>Healthcare professionals including but not limited to doctors, nurses, healthcare support workers, mental health workers, psychologists, mental health nurses, physiotherapists, SLT.</p>	<p>Any staff without direct patient contact.</p> <p>Studies focused on healthcare professionals working with patients under 18 years-old.</p>
Intervention	Both qualitative and quantitative research methods will be included (i.e. online surveys, questionnaires, focus groups).	Secondary data analysis
Comparator	Studies both comparing professionals' perceptions and those with no comparators	
Outcomes	<p>Any study reporting on healthcare professionals' beliefs towards MUS (both positive and negative)</p> <p>Any study reporting on processes influencing beliefs</p>	
Study design	Qualitative and quantitative analysis.	Case studies

Appendix A

Factor	Inclusion criteria	Exclusion criteria
	Any study that considers the perceptions of more than one practitioner.	
Settings	All inpatient and outpatient settings	Third sector settings (i.e. charity organisations)
Journal	Peer reviewed journals Papers presented in English Time frame of 20 years (1999-2019).	Posters Unable to access full text Book chapters Review articles Grey literature

Appendix B Quality assessment table

Category of study designs	Methodological quality criteria	Studies																							
		Yogarajah et al (2019)	Lehn et al (2019)	Jorden et al (2019)	Bradley et al (2018)	Warner et al (2017)	Sirri et al (2017)	Hughes et al (2016)	Howman et al (2016)	Yon et al (2015)	Shattock et al (2013)	Pastor et al. (2012)	Edwards et al (2012)	Monzoni et al (2011)	Karaan et al (2011)	Cranford et al (2011)	Kanaan et al (2009).	Ahern et al (2009)	Ali et al (2008)	Salmon et al (2007)	Ringsburg et al (2006)	Bowen et al (2005)	Woivalin et al (2004)	Åsbring et al (2003)	Wileman et al (2002)
Screening questions (for all types)	S1. Are there clear research questions?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	S2. Do the collected data allow to address the research questions?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	-	CT	✓	✓	✓	-	-	✓	✓	✓	-	CT	✓	CT	✓	✓	CT	-	✓	✓	-	✓	✓	✓
	1.2. Are the qualitative data collection methods adequate to address the research question?	-	✓	✓	✓	✓	-	-	✓	✓	✓	-	CT	✓	CT	✓	✓	✓	-	✓	✓	-	✓	✓	✓
	1.3. Are the findings adequately derived from the data?	-	CT	✓	✓	✓	-	-	✓	✓	✓	-	CT	✓	CT	✓	✓	CT	-	✓	✓	-	✓	✓	✓
	1.4. Is the interpretation of results sufficiently substantiated by data?	-	✓	✓	✓	✓	-	-	✓	✓	✓	-	✓	✓	CT	×	✓	✓	-	✓	✓	-	✓	✓	✓
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	-	×	✓	✓	✓	-	-	✓	✓	✓	-	×	✓	×	×	✓	×	-	✓	✓	-	✓	✓	✓

Appendix B

4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	✓	✓	-	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	-	-	✓	-	-	
	4.2. Is the sample representative of the target population?	✓	✓	-	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	-	-	✓	-	-	
	4.3. Are the measurements appropriate?	×	✓	-	×	-	×	×	×	-	✓	×	×	×	×	-	×	×	-	-	✓	-	-	
	4.4. Is the risk of nonresponse bias low?	×	×	-	×	-	✓	×	✓	-	×	✓	×	✓	×	-	✓	✓	-	-	✓	-	-	
	4.5. Is the statistical analysis appropriate to answer the research question?	×	✓	-	✓	-	✓	CT	×	-	✓	CT	✓	✓	×	-	✓	✓	-	-	CT	-	-	
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	-	CT	-	✓	-	-	✓	-	-	CT	-	×	×	-	×	-	-	-	-	-	-	-	
	5.2. Are the different components of the study effectively integrated to answer the research question?	-	✓	-	✓	-	-	✓	-	-	✓	-	✓	✓	-	×	-	-	-	-	-	-	-	
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	-	×	-	✓	-	-	✓	-	-	×	-	✓	✓	-	CT	-	-	-	-	-	-	-	
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	-	✓	-	✓	-	-	✓	-	-	✓	-	✓	✓	-	CT	-	-	-	-	-	-	-	
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	-	×	-	✓	-	-	✓	-	-	×	-	×	×	-	×	-	-	-	-	-	-	-	

Note. Sections 2&3 of MMAT quality tool have been removed from this table due to no papers using those designs. Green denotes 'Yes', red denotes 'No' and yellow denotes 'Can't tell'.

Appendix C Data coding table

Theme	Codes	Extracted data/units of meaning	Empirical paper
Doubt	Indication that the clinician doubts validity of the condition. Question patient control (Malingering)/ Validity?	<ul style="list-style-type: none"> • Around half of GPs (53.3%) agreed that, or did not know whether, patients had voluntary control over their functional seizures. 	Yogarajah et al (2019)
		<ul style="list-style-type: none"> • 10% of HCP were unable to agree that the symptoms of FND were 'real' 	Lehn et al (2019).
		<ul style="list-style-type: none"> • Some physiotherapists harbour concerns about feigning in a substantial proportion of patients. 	Edwards et al (2012)
		<ul style="list-style-type: none"> • Neurologists would rather remain non-committal as to the motivations or consciousness of their patients' behaviour. • Most Neurologists saw feigning as entangled with conversion disorder • Those Neurologists who favoured models in terms of feigning were older. 	Karaan et al (2011)
		<ul style="list-style-type: none"> • Many psychiatrists did not see conversion disorder as clearly distinct from feigning 	Kanaan et al (2009).
		<ul style="list-style-type: none"> • 16% neuroscience nurses disagreed that conversion symptoms were "real;" 	Ahern et al (2009)
		<ul style="list-style-type: none"> • more than half (57%) GP's agreed that these patients have undiagnosed physical illness. 	Ali et al (2008)
		<ul style="list-style-type: none"> • Medical trainees described frequently hearing views that denied the existence of patients' symptoms and, in some cases, that patients were mentally ill (MUS) 	Shattock et al (2013)
		<ul style="list-style-type: none"> • Physicians expressed from a natural science approach, a scepticism for conditions characterised by a lack of objective measurable values that would make it possible to establish the cause of the condition • Scepticism was expressed by physicians regarding especially CFS, but also fibromyalgia. • According to the physicians there was a discrepancy between how persons with CFS and fibromyalgia represented themselves in the encounter with the physician and how a sick person, according to the physician's assessment, is expected to look and behave. 	Åsbring et al (2003)
		<ul style="list-style-type: none"> • GPs construed that personal gains derived from the sick role (notably attention from others) encouraged and amplified its presentation. 	Wileman et al (2002)
Perceived knowledge	Clinician's reported sense of knowledge or lack of knowledge, surrounding the condition.	<ul style="list-style-type: none"> • Rates of incorrect or absent knowledge about functional seizures among GPs were still approximately 20% 	Yogarajah et al (2019)
		<ul style="list-style-type: none"> • Most health professionals did not think they received adequate education about FND and self-perceived knowledge was low in most groups. • HCP's voiced the need for more training in this area 	Lehn et al (2019).

Definitions and Abbreviations

		<ul style="list-style-type: none"> Hospital Doctors reported Little training Hospital Doctors described learning from their own experience and from senior role models. 	Warner et al (2017)
		<ul style="list-style-type: none"> Most Nurse Practitioners' had to self-educate about fibromyalgia and found diagnosis to be difficult. 	Hughes et al (2016)
		<ul style="list-style-type: none"> GP's report having low understanding of fibromyalgia 	Pastor et al. (2012).
		<ul style="list-style-type: none"> Nurse Practitioner Students reported learning about the diagnosis (fibromyalgia) primarily through practice experiences. 	Cranford et al., (2011)
		<ul style="list-style-type: none"> Neuroscience nurses' levels of self-perceived knowledge of conversion disorder were low. 	Ahern et al (2009)
		<ul style="list-style-type: none"> Physiotherapists had low self-judged knowledge of FND 	Edwards et al (2012)
		<ul style="list-style-type: none"> GP's expressed an eagerness to find explanations that could be of help in their understanding of these patients (MUS) 	Woivalin et al (2004)
		<ul style="list-style-type: none"> The majority of GP trainees said they had some MUS teaching at undergraduate level, mainly within mental health lecture. Only 15% stated they had postgraduate teaching and this was usually a discussion with their GP trainer or during a Psychiatry post. 	Howman et al (2016)
		<ul style="list-style-type: none"> Medical trainees unanimously reported having never had any formal teaching about MUS Understanding of MUS arose from experiential learning within clinical placements where medical students learnt from health professionals that such presentations were problematic and, in some cases, illegitimate medical presentations 	Shattock et al (2013)
		<ul style="list-style-type: none"> Many of the physicians pointed out gaps in medical training. The need for support and supervision in working with patients with a complicated problem was also mentioned, such as help from colleagues and other staff. 	Åsbring et al (2003)
Confidence	Clinicians reported sense of their ability to diagnose, manage or treat patients with the condition and concerns with making mistakes.	<ul style="list-style-type: none"> 48% GP's reported a lack of confidence in dealing with their queries. 60.8% of GPs felt that neurology and psychiatry together should be responsible for the diagnosis 	Yogarajah et al (2019)
		<ul style="list-style-type: none"> Increased patient contact and greater knowledge of FND, rather than years in practice, were related to more confidence in diagnosing FND as well as explaining the diagnosis in HCP 	Lehn et al (2019).
		<ul style="list-style-type: none"> Majority of Nurse Practitioners' were not fully confident in treating fibromyalgia. Nurse Practitioners' were worried about labelling their patients Nurse Practitioners' expressed difficulty diagnosing fibromyalgia 	Hughes et al (2016)
		<ul style="list-style-type: none"> GP's Self-efficacy for dealing with FM was only moderate More tests were ordered by GPs with greater experience of working with FM patients and who saw the condition as more severe. 	Pastor et al. (2012).

		<ul style="list-style-type: none"> Nurse Practitioner Students' lacked confidence in treating FMS pain 	Cranford et al., (2011)
		<ul style="list-style-type: none"> In this study, more than half of the GP's reported their worries of missing physical illness among MUS patients that may be a reflection of the concern of missing diagnosis in the face of increasing medical litigation 	Ali et al (2008)
		<ul style="list-style-type: none"> practitioners devalued their psychological skills 	Salmon et al (2007)
		<ul style="list-style-type: none"> GP's reported fear of neglecting a medical disease 	Sirri et al (2017)
		<ul style="list-style-type: none"> There was a constant fear of missing a condition that could be treated medically amongst GP's 	Woivalin et al (2004)
		<ul style="list-style-type: none"> The hospital doctor's level of experience appeared to be a more important factor in their investigation and management strategies than their medical specialty Investigations were often ordered without a clear rationale (quotes suggest reassurance) 	Warner et al (2017)
		<ul style="list-style-type: none"> The need for experience - in order to diagnose and treat DS, the clinician needed to have a significant level of experience with the disorder and that treatment should be undertaken in a specialist setting (psychiatrists') 	Jorden et al (2019)
		<ul style="list-style-type: none"> Most physiotherapists felt physiotherapy had more to offer patients with FMS 	Edwards et al (2012)
		<ul style="list-style-type: none"> Most GP trainees did not feel well prepared for managing people with MUS. GP Trainees reported a range of feelings towards MUS patients, from negative to more positive, with, fear of misdiagnosis identified as one key explanation for the negative emotions experienced. 	Howman et al (2016)
		<ul style="list-style-type: none"> Medical trainees reported experiencing a lack of confidence due to being unable to explain why MUS occur 	Shattock et al (2013)
		<ul style="list-style-type: none"> GP's reported a fear of missing a serious diagnosis, which they coped with by Taking tests, making referrals and having an alternative diagnosis in mind 	Ringsburg et al (2006)
		<ul style="list-style-type: none"> 48% of GP's did not feel confident with diagnosis of CFS 41% did not feel confident in treatment of CFS 	Bowen et al (2005)
Felt sense of helplessness	Clinicians belief that they have little control and are unable to do anything to help these patients and the felt consequence of that.	<ul style="list-style-type: none"> For neurologists and nurses, a greater negative attitude was related to finding it more difficult to help patients with FND ($p < .01$). 	Lehn et al (2019).
		<ul style="list-style-type: none"> Several hospital doctors felt unsatisfied or frustrated at times when they felt unable to treat patients effectively. 	Warner et al (2017)
		<ul style="list-style-type: none"> Junior doctors' described MUS as challenging group of individuals who are often perceived as 'impossible to help' 	Yon et al (2015)

Definitions and Abbreviations

		<ul style="list-style-type: none"> GP's consider they have low personal or treatment control over FM. 	Pastor et al. (2012).
		<ul style="list-style-type: none"> GPs reported occasional frustration and powerlessness 	Woivalin et al (2004)
		<ul style="list-style-type: none"> The cognitive dissonance that arises when practitioners say that patients cannot or should not be helped, but then try to help the patient, may further compound GPs' discomfort. 	Salmon et al (2007)
		<ul style="list-style-type: none"> Medical trainees identified feeling frustrated and powerless when working with these patients. Many reported feelings of hopelessness, uncertain how to help 	Shattock et al (2013)
		<ul style="list-style-type: none"> GP's had feelings of unease and disharmony. 'Getting stuck' was described as being caught up in something that was impossible to solve, which they coped by meeting more regularly, bouncing it back to the patient and seeking emotional support from colleagues 	Ringsburg et al (2006)
		<ul style="list-style-type: none"> Feelings of frustration, helplessness and failure can be a consequence of the discrepancy between 'ideal and reality roles of the physician', experienced by the physicians. 	Åsbring et al (2003)
Sitting with Uncertainty	The felt sense of sitting with the doubt and ambiguity surrounding the condition itself, diagnoses, management, treatment pathways.	<ul style="list-style-type: none"> HCPs ill-equipped to deal with DS - Psychiatrists thought other Healthcare Professionals' uncertain and unprepared to work with FND 	Jorden et al (2019)
		<ul style="list-style-type: none"> Such clinicians (GPs) readily admit uncertainty that surrounds IBS There was an element of discord regarding the extent to which psychological or other incompletely understood pathological processes account for IBS symptoms (GPs) GP's suggested degrees of uncertainty and discomfort around the aetiology of IBS 	Bradley et al (2018)
		<ul style="list-style-type: none"> Hospital doctors' perceptions of their role when dealing with MUS varied considerably Hospital doctors Investigations were often ordered without a clear rationale (quotes suggest reassurance) 	Warner et al (2017)
		<ul style="list-style-type: none"> Junior doctors appeared unclear about their role in patient management, and spoke about avoiding conversations or ordering multiple tests because of this uncertainty. Junior doctors described feeling unprepared and unsure what they as doctors could offer in terms of on-going management. Junior doctors spoke of over-investigating patients or avoiding patient contact altogether due to the challenging nature of MUS and difficulty in managing the accompanying uncertainty. 	Yon et al (2015)
		<ul style="list-style-type: none"> Difficulty dealing with uncertainty appeared to underpin much of the unease described by GP trainees GP Trainees reported a range of feelings towards MUS patients, from negative to more positive, with uncertainty, identified as one key 	Howman et al (2016)

		<p>explanation for the negative emotions experienced.</p>	
Support	<p>The reported levels of support or need for more support, either from other disciplines, the organisation or governing body guidance.</p>	<ul style="list-style-type: none"> 72.3% GP's reported feeling adequately supported by neurology, only 39.5% reported feeling adequately supported by psychiatry in managing More than 75% of GPs would actively welcome a dedicated diagnostic and management service for these patients. 60.8% of GPs felt that neurology and psychiatry together should be responsible for the diagnosis majority (45%) felt that general practice together with psychiatry should be responsible for the management 	<p>Yogarajah et al (2019)</p>
		<ul style="list-style-type: none"> Many participants (HCPs) pointed out the need for multi-disciplinary management and several complained about having patients referred without the diagnosis having been explained "Doctors/neurologists often avoid making such diagnoses and explaining to patients about their symptoms, which makes following treatment and education extremely difficult" (physiotherapist). 	<p>Lehn et al (2019).</p>
		<ul style="list-style-type: none"> Organisational barriers were identified by hospital doctors, to the effective management of these patients, particularly in terms of continuity of care 	<p>Warner et al (2017)</p>
		<ul style="list-style-type: none"> Physiotherapists felt poorly supported by referring neurologists and by inadequate service structures. Physiotherapists indicated dissatisfaction with current service structures, particularly with neurological and psychological support Physiotherapists felt that patients often appeared to be 'dumped' on physiotherapy services without a clear diagnosis and explanation of symptoms being given, and without adequate support for treating physiotherapists from other relevant professionals, especially neurologists. 	<p>Edwards et al (2012)</p>
Interpersonal difficulties	<p>Clinicians reported challenges with interacting and communicating with these patients and the clinician's emotional experience from interaction.</p>	<ul style="list-style-type: none"> Complex interpersonal relationships - psychiatrists' identified challenges such as patient avoidance, interpersonal relationships 	<p>Jorden et al (2019)</p>
		<ul style="list-style-type: none"> Some hospital doctors found managing patients with MUS exhausting described them as very time-consuming. 	<p>Warner et al (2017)</p>
		<ul style="list-style-type: none"> GP's reported MUS patients to be time consuming and can turn up in emergency appointments, which GP's coped with by booking a new appointment, preparing mentally and showing a negative attitude 	<p>Ringsburg et al (2006)</p>
		<ul style="list-style-type: none"> Excessive Formulation Effort (FE) from the outset shows that neurologists treat these consultations as particularly delicate The unusual displays of accounting activity, whether in their discussion of test results or physical examination findings, reflect neurologists' defensiveness about the 	<p>Monzoni et al (2011)</p>

Definitions and Abbreviations

		<p>messages they are trying to convey, and that, from their own point of view, they are communicating an unwelcome diagnosis.</p> <ul style="list-style-type: none"> • Formulation Effort and accounting activities were sometimes linked to objective interactional problems (neurologists) • Neurologists also seemed to engage in these practices for no clear interactional reasons, suggesting a degree of defensiveness or prior concern about the consultation 	
		<ul style="list-style-type: none"> • GP's agreed on the difficulty they encounter when managing patients with MUS. • GP's agreed on the contribution of personality factors to the development of somatoform disorders 	Ali et al (2008)
		<ul style="list-style-type: none"> • Neurologists, nurses and general practitioners reported less clinical interest and greater negative attitudes and negative experiences 	Lehn et al (2019).
		<ul style="list-style-type: none"> • GP's spent 'much' or 'very much' time and energy for MUS 	Sirri et al (2017)
		<ul style="list-style-type: none"> • 46% of Neuroscience Nurses thought the patients were "manipulative;" 	Ahern et al (2009)
		<ul style="list-style-type: none"> • Most GP trainees described consultations with patients with MUS as challenging, often provoking emotions of anxiety, frustration, unease, feeling overwhelmed and sometimes anger 	Howman et al (2016)
		<ul style="list-style-type: none"> • Medical trainees reported having experienced frustration towards the patients. Some claimed that patients had unrealistic expectations of their doctors, which further intensified the difficulty in communicating the limited amount of care that could be offered in practice 	Shattock et al (2013)
		<ul style="list-style-type: none"> • GP's reported the sense that patients possessed real power, and could dominate and direct the course of the consultation. • Patients were seen by GPs as being able to gain authority by undermining the opinion of the doctor or lacking trust in the doctor's abilities. This is frustrating for the doctor and potentially harmful to the outcome of the consultation. 	Wileman et al (2002)
Felt sense of incompetence	Clinician's experiences resulting in an internalised criticism for not fulfilling their 'role'. Feelings of incompetence, stupidity, ineffectiveness.	<ul style="list-style-type: none"> • Several GP Trainees described a sense of dissatisfaction or failure at their inability to make a diagnosis or alleviate a patient's symptoms. 	Howman et al (2016)
		<ul style="list-style-type: none"> • Junior doctors' expressed feelings of anxiety, frustration and a self-perceived lack of competency in this area • The uncertainty associated with MUS seemed linked to a feeling of incompetence, particularly as they were more accustomed to dealing with cases involving clear organic pathology (junior doctors) 	Yon et al (2015)
		<ul style="list-style-type: none"> • Many medical trainees believed that being unable to offer treatment emphasised their incompetence as doctors and devalued their skill. 	Shattock et al (2013)

		<ul style="list-style-type: none"> Satisfaction in managing FM patients was also moderate but lower for technical than for interpersonal aspects of management. These results support previous findings that General physicians are unhappy with the care they provide 	Pastor et al. (2012).
		<ul style="list-style-type: none"> The GPs stated that some patients were more demanding than others. These were the patients who 'know everything about their disease'. The GPs described that they occasionally felt questioned by these patients and found themselves being pushed into negotiations to perform various investigations, which they coped with using positive affirmations, referring on, showing authority and reflecting over transference GPs reflected on their role as medical doctors in relation to society. As a consequence, feelings of insufficiency occasionally developed when they could not help to cure these patients, which they coped with by Reflecting on whose demands are involved and sharing responsibility 	Ringsburg et al (2006)
		<ul style="list-style-type: none"> Physicians felt there is a discrepancy between the ideal role of the physician and reality in the everyday work in interaction with these patients. This may lead to the professional role being questioned. For the physicians the encounter with the patients with CFS and fibromyalgia may lead to a questioning of their own professional role. 	Åsbring et al (2003)
		<ul style="list-style-type: none"> Patients were described by GP's as 'frustrating' or 'heartsink'. Exploration of such feelings revealed a spectrum of emotions from inadequacy to the resentment and fear of such patients who could dominate and manipulate the course of the consultation 	Wileman et al (2002)
		<ul style="list-style-type: none"> The tendency to dichotomize medical practice into a biomedical and a psychosocial perspective leads many GPs to dismiss parts of their knowledge and may then result in feelings of distress, insecurity and incompetence. 	Woivalin et al (2004)

Appendix D Demographic and professional questions



Factors influencing healthcare professionals' attitudes towards functional neurological disorders

1. Prize draw

We are very grateful for you taking the time to complete this survey. As an offer of thanks and compensation for your time, we would like to give you the opportunity to win one of four Amazon vouchers to the value of £50, £50, £100 and £200. In order to be entered into this draw you will need to provide an email address so that you can be contacted in the event that you win!

Please note that this personal information will not be stored with the rest of your responses on this survey.

Question 1.

Email address:



Factors influencing healthcare professionals' attitudes towards functional neurological disorders

1. Demographic

Question 1.

Please select your age

Question 2.

Please select your gender

Question 3.

What is your ethnicity?

a) Black or Black British

- Caribbean
- African
- Any other Black background within (a)

b) White

- British
- Irish
- American
- Any other White background

c) Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background within (c)

d) Mixed

- White & Black Caribbean
- White & Black African
- White & Asian
- White & Hispanic
- Any other mixed background

e) Other ethnic groups

- Chinese
- Japanese
- Hispanic
- Any other ethnic group
- Do not state



Factors influencing healthcare professionals' attitudes towards functional neurological disorders

1. Professional

Question 1.

How much experience have you had working with Functional Neurological Disorders?

Question 2.

How much training have you had on Functional Neurological Disorders?

Question 3.

What is your professional grade?

Question 4.

What is your job title?

Question 5.

Which specialty area/department do you work in?

Question 6.

In which area of the UK do you work?

Appendix E **Effective Working with Complex Clients**

Questionnaire (EWCC)

Effective Working with Complex Patients Questionnaire

What improvement to the quality of life of this patient group do you believe that you can make?

1	2	3	4	5
None	A little	Some	Quite a lot	A great deal

How competent do you feel when dealing with individual's difficulties?

1	2	3	4	5
Not at all	A little	Quite	Very	Extremely

How well prepared / trained do you feel to work with this patient group

1	2	3	4	5
Not at all	A little	Quite	Very	Extremely

How well supported do you feel when working with this patient group?

1	2	3	4	5
Not at all	A little	Quite	Very	Extremely

How confident do you feel about enabling patients to improve strategies or ideas to help them cope in the future?

1	2	3	4	5
Not at all	A little	Quite	Very	Extremely

How often do you believe that you will never be able to help this patient group make long-term change?

1	2	3	4	5
Never	Sometimes	Half of the time	Most of the time	Always

At these times, how much stress /distress do you feel?

1	2	3	4	5
---	---	---	---	---

None	A little	Some	Quite a lot	A great deal
------	----------	------	-------------	--------------

To what extent do you believe your interventions are structured and focussed?

1	2	3	4	5
Never	Sometimes	Half of the time	Most of the time	Always

To what extent do you believe your interventions have clear goals?

1	2	3	4	5
Not at all	Sometimes	Half of the time	Most of the time	Always

Generally, how stressful do you find work with this patient group?

1	2	3	4	5
Not at all	Slightly	Quite	Very	Extremely

How often do you become stressed as a result of difficult interactions with individual patients?

1	2	3	4	5
Never	Sometimes	Half of the time	Most of the time	Always

How distressed do you feel at these times?

1	2	3	4	5
Not at all	Slightly	Quite	Very	Extremely

How rewarding do you find the work with this patient group?

1	2	3	4	5
Not at all	Slightly	Quite	Very	Extremely

Appendix F Perceived Stress Scale (PSS)

Perceived Stress Scale

A more precise measure of personal stress can be determined by using a variety of instruments that have been designed to help measure individual stress levels. The first of these is called the **Perceived Stress Scale**.

The Perceived Stress Scale (PSS) is a classic stress assessment instrument. The tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. The questions in this scale ask about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

0 - never 1 - almost never 2 - sometimes 3 - fairly often 4 - very often

- _____ 1. In the last month, how often have you been upset because of something that happened unexpectedly?
- _____ 2. In the last month, how often have you felt that you were unable to control the important things in your life?
- _____ 3. In the last month, how often have you felt nervous and stressed?
- _____ 4. In the last month, how often have you felt confident about your ability to handle your personal problems?
- _____ 5. In the last month, how often have you felt that things were going your way?
- _____ 6. In the last month, how often have you found that you could not cope with all the things that you had to do?
- _____ 7. In the last month, how often have you been able to control irritations in your life?
- _____ 8. In the last month, how often have you felt that you were on top of things?
- _____ 9. In the last month, how often have you been angered because of things that happened that were outside of your control?
- _____ 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Appendix G Questionnaire on nursing attitudes to patients with functional symptoms in neurology (NAPFS)

Selected FND questions

1. My knowledge of functional symptoms is limited.
2. I received adequate education on functional symptoms in my training.
8. Functional symptoms are a big problem in the NHS.
10. Organic and functional symptoms can occur in patients at the same time.
13. These patients are responsible for their symptoms.
14. People with functional symptoms are in control of their symptoms.
15. People with functional symptoms need a psychiatric referral.
16. Neurology is an appropriate place for these patients.
19. People with functional symptoms are manipulative.
20. These patients' symptoms are real.
22. I am willing to spend time caring for people with functional symptoms.
25. Functional patients' symptoms are in their mind.
26. People with functional symptoms are interesting to work with.
28. People with functional symptoms deserve the same level of care as people with organic disease.
29. People with functional symptoms waste doctors' and nurses' time.
30. Patients with functional symptoms are truthful about their symptoms.
31. Other staff view these patients negatively.
37. If I had a choice I would rather not care for patients with functional symptoms.
41. Patients with functional symptoms are annoying.

Definitions and Abbreviations

43. I enjoy working with patients who have functional symptoms.

Appendix H Recruitment email with poster advert

Dear

I hope this email finds you well.

My name is Kelly Phipps and I am a third year Trainee Clinical Psychologist at the University of Southampton. As part of my doctoral research project I am interested in hearing about healthcare professionals' experiences of working with individuals diagnosed with functional neurological disorders (FND), including dissociative seizures (non-epileptic attacks/NES/NEAD), movement disorders, paralysis or weakness, sensory difficulties and cognitive issues.

These patients are often admitted to A&E and signposted towards mainstream mental health services. Therefore, this project is specifically focused on factors influencing staff attitudes towards FND, with the hope of improving training, awareness and ultimately treatment outcomes (McKenzie et al., 2010).

I would be very grateful if you would consider forwarding the study link email to all of your staff who have direct patient contact. The brief online survey takes approximately 15 - 20 minutes to complete.

<https://www.isurvey.soton.ac.uk/32155>

Your support with this project is greatly valued and if there are any questions you might have, please do not hesitate to contact me.

Kind regards,

Kelly

Trainee Clinical Psychologist

University of Southampton

Calling NHS Staff!

Participants needed

Can you spare 15-20 minutes to complete an online survey?

We are looking at NHS staff's experiences of working with patients with a diagnosis of **Functional Neurological Disorders (FND)**



To THANK YOU for your time, you will be entered into a raffle draw for a chance to win one of four amazon vouchers!



Participate at:
<https://www.isurvey.soton.ac.uk/32155>

For more information email k.m.phipps@soton.ac.uk or speak with your team manager for the link

Version 3.1, 30/7/2019

IRAS Project ID: 262006



Appendix I Participant information sheet and consent

Participant Information Sheet



Study Title: Factors influencing healthcare professionals' attitudes towards functional neurological disorders

Researcher: Kelly Phipps

ERGO number: 48573

IRAS number: 262006

Version 1.3. Date: 22.10.2019

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully. If you would like any more information before you take part in this research please contact the chief investigator using the contact details below. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

My name is Kelly Phipps and I am currently undertaking my Doctorate in Clinical Psychology at Southampton University, for which this research will make up my thesis. This survey aims to consider the factors influencing staff attitudes towards Functional Neurological Disorders (FND). It is hoped that this information will help to focus training to meet the correct needs for staff working with this patient group. A more effective and focused training programme could help to improve the communication of the diagnosis of FND to patients, which has been shown to be a highly effective treatment. If patients are exposed to this first line treatment in the early stages of their care, this could result in less use of emergency services, supporting staff pressures and have a financial benefit to the NHS (McKenzie et al., 2010). Furthermore, your information will be used to validate questionnaires used within the study.

This research is sponsored by Southampton University.

Why have I been asked to participate?

To date the research conducted in this area has focused solely on specialist healthcare professional groups. This research hopes to expand on this and collect data from a wider range of healthcare professionals who are likely to come in contact with this patient group, i.e. emergency departments and mental health teams.

What will happen to me if I take part?

Definitions and Abbreviations

Your participation in this study will require you to complete an online survey, taking approximately 20 minutes. This survey will consist of questions on demographic information (e.g. age, gender, ethnicity, job), three questionnaires that will be answered by selecting from a scale of 1- 5 and two free text questions. Your data will be kept anonymously and stored securely.

You will be able to save your responses and return to the survey any time before the 1st May 2020.

This research study is expected to last up until May 2020, after which point the results of the study will be made available to your departmental leads to be distributed.

Are there any benefits in my taking part?

In order to compensate you for your time, you will be entered into a prize draw for the opportunity to win one of four amazon vouchers, to the value of £50, £50, £100 and £200. This draw will take place no later than the 5th June 2020. So that you can be entered into the draw and contacted should you win, you will be asked to provide an email address. This personal identifiable data will be stored securely and separately from your survey responses.

The literature to date has established that staff training is required. Developing a greater understanding of a wider range of healthcare professionals will support services to target staff training in the most needed areas. More focused training will in turn benefit patient experience and treatment.

Are there any risks involved?

It is not anticipated that there will be any adverse effects as a consequence of participating in this study. The questions aim to capture insight into staff's own beliefs and attitudes towards patients with functional neurological disorders. Should this process cause any concerns, you will have the researchers contact information and brief psychoeducation on the condition can be provided. This information will also be provided in the debriefing form following participation in the study. Should the nature of the concern be more specific then appropriate support will be sought.

What data will be collected?

Once you have read this information sheet and agree to participate in this research study, you will be directed to confirm your consent to participate. This will allow you to continue into the survey. Here you will be asked to complete a demographic section which includes special category data according to the Data Protection Act (1998) and the General Data Protection Regulation (2018) legislation, such as age, gender and ethnicity. You will also be asked to complete three Likert scale questionnaires and two free text questions. This should take approximately 20 minutes to complete.

You will also be asked to provide a personal email address, so that you can be entered into the prize draw and contacted should you win. Once the prize draw has taken place, all email addresses will be destroyed.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Demographic information being collected (age, gender, ethnicity) will not be sufficient to uncover your identity. Data from the online questionnaires will be downloaded and stored in an electronic file that is password protected. iSurvey uses secure encryption in the form of Secure Sockets Layer (SSL). This ensures that data sent by participants cannot be intercepted by third parties. Access to the admin interface is also secured using the SSL. Data is stored on site, and therefore 3rd party hosting companies cannot access data. This data will only be accessed by the researchers and analysed on the investigator's computer, which is also password protected. If the data needs to be accessed elsewhere, the data will be transported using an encrypted memory stick.

In order to notify the prize winner following participation, it will be necessary to record your email address. This information will be kept in a separate electronic spreadsheet, which will also be password protected and only available to the chief investigator and not any of the other researchers involved with the study. On selecting the winner and contacting the participant to receive their voucher, all personal email addresses will be destroyed.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you do decide you want to take part, you will need to acknowledge your consent by ticking the box below to continue with the survey.

What happens if I change my mind?

You have the right to change your mind at any point while you are completing the survey. If you wish to withdraw before completing the survey simply close the window and no data will be saved. However, once you have fully completed and submitted your responses it will not then be possible to withdraw your data, as all submissions are anonymous.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The research findings will be made available to your departmental lead to be distributed amongst your team.

Where can I get more information?

For more information on this study you can contact the chief investigator Kelly Phipps at k.m.phipps@soton.ac.uk

What happens if there is a problem?

Definitions and Abbreviations

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Chief investigator: Kelly Phipps – k.m.phipps@soton.ac.uk

First supervisor: Dr Sarah Kirby – Sarah.Kirby@soton.ac.uk

Second supervisor: Dr Laura Flower – laura.flower1@nhs.net

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at

<http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank you for taking the time to read this information sheet and considering taking part in this research. Please tick (check) this box to indicate that you consent to taking part in this survey.

[Click here to start this survey](#) 

Appendix J Debriefing statement



Title: Factors influencing healthcare professionals' attitudes towards functional neurological disorders

Debriefing Statement

ERGO ID: 48573

IRAS: 262006

Version 1.2 Date:6.9.2019

The aim of this research is to identify whether psychological factors (effective working with complex clients and work-related stress) and professional factors (experience working with FND, training, professional role and specialty area) predict attitudes of healthcare professionals towards patients with FND. Informed by the literature in this area, it is expected that there will be stigmatising attitudes towards patients with FND, associated with staff's perceived personal stress and confidence to work effectively with complex clients.

Your data will help our understanding of the factors influencing attitudes towards patients with FND. Developing a greater understanding of a wider range of healthcare professionals will support services to target staff training in the most needed areas. More focused training will, in turn, benefit patient experience and treatment.

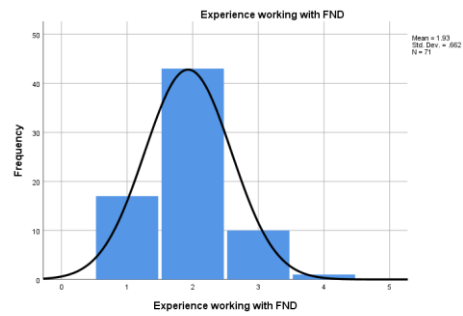
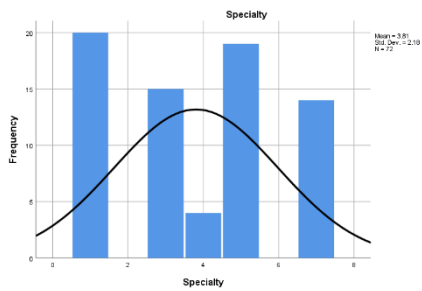
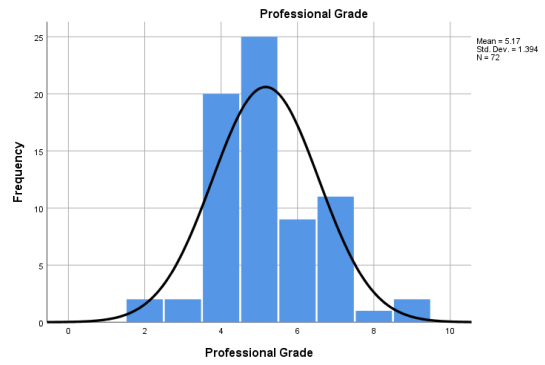
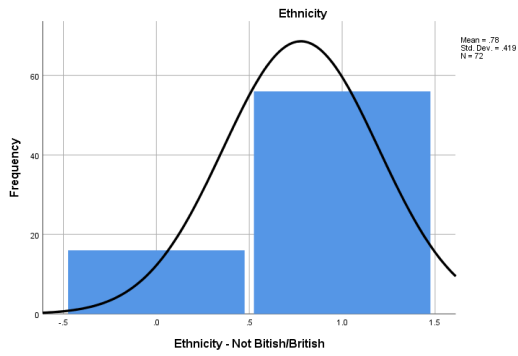
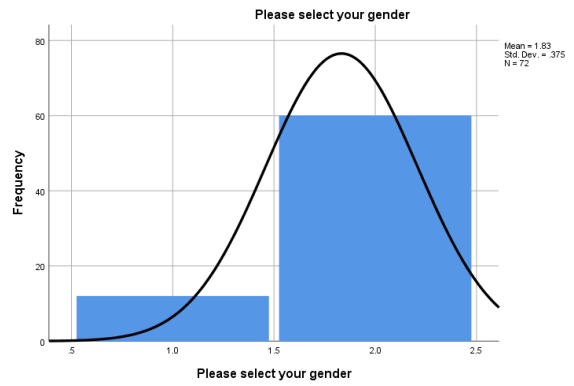
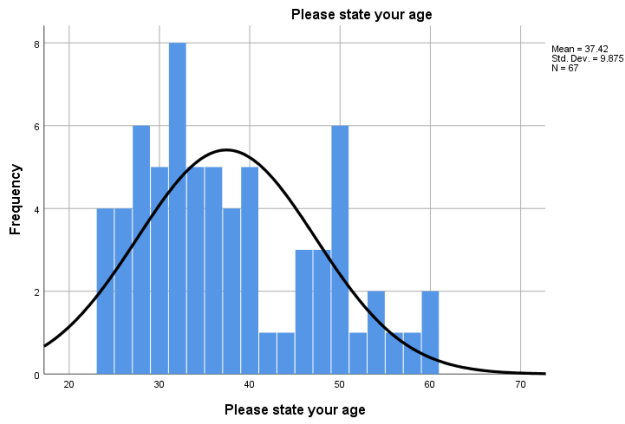
Once again results of this study will not include your name or any other identifying characteristics. The research did not use deception. You may have a copy of this summary if you wish. Once the research is complete a summary of the research findings will be made available to your team for dissemination.

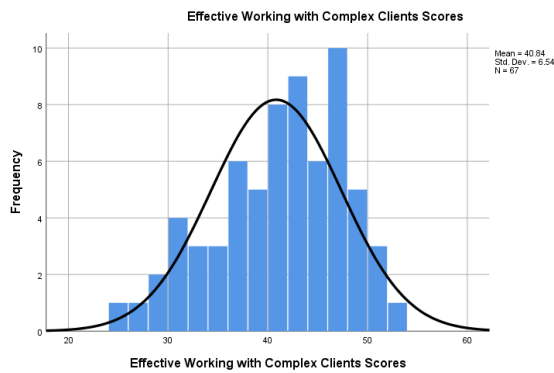
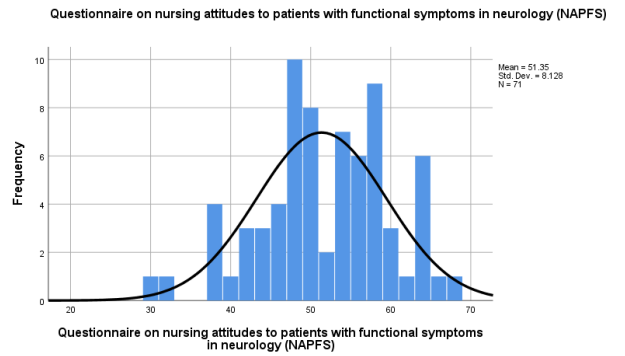
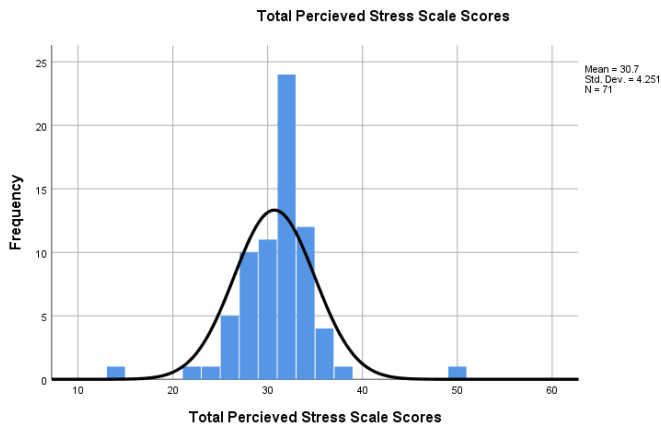
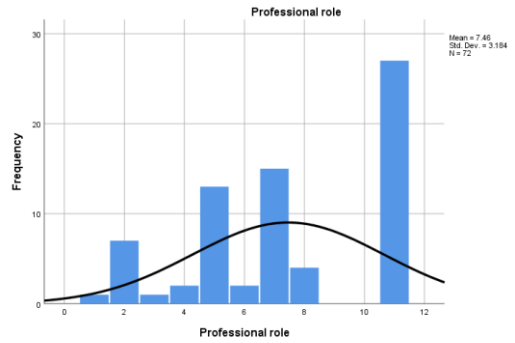
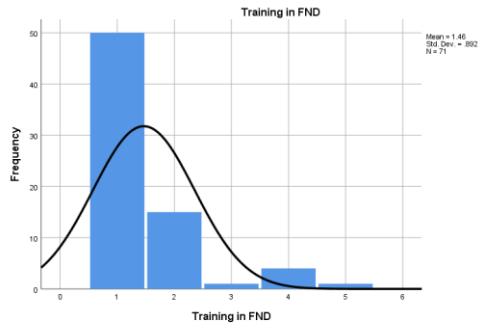
If you have any further questions please contact Kelly Phipps at k.m.phipps@soton.ac.uk (Chief investigator). Alternatively, you can contact Dr Sarah Kirby at Sarah.Kirby@soton.ac.uk (Study Supervisor, Southampton University) or Dr Laura Flower at laura.flower1@nhs.net (Study Supervisor, Department of Psychological Medicine, Southern Health)

Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix K Histograms





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