Research Project Portfolio

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Functional Neurological Disorder: A Qualitative Study Exploring Experiences of Psychological Services

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Portfolio Abstract

Background: Functional Neurological Disorder (FND) is classified as a “disorder of the voluntary motor or sensory system with symptoms including paralysis, tremor, dystonia, sensory disturbance (including visual loss), speech symptoms, and seizures” (Stone et al., 2020, p.1). Individuals with a diagnosis of FND have reported negative and stigmatising interactions with healthcare professionals in medical settings. This is hypothesised to be linked to the etiologic uncertainty and historical context of the condition. Due to current NICE guidelines and service provision, individuals with FND are routinely referred to psychological/mental health services. However, there is no research exploring individuals’ experiences in these settings. The perspectives of those accessing services are essential in understanding and improving the quality of healthcare provision. The aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with FND.

Method: This study utilised a qualitative approach with data collected from semi-structured interviews and analysed using reflexive thematic analysis. Demographic data was collected and used to contextualise the findings from the semi-structured interviews. 15 participants (12 women and 3 men) were recruited via social media platforms.

Results: One superordinate theme, ‘*the stigmatised self within the therapeutic relationship’*, and five interrelated main themes were identified: ‘*internalised stigma and self-doubt', ‘selective disclosure to professionals’, ‘perceptions of psychological explanations’, ‘having to educate the professionals’* and *‘attunement and trust within the therapeutic relationship’.* The way in which participants conceptualised themselves and their condition appeared to be heavily influenced by their experiences of therapeutic relationships. These were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services. The themes also captured how the concept of stigma interacted with perceptions of and the meaning made of interactions with professionals.

Conclusions: Intra-personal, interpersonal, and organisational stigma impact access and engagement to psychological treatment. In the intra-personal domain, experiences of perceived stigma appeared to negatively impact how individuals conceptualised themselves and their condition. Perceptions of stigma in mental health services may be viewed in the context of personal-level barriers (internalised stigma, perceptions of ineffective service) and system-level barriers (lack of FND knowledge and training, service development constraints). The lack of specialist provision for FND results in individuals accessing general mental health services that are not resourced to meet their needs. This may highlight more fundamental issues regarding the false mind-body dualism that underpins service provision. Positive therapeutic relationships were highlighted as mitigating the impact of these perceived barriers. Furthermore, the therapeutic alliance may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention. The findings of this study highlight the need for increased training provision for practitioners with a focus on actively challenging FND stigma within services at both an individual and systemic level.

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For the participants who shared their experiences – thank you for your huge contribution, without you this research would not have been possible.

To my family, thank you for your ongoing love, patience, and support. Thank you to my partner Anand. You have been my rock throughout the last few years, and I could not have done this without your support.

Dedicated in loving memory of my dad, Paul Staton, and my grandad, John Derek Bryan.

Statement of Contribution

Systematic Review

Project design: Amelia Staton, Dr Sarah Wilde, Dr David Dawson

Data analysis: Amelia Staton under the supervision of Dr Sarah Wilde and Dr David Dawson

Write-up: Amelia Staton under the supervision of Dr Sarah Wilde and Dr David Dawson

Journal Paper

Project design: Amelia Staton, Dr David Dawson, Dr Hannah Merdian, Dr Anna Tickle, Dr Tammy Walker, Hannah Harris

Application for ethical approval: Amelia Staton

Participant recruitment: Amelia Staton, Hannah Harris

Data collection: Amelia Staton under the supervision of Dr David Dawson and Dr Hannah Merdian

Data analysis: Amelia Staton under the supervision of Dr David Dawson, Dr Hannah Merdian, Dr Anna Tickle, and Dr Tammy Walker

Write-up: Amelia Staton under the supervision of Dr David Dawson, Dr Hannah Merdian, Dr Anna Tickle and Dr Tammy Walker

Small Scale Research Project

Project design: Amelia Staton, Dr David Dawson, Dr Nima Moghaddam, Barbara McGrath

Data collection: Amelia Staton under supervision of Dr David Dawson, Dr Nima Moghaddam and Barbara McGrath

Data analysis: Amelia Staton under supervision of Dr David Dawson and Dr Nima Moghaddam

Write-up: Amelia Staton under supervision of Dr David Dawson and Dr Nima Moghaddam

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SYSTEMATIC REVIEW

The Effectiveness of Eye Movement Desensitisation and Reprocessing (EMDR) for Medically Unexplained Symptoms: A Systematic Literature Review

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Ethical Information: No ethical approval was required for this systematic literature review. The review was prospectively registered with PROSPERO (18th October 2021) registration number CRD42021268332.

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Abstract

Introduction: It has been hypothesised that certain persistent physical symptoms (PPS) may be linked to unresolved traumatic or distressing somatic-symptom related memories. EMDR intervention targets and reintegrates distressing memories, thus reducing the re-experiencing of physical sensations. The primary aim of this review was to examine effectiveness of EMDR for PPS. Secondary aims were to investigate effectiveness of EMDR on secondary outcomes (post-traumatic stress, anxiety, and depression), and to evaluate the acceptability of EMDR for this client group.

Method: Six electronic databases (PsycInfo, PsycArticles, CINAHL, MEDLINE, Web of Science and SCOPUS) were searched for peer-reviewed literature, with no restrictions on publication dates. Twenty-eight studies met inclusion criteria. Studies were included if the primary aim of EMDR intervention was to reduce intensity, frequency or reported distress associated with PPS. Studies were quality appraised using the MMAT tool prior to narrative synthesis of key findings.

Results: Studies varied in design and included RCT, UCT, case study and case series. EMDR treatment length varied between studies; 1-20 sessions. All studies reported significant improvement in PPS at post-test. Effect sizes were available to report in five studies and ranged from moderate to large. Improvement in secondary outcomes were reported in all repeated measure studies. Where available, large effect sizes were reported for reduction in anxiety and depression. Overall drop-out rates in studies with representative samples was low (10.6%). Quality of research varied; low (42.8%), medium (21.4%), and high (35.7%).

Conclusions: There is promising emerging evidence for effectiveness and acceptability of EMDR for a range of PPS. However, firm conclusions on efficacy cannot be made. Whilst comparisons between PPS presentations cannot be drawn due to methodological differences, the findings for pain and tinnitus are the most compelling due to methodological quality. High-quality sufficiently powered RCTs are recommended to determine efficacy.

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Keywords: EMDR; eye movement desensitisation and reprocessing; persistent physical symptoms; PPS; medically unexplained symptoms; MUS; systematic review.

Introduction

Persistent physical symptoms (PPS), previously referred to as medically unexplained symptoms (MUS) is considered an umbrella term that encompasses “persistent bodily complaints for which adequate examination does not reveal sufficiently explanatory structural or other specified pathology” (Henningsen et al., 2007). PPS encompasses several different presentations affecting different systems of the body (e.g., perception, sensation, movement) (Gupta, 2013; Wessely et al., 1999). There is a current paradigm shift in this area of research following revision in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013). Most notably, medically explained and medically unexplained somatic symptoms are no longer differentiated, instead focus is given to the level of associated distress. Whilst this change occurred with the aim to destigmatise medically unexplained presentations, there is no scientific consensus on whether the mechanisms that underpin biomedical conditions are the same in symptoms in which there is no known medical cause (Rief & Martin, 2014). This has potential implications on research and clinical practice. Biopsychosocial models of MUS/PPS highlight a complex interaction between multiple biological and psychosocial aetiological factors (Brown, 2007). More recent models have proposed multi-factorial mechanisms of symptom perception and propose that clinical intervention should focus on targeting inferential processes (Van den Bergh et al., 2017).

Whilst true prevalence is unknown, a meta-analysis estimated that 45% of primary care appointments may be attributed to medically unexplained presentations (Nimmuan et al., 2001). Comparably, an epidemiological study found that approximately 50% of patient presentations in secondary care settings were deemed medically unexplained (Haller at al., 2015). For presentations indicative of functional neurological disorder, estimations stand between 4 and 12 per 100,000 (Carson et al., 2012). PPS can be disabling for individuals, resulting in unemployment, sickness absences, frequent healthcare appointments and invasive medical investigations (Bermingham et al., 2010; Burton et al., 2012). UK estimates of the annual cost of MUS are around £18 billion (Bermingham et al., 2010).

Treatment outcomes for individuals with PPS are generally poor with insignificant effects for reduction of symptoms (van Dessel et al., 2014) and frequent healthcare use (Jones & Williams, 2019). Lack of guidelines and the limited evidence-base for this client group are considered barriers to improving long-term outcomes (Rommelfanger et al., 2017). In England, there are limited NHS National Institute for Health and Care Excellence (NICE) guidelines regarding evidence-based psychological interventions for PPS (e.g., tinnitus, irritable bowel syndrome, functional neurological disorder, non-epileptic attack), with the exception of chronic pain (NICE, 2021). In addition, clients with PPS report poor experiences of healthcare professionals and clinical intervention (Robson & Lian, 2017; Burke, 2019). Whilst there have been attempts to determine effective psychological interventions for this client group, confirmatory conclusions have not been drawn due to the paucity of research.

Cognitive behavioural therapy (CBT) for PPS focuses on challenging maladaptive cognitions and "unhelpful illness behaviours" such as avoidance (Gutkin et al., 2021), whereas psychodynamic therapy (PDT) aims to resolve intrapsychic conflict and maladaptive defence mechanisms (e.g., emotional avoidance and somatization) (McCullough et al., 2001). Meta-analysis (Kleinstauber et al., 2011) of CBT for PPS found magnitude of treatment effect to be small (d = 0.25). These findings are consistent with more recent meta-analysis that reported small and moderate effect size for CBT (d = 0.49) and PDT (d = 0.69) respectively (Gutkin et al., 2021). In the chronic pain literature, meta-analysis on the effectiveness of Acceptance and Commitment Therapy (ACT) highlighted significant medium to large effect sizes on self-reported pain acceptance but insignificant effect on measures of pain intensity and quality of life (Hughes et al., 2017). However, these findings should be interpreted with caution due to lack of active control groups, small sample sizes, and low-quality data.

Within the wider literature, psychological trauma and stress are considered relevant in terms of PPS in which aitiology and maintenance is not better explained by biomedical factors. In presentations consistent with functional neurological disorder (FND), meta-analysis found that adverse life events were reported eight times more commonly in individuals with FND than non-clinical controls and two times more commonly than other clinical populations (Lehn et al., 2016). Similarly, individuals presenting with functional non-epileptic seizures were found to have significantly higher rates of PTSD than individuals with epilepsy (Marchetti et al., 2008). These findings are consistent with a range of PPS presentations. Trauma and emotional neglect are considered risk factors to developing psychogenic seizures (Marchetti et al., 2011) chronic fatigue (Crawley et al., 2012; Heim et al., 2006; 2009) and chronic pain (Fishbain et al., 2017). In addition, trauma and complex and ongoing life stressors have been hypothesised to trigger and maintain episodes of phantom pain (Fuchs et al., 2018; Otis et al., 2010) general somatic complaints (Afari et al., 2014), tinnitus (Fagelson, 2007; 2016; Gupta, 2013) and dermatologic symptoms (Bilkis, 1998). Whilst causal mechanisms are complex and widely debated, recent meta-analysis findings suggest that chronic exposure to psychological trauma is associated with autonomic nervous system dysfunction, as measured by heart-rate variability (Schneider & Schwerdtfeger, 2020). Compared to “healthy” controls, patients with MUS have been found to show a reduction in heart-rate variability, indicating reduced parasympathetic activity (Ruschil et al., 2021). Eye-movement desensitisation and reprocessing (EMDR) has been found to reduce arousal by engaging the parasympathetic nervous system (Voitova & Hasto, 2009), highlighting its potential usefulness for individuals presenting with PPS.

Eye movement desensitisation and reprocessing (EMDR) is an eight phased protocol that aims to sequentially target and reintegrate distressing memories using bilateral eye movements (Shapiro, 2001). EMDR is underpinned by the Adaptive Information Processing model (AIP) which postulates that “symptoms” may be the result of unprocessed traumatic or somatic-symptom related memories (Shapiro, 2001). When triggered, these memories result in the re-experiencing of associated emotions, cognitions, and physical sensations (Shapiro, 2014). By focusing on the reprocessing of specific memories, somatic and emotional arousal is decreased and thus the re-experiencing of physical sensations is reduced (Shapiro, 2001). In the context of PPS, it is hypothesised that symptoms are a physical re-experience (van der Kolk & Fisler, 1995, as cited in van Rood & de Roos, 2009) that can be maintained through cognitive and emotional re-experience (van Rood & Visser, 2008, as cited in van Rood & de Roos, 2009). For example, the sound of a car may trigger myoclonic limb movements in an individual who had previously survived a car accident (e.g., physical re-experience). Additionally, associated cognitions (e.g., "I'm weak") and physiological arousal (e.g., anxiety) may also re-activate unprocessed memories and trigger physical symptoms (e.g., emotional and cognitive re-experiencing). Van Rood and de Roos (2009) hypothesised that "both the posttraumatic stress that is the result of the triggering of the traumatic memory and the way the patient copes with this stressful situation may maintain the physical complaint and hinder recovery".

The evidence base for EMDR and PTSD is generally well established, with meta-analysis finding EMDR as efficacious as trauma-focused CBT (Bisson et al., 2013; Siedler & Wagner, 2006). However, the evidence base for EMDR and PPS is still emerging. Van Rood and de Roos (2009) conducted a systematic review of EMDR in the treatment of MUS, although conclusions on direction of effect could not be made due to methodological limitations of studies. Furthermore, the review included body dysmorphic disorder and olfactory reference syndrome which are no longer considered somatic presentations. Whilst narrative accounts of the literature in this area have been published (Mathijssen et al., 2020; Tefft & Jordan, 2016; Shapiro, 2014), these were not systematic in nature. Other systematic reviews published in the literature have been broader in context, synthesising findings of all RCTs of EMDR. In one such review, only one RCT of MUS (chronic pain) was included and therefore conclusions on effectiveness could not be established (Gomez et al., 2017). The chronic pain literature has been systematically reviewed in 2014 and 2019 (Tesarz et al., 2014; 2019) and concluded that consistent findings on the efficacy of EMDR was promising, however interpretations of these results should be considered in light of varying intervention protocols and methodological limitations. In 2018, a systematic review of the effectiveness of EMDR for FND was conducted and concluded that emerging evidence was promising but further research was needed. However, this review only included three papers in total (case series/studies) published before 2008 (Cope et al., 2018).

At present, the overall literature regarding effectiveness of EMDR for PPS has not been systematically reviewed and quality appraised since 2009. The purpose of this review was to provide on update on Van Rood and de Roos systematic review and examine all available studies using EMDR in the treatment of PPS, regardless of study design or publication date. The primary aim of this review was to examine the effectiveness of EMDR for reducing frequency, intensity and associated distress of PPS in adult populations. Secondary aims were to investigate effectiveness of EMDR on secondary outcomes (post-traumatic stress, anxiety, and depression), and to evaluate the acceptability of EMDR for this client group.

Methods

Registration

This systematic literature review has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) CRD42021268332.

Search Strategy

The search strategy was completed in adherence to PRISMA guidelines (Page et al, 2021). Six electronic databases (PsycINFO, PsycArticles, CINAHL, MEDLINE, Web of Science and SCOPUS) were searched for peer-reviewed literature, with no restrictions on publication dates. The last search was conducted on 27/02/2022.

Database	Coverage
PsycINFO	1806 to present
PsycArticles	1935 to present
CINAHL	1982 to present
MEDLINE	1946 to present
Web of Science	1900 to present
SCOPUS	1788 to present

The search terms included: (“eye movement desensitisation and reprocessing” OR “eye movement desensitization and reprocessing” OR “eye movement desensiti?ation therap*” OR EMDR) AND (“medically unexplained” OR “medically unexplained symptoms” OR “persistent physical symptom” OR somatic OR “somatic symptom” OR “conversion disorder” OR somatoform OR “functional neurological disorder” OR functional neurological symptom OR “phantom pain” OR “pain” OR “non-epileptic attack” OR “non-epileptic seizure” OR “idiopathic drop attack” OR “chronic fatigue” OR “tinnitus” OR psychogenic OR psychosomatic).

Terms were applied to titles, abstracts, and keywords. Search syntax were adapted, and controlled vocabulary indices were used for each database, where possible.

Ancestry searches were completed on relevant meta-analyses (Kleinstäuber et al., 2011), systematic reviews (Cope et al., 2018; Tesarz et al., 2014; Tesarz et al., 2019; Valiente-Gómez et al., 2017; van Rood & de Roos, 2009), and literature reviews (Mathijssen et al., 2020; Shapiro, 2014; Tefft & Jordan, 2016). The reference lists of studies identified for inclusion in this review were also searched. Conference abstract searches were completed in SCOPUS, and authors were contacted requesting full texts.

Study Selection

The referencing software EndNote was used to manage citations. After duplicates were removed, all studies were reviewed using the inclusion criteria (see Appendix A). Two of the three authors worked independently in the screening of each record with any disagreements resolved by referral to third author.

Inclusion Criterion	**Rationale**
All empirical studies	Due to limited studies published in this area, inclusion of all studies widens the scope of the review
Primary aim of EMDR intervention to reduce intensity, frequency, or reported distress associated with “medically unexplained symptom”	Primary focus of review
Adult participant sample characterised by persistent physical symptoms in which onset or maintenance is not better explained by biological factors.	Primary focus of review and theoretically consistent with adaptive information processing (AIP) model that underpins hypothesised mechanisms of EMDR

Peer-reviewed	To provide a measure of quality control
All studies available in English language	Translation resources not available

The inclusion of studies solely adhering to full EMDR protocol (Shapiro, 2001) without adaptations (e.g., integrated therapies), was initially considered to answer the review question. However, much of the research in this area are case studies from clinical settings where adaptations or pharmacological intervention may be used in conjunction. Due to limited studies published in this area, it was deemed important to broaden the scope of the review. PPS in which onset or maintenance is not better explained by biological factors were included (e.g., psychogenic seizures, myoclonic movements, chronic fatigue). Studies in which it was hypothesised that distressing memories underpinned the onset or maintenance of symptoms were also included (e.g., tinnitus, migraine, dermatologic complaints).

Articles examining the effects of EMDR on physical symptoms in which onset or maintenance of symptoms was predominantly explained by biomedical factors; post-surgery pain (Maroufi et al., 2016), arthritis (Höfel et al., 2018, Nia et al., 2018), cancer related pain (Gielkens et al., 2018) were excluded. Research including child participants were also excluded (Dautovic et al., 2016; Demirci and Sagaltici, 2021; Gauvry et al., 2013). Grey literature (not peer-reviewed) was excluded to provide a measure of quality control (Estergard, 2009; Kavakci et al., 2012). Studies that used EMDR related protocols (e.g., EMD or BLS) or experimentally induced symptoms were excluded (Friedberg, 2004).

In cases in which studies were considered appropriate based on abstract but full texts were not available in English, enquiries were made to authors regarding translated versions. One response was received, resulting in inclusion of an additional study (Rostaminejad et al., 2017). Due to lack of translator resources, five papers were unable to be considered in this review (Brennstuhl et al., 2016; Flik & De Roos, 2010; Gündoğmuş et al., 2020; Kavakci et al., 2014; Sinici, 2016). Twenty-eight studies met the outlined eligibility criteria.

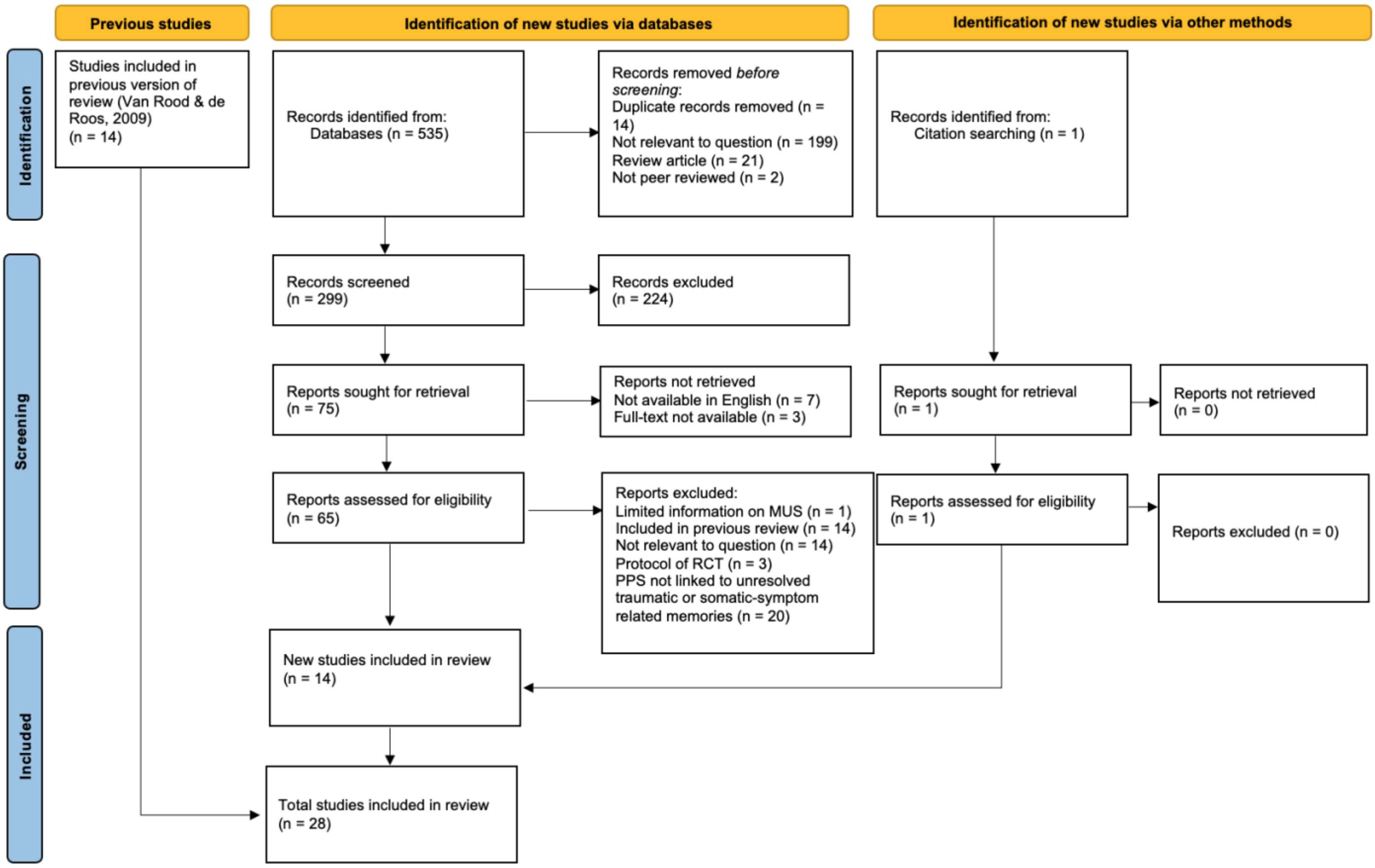

Figure 1. PRISMA flowchart of study selection process

Data Abstraction

To reduce bias in reporting, data extraction was completed prior to quality appraisal. The data extracted included characteristics of studies (author(s), date, location, study design, sample, medically unexplained symptom, comorbidities, intervention length, outcome measures, follow up), and a summary of key findings. All measures of PPS symptoms (frequency, intensity, distress) and secondary outcomes (post-traumatic stress, anxiety and depression) were included if a minimum of pre and post-test scores were reported. There were no other restrictions on number of data points collected, however length of follow up was considered when interpreting findings. Clinically significant change (CSC) and reliable change index (RCI) analysis was completed for studies that did not include analysis of data (e.g., case reports/series). Effect sizes were calculated where possible. One reviewer collected data from each study and this was checked by the remaining two reviewers. Any discrepancies were resolved by consensus.

Quality Appraisal

Quality appraisal was completed using The Mixed Methods Appraisal Tool (Hong et al., 2018). The MMAT tool was developed for systematic reviews that include studies with heterogeneous designs. Mixed reviews are often required when aiming to evaluate interventions relevant to clinical practice in which the evidence-base is still emerging (Pluye & Hong, 2014). Whilst the updated version of this tool includes two screening questions (regarding coherence of research question and data collection), these were not used as part of appraisal due to the large number of retrospective case studies included in the review. The MMAT requires researchers to select the appropriate methodological category for each study, apply the five separate criteria, and assign a rating (“Yes”, “No”, “Can’t tell”). Conversion of ratings into metrics and presenting an overall score of each study without rationale is discouraged, as this is unlikely to provide sufficient information (Hong et al, 2018). Whilst there are no cut off values outlined in the MMAT, each study was rated “low”, “moderate”, and “high” quality based on the number of criteria met. Exclusion of “low” quality studies may limit the breadth of review (Verhage & Boels, 2017) thus no studies were excluded due to methodological quality. However, quality of study was taken into account when synthesising data. All three authors rated quality of studies independently. Interrater reliability was 94.3%, with any discrepancies discussed and agreed upon.

Data Synthesis

Due to the paucity of research in this area, the search strategy was not restricted to Randomised Controlled Trials (RCTs) and therefore meta-analysis was not appropriate. The studies included were heterogeneous in design and thus findings were organised and summarised through narrative synthesis. This allowed for the exploration of similarities and differences between studies, and identification of relationships within the data relevant to the focus of the review. Narrative synthesis was conducted in line with established framework and guidance (Popay et al, 2006).

Where available, standardised mean differences were used to determine effectiveness. Magnitude of treatment effect was reported using different effect size measurements across studies. Interpretations were made in line with relevant benchmarks described in the literature (Cohen, 1988). Clinically significant change (CSC) and reliable change index (RCI) analysis was completed for studies that did not include analysis of data (e.g., case reports/series) (Jacobson & Truax, 1992). RCI analysis was calculated by dividing the standard error with the difference between pre-post treatment scores (Jacobson & Truax, 1992). CSC was defined by meeting one of three criteria; 1) a pre-and-post change of >2 standard deviations from baseline mean, 2) post-test scores within 2 standard deviations of reported normative sample mean, 3) post-test scores fall within sub-clinical or non-clinical ranges (as defined by benchmarks reported in psychometric manual) (Jacobson & Truax, 1992). These calculations can only be used for outcome measures for which normative values are available and therefore cannot be applied to frequency or intensity of physical symptoms.

Client self-report and relevant health information was used to contextualise the findings. Drop-out rates and follow up data were used to measure acceptability and long-term effectiveness of intervention.

Results

Characteristics of Studies

As displayed in Appendix B, each study was allocated a number for reference purposes. The twenty-eight peer-reviewed studies were published between 2000-2020. Thirteen studies were conducted in Europe, seven in North America, one in South America, three in Australia, and four in Asia. Studies were published in the English language, with the exception of one in which a translated version was provided following a request to the first author. Regarding methodology, case reports/studies were the most common design, followed by case series. Of the sixteen case reports/series, ten used pre-post measures and six provided a qualitative account of a clinical case. The remaining studies were seven randomised controlled studies, four uncontrolled clinical trials and a within-groups design.

The gender of participants was reported in all studies except one; however, gender ratio of participants in said study was later clarified by the author for the purpose of a review (van Rood & de Roos, 2009). Of the total sample who received EMDR, 253 were female (70.2%) and 107 were male (29.8%). The same participant was reported in both Grant (2000) and Grant and Threlfo (2002) paper. Ethnicity and nationality of participants was explicitly reported in only five studies: Caucasian (n = 51), Asian (n = 12), Hispanic (n = 9) and African American (n = 1). Subsequently, 80% of the review sample's ethnicity is unknown.

All participants experienced a range of persistent physical symptoms. Presentation indicative of Functional Neurological Disorder and Pain (chronic, migraine, complex regional) was the most common amongst participants, followed by Phantom Pain, Tinnitus, Chronic Fatigue and Dermatologic Disorders. Unresolved traumatic or somatic-symptom related memories were linked to onset or maintenance of PPS. In six studies, participants met diagnostic criteria for PTSD. In the remaining studies, it was unclear whether participants had or would meet criteria for formal diagnosis of PTSD. A range of comorbidities were reported amongst participants: complex trauma, borderline personality disorder, dissociation, health anxiety, substance use, obsessive compulsive disorder, depression, psychosis, anxiety, fatigue, insomnia and traumatic brain injury.

All twenty-eight studies used EMDR (Shapiro, 2001) to target PPS. Six studies used pain protocols, one study used elements of the pain protocol and another developed a headache protocol for the purposes of their study. Treatment length varied across studies, ranging from 1-20 sessions. In three of the randomised controlled trials, EMDR was delivered as the sole intervention and compared to treatment-as-usual (TAU) control group (Demirci et al., 2017; Gerhardt et al. 2016; Rostaminejad et al., 2017). Three randomised controlled trials delivered an integrated EMDR; tinnitus retraining therapy plus EMDR (Luyten et al., 2020), cranial pressure plus EMDR (Marcus, 2008) and hypnosis plus EMDR (Ray & Page, 2002). In several other studies, EMDR was delivered in conjunction with other interventions; pharmacological (Chemali & Meadows, 2004); de Roos et al., 2010; Konuk et al., 2011; Mazzolla et al., 2009, Marcus, 2008; Schneider et al., 2008), counselling sessions (Kelley & Benbadis. 2007), solution-focused and cognitive-behavioural therapies (Proudlock, 2015).

PPS were measured via self-report of frequency, severity, and associated distress (e.g., number of episodes, pain rating scales). Secondary outcome measures were most frequently measured by standardised psychometrics; Impact of Events Scale (IES), Beck's Anxiety/Depression Inventory (BAI; BDI). See Appendix B for all included outcome measures.

Pre-test and post-test measurements were included in twenty-one of the twenty-eight studies. Follow up was completed for all studies except four (Andrea et al, 2021; Demirci et al., 2017; Grant, 2000); Mazzolla et al., 2009). Follow up periods ranged from 1 day to 40 months. Of the total 523 participants, 360 received EMDR and 163 received treatment as usual (TAU) control group.

Quality Appraisal

An overview of the quality appraisal process is outlined in Appendix A. In line with MMAT scoring guidance (Pluye et al, 2011), quality ratings were assigned to each study based on the number of criteria met within their study category. A study was deemed "high" quality if four or more criteria were clearly met; "medium" quality if three criteria were clearly met, and "low" quality for two or less (Pluye et al, 2011). The methodological quality of studies impacts the risk of bias and subsequently the reliability of the conclusions drawn from the data. Following quality appraisal, eleven studies were found to be high quality (Andrea et al., 2021; Brennstuhl et al., 2015; de Roos et al., 2010; Gerhardt et al., 2016; Luyten et al., 2020; Phillips et al., 2019; Rikkert et al., 2018; Rostaminejad et al., 2017; Mazzolla et al., 2002; Suárez et al., 2020); six studies moderate quality (Demirci et al., 2017; Konuk et al., 2011, Marcus et al., 2008; Schneider et al., 2008; Silver, Rogers, & Russell, 2008; Wilensky, 2008), and eleven studies low quality (Altunbaş, 2018; Chemali & Meadows, 2004; Cope, 2020; Gupta & Gupta, 2002; Grant, 2000; Grant & Threlfo, 2002; Ray & Page, 2002; Kelley & Benbadis, 2007; Proudlock, 2015; Royle, 2008; Russell, 2008).

Four of the six included RCTs were judged to be high quality (Gerhardt et al., 2016; Luyten et al., 2020; Rostaminejad et al., 2017; Suárez et al., 2020). Strengths of these studies included comparable group baselines at pre-test, detailed description of randomisation strategy and researcher blinding. Whilst effect sizes were reported in six RCTs, they were not reported in one (Rostaminejad et al., 2017) and were therefore calculated for purpose of this review. None of the RCTs were sufficiently powered to provide confirmatory evidence of efficacy, this was appropriately acknowledged and reflected in interpretation of findings. The other three RCTs were found to be moderate (Demirci et al., 2017) and low quality (Marcus, 2008) due to it being unclear whether randomisation was appropriately performed, lack of assessor blinding, and non-representative samples. In the moderate quality RCT (Marcus et al., 2008) it was unclear whether appropriate randomisation had been performed and outcome assessors were not blinded to the intervention. In all RCTs, intervention adherence was judged to be high.

The remaining high quality studies, were uncontrolled clinical trials (Andrea et al., 2021; de Roos et al., 2010; Phillips et al., 2019; Mazzolla et al., 2002; Rikkert et al., 2018) and case study (Brennstuhl et al., 2015). Whilst the uncontrolled studies included a sample representative of the target population, appropriate measures, and complete outcome data, it was unclear whether confounders were controlled for in the analysis. The high quality case study included a representative sample and appropriate measures, however it was unclear whether appropriate statistical analysis was used. The moderate quality case reports and case series lacked control groups making it difficult to determine whether reported outcomes were related to impact of EMDR or other confounding variables. It was unclear whether appropriate methods to account for confounders were implemented. Similarly, in studies that used EMDR in conjunction with another intervention, it was difficult to isolate benefits of the independent variable.

A large percentage of included studies (42.8%) were judged to be low in quality. The qualitative case studies (Kelley & Benbadis, 2007; Grant, 2000; Gupta & Gupta 2002; Proudlock, 2015, Royle, 2008) provided a narrative account of a clinical case, and it was unclear whether findings were adequately substantiated by data. In multiple studies vague statements such as “improvement in symptoms” or “fewer symptoms” were not adequately derived from reported data, and it was unclear whether this was clinical judgement or client self-report. In two studies (Chemali & Meadows, 2004; Proudlock, 2015), psychometrics (IES, BDI, BAI) were completed at pre-test but were not repeated at post-test, resulting in incomplete outcome data. Further limitations were highlighted in the analysis and interpretation of findings. In several case studies/series, statistical analysis of data was not reported and was therefore completed for purpose of this review. In the non-randomised quantitative study (Ray & Page, 2002), it was unclear whether a representative sample had been sought or whether confounders had been accounted for in the design and analysis.

Due to heterogeneity of presentation, representation within this population is difficult. In several studies the sampling strategy was unclear and there were no indicators that a representative sample that been sought (e.g., characteristics of population, inclusion/exclusion criteria). These studies appeared to be retrospective accounts of clinical cases, and likely utilised convenience sampling.

Overall, studies used standardised outcome measures for secondary outcomes (IES, BDI, BAI). In the chronic pain and phantom pain studies, standardised pain measures were commonly used (NRS; MPI-D) alongside general health measures (SF-36). However, due to lack of standardised outcome measures for other medically unexplained presentations, remaining quantitative studies measured change via frequency, intensity, or associated distress. In one study (Silver, Rogers, & Russell, 2008), this numerical data was contextualised with client and family self-report, clinical judgement, and medical records.

Across all studies, except one (Marcus, 2008), it was unclear whether attempts were made to assess fidelity of intervention. In addition, no assessments of proposed mechanisms of action were included.

Effectiveness of EMDR for Persistent Physical Symptoms

The key findings from each study are summarised in Appendix B. Due to heterogeneity of study design, this preliminary synthesis aimed to synthesise findings regarding the direction of effects. Where possible, results were summarised using magnitude of treatment effect sizes. Effect sizes were calculated for the purpose of this review in studies that reported the relevant raw data (standardised mean difference and standard deviation). All twenty-eight studies reported an improvement in primary and secondary outcomes following EMDR intervention. However, definitive conclusions on effectiveness cannot be made due to methodological differences and quality of data.

The six included RCTs reported significant reduction in PPS at post-test compared to control group (TAU). Demirci et al. (2017) reported a significant improvement in somatic symptoms and pain following EMDR ($n^2 = 0.94$; $n^2 = 0.89$) versus Duloxetine control group ($n^2 = 0.68$; $n^2 = 0.48$). However, caution should be made when interpreting eta-squared effect sizes as this is considered a biased measure of population variance that increases likelihood of overestimations. Gerhardt et al. (2016) found that 45% of participants who received EMDR experienced significant reduction in pain intensity at post-test versus 0% in TAU control group ($d = 0.79$). In addition, 50% of participants who received EMDR rated their condition as “much improved” or “very much improved” compared to 0% in control group ($d = 1.69$). Similarly, large effect sizes were reported in Rostaminejad et al. (2017) with statistically significant reduction in pain intensity and associated distress at post-test ($d = 3.23$), superior to TAU ($d = 0.8$). These findings were consistent with other included pain RCTs with significant reduction in pain intensity at post-test compared to TAU (Suárez et al., 2020) and significantly greater improvement in rapidity of pain reduction compared to TAU (Marcus, 2008). Five of the six RCTs reported follow up data with EMDR being superior to TAU with moderate to large effect; Marcus (2008) ($f = 0.247$) Gerhardt et al. (2016) ($d = 0.50$), Rostaminejad et al. (2017) ($d = 3.9$). These results were maintained at follow up. Whilst RCTs reported moderate to large effect sizes, study samples were small and spontaneous remission was not controlled for as waiting list control groups were not included. None of the RCTs were sufficiently powered to provide confirmatory evidence of efficacy, this was appropriately acknowledged and reflected in interpretation of findings.

Findings from the uncontrolled clinical trials, were consistent with those reported in the RCTs. De Roos et al., 2010 outlined that 80% of patients reported clinically significant reduction in pain at post-test with medium effect sizes indicated ($n^2 = 0.63$). In addition, 40% of participants reported themselves to be “pain free” following EMDR and discontinued their pain medication. Similarly, statistically significant reductions were reported in pain levels and subsequent reduction of medication (Mazzolla et al., 2002). These findings were consistent with the tinnitus uncontrolled clinical trials, with statistically significant reduction in symptoms in the “majority” of participants (Andrea et al., 2021; Phillips et al., 2019) with moderate effect sizes observed ($d = .72$) (Rikkert et al., 2018). These results were maintained at follow up.

Effect sizes were not reported in the case series/studies, and relevant data needed for these calculations were not included for primary outcomes. In the case studies/series, all participants experienced marked improvement in their persistent physical symptoms (e.g., reduction in frequency, severity, or distress). Altunbas (2018) reported improvement in vision clarity compared to pre-treatment. However, it was unclear whether this finding was substantiated in the data, as there was no quantitative measure repeated over time to assess impact of EMDR. Improvement in primary outcomes were also observed in the remaining case reports; complete elimination of seizures, reduction in pain (chronic, complex, phantom), improvement in dermatologic symptoms, decrease in fatigue, reduction in somatic symptoms, and complete elimination of myoclonic movements. In several studies (Chemali & Meadows, 2004; Gupta & Gupta, 2002; Grant, 2000; Kelley & Benbadis, 2007; Proudlock, 2015; Royle, 2008) it was unclear whether findings were derived from client self-report or clinical judgement. These improvements were reported to be maintained at follow up, except for Grant (2000) which did not report follow up data and Proudlock (2015) which reported additional EMDR sessions delivered at 6-month follow up. However, due to lack of extended baseline or data collected over multiple time points, it is difficult to conclude at what point these changes occurred. The absence of a control group makes it difficult to assess whether these changes occurred directly as a result of EMDR intervention. These findings should be interpreted with caution due to the limitations in methodology and quality of data.

Comparisons between PPS cannot be drawn due to paucity of studies and differences in methodological quality.

Effectiveness of EMDR for secondary outcomes

Improvement in secondary outcomes were reported in all repeated measure studies. With regard to studies that measured post-traumatic stress symptoms, clinically significant and reliable change was observed in IES scores in several studies with clients scoring within sub-clinical (Cope et al., 2020; de Roos et al., 2010; Schneider et al., 2008), or non-clinical ranges at post-test (Russell, 2008; Silver, Rogers, & Russell, 2008; Wilensky, 2008).

Three studies used the BAI to measure anxiety symptoms, two of which reported clinically significant and reliable change at post-test (Altunbas, 2018;

Demirci et al., 2017). Effect sizes were calculated for Demirci et al. (2017) (d = 4.1) which indicated larger magnitude of effect in comparison to the Duloxetine control group (d = 0.7).

Seven studies used the BDI to measure depressive symptoms and reported clinically significant and reliable change (Altunbas, 2018; Demirci et al., 2017; Phillips et al, 2019; Russell, 2008; Silver, Rogers, & Russell, 2008; Wilensky, 2008), and sub-clinical scores at post-test (Schneider et al., 2008). Where effect sizes were reported (Demirci et al., 2017) magnitude of treatment calculations indicated a larger effect size (d = 2.6) in comparison to the Duloxetine control group (d = 0.6)

Acceptability of EMDR for Medically Unexplained Symptoms

Drop-out rates can be useful in determining acceptability of intervention. Due to the convenience sampling utilised in several studies included in the review (e.g., case studies/series), results on drop-out rates are limited to studies with a representative sample. Of the 262 participants in studies with representative samples, 28 dropped out during intervention (10.6%). Reasons for drop-out during intervention were cited as physical and mental health difficulties, no change in symptoms, travel, work commitments, and reduction of pain to acceptable level for client as reasoning. In several studies no explanations were given by participants who dropped out during intervention. Rikkert et al. (2018) reported that one participant experienced painful childhood memories which they did not wish to explore and therefore chose to withdraw from the study. In the RCTs that included data on drop-out, rates in the EMDR arm were less than or equal to control groups. Kelley & Benbadis (2007) outlined that 50% of clients declined EMDR following consultation, with limited information on reasoning provided. However, it was unclear whether participants declined to participate in research or EMDR specifically. In the remaining studies, data regarding clients who declined to engage in EMDR was not reported.

In all studies, but two (Kelley & Bendadis, 2007; Konuk et al., 2011) no iatrogenic effect associated with intervention were reported. One client experienced a dissociative episode during EMDR protocol (Kelley & Benbadis, 2007) and was later diagnosed with a pre-existing dissociative disorder. The authors acknowledged that had this information been known prior, extensive stabilisation and preparation work would have been included in the treatment plan. In addition, Konuk et al. (2011) reported that whilst frequency and duration of migraines had significantly decreased at post-test, these had been observed to increase during the intervention phase.

No other studies collected data on client experience of intervention and therefore firm conclusions on acceptability of EMDR for this client group cannot be drawn.

Discussion

The aims of this review were to 1) examine the effectiveness of EMDR for persistent physical symptoms, 2) examine effectiveness of EMDR for secondary outcomes (post-traumatic stress, anxiety, and depression) and, 3) evaluate the acceptability of EMDR for this client group. All twenty-eight included studies reported reduction in severity or frequency of medically unexplained symptoms and improvement in secondary outcomes. Treatment outcomes were maintained in all studies, except one (Proudlock, 2015) which required delivery of additional EMDR sessions due to rebound of pain. Where reported, effect sizes for PPS were moderate to very large, with EMDR outperforming TAU control groups. None of the studies were sufficiently powered to provide confirmatory evidence of efficacy and therefore firm conclusions cannot be made. TAU controls were primarily psychopharmacological and thus future RCTs should aim to compare EMDR with other trauma-focused therapies (e.g., NET, TF-CBT) whilst including a waiting list comparator to control for spontaneous remission.

In studies measuring secondary outcomes, clinically significant and reliable change was reported for post-traumatic stress symptoms (IES), depression (BDI), and anxiety (BAI). Whilst effect sizes for post-traumatic stress were not reported, the direction of effect is consistent with meta-analysis findings in the literature (Chen et al., 2014; Wilson et al., 2018). Magnitude of treatment effect for anxiety and depression were large, and superior to TAU control groups. These positive findings are consistent with RCTs examining the effectiveness of EMDR for anxiety (Triscari et al., 2015; Meentken et al., 2020) and depression (Hase et al., 2015; Meentken et al., 2020).

Overall drop-out rates were low (10.6%) in studies with representative samples suggesting that EMDR is generally tolerated by this client group. Iatrogenic effects were reported two studies. In one study, this appeared to be due to a pre-existing dissociative disorder (Kelley & Bendadis, 2007). In another study, frequency of migraines was observed to increase during intervention and decrease in frequency and duration at post-test (Konuk et al., 2011). Despite this, there is evidence to suggest EMDR is a potentially acceptable and clinically safe intervention for MUS. However, attrition rates alone are not adequate in examining acceptability and future qualitative research is needed to explore this. For case study research, the inclusion of change interviews (Elliott et al, 2001) following intervention is recommended to assess acceptability and feasibility.

When considering strengths of the reviewed evidence, EMDR was evaluated with diverse samples in terms of age, medically unexplained presentation, psychological comorbidity, and cultural background. This suggests tentative evidence for its use with a variety of populations. However, the limitations of the included studies must be considered. Whilst demographic data was generally well reported, the details of intervention format and delivery was significantly lacking in several studies. Number of EMDR sessions varied considerably between 1-20 sessions. In addition to these inconsistencies, the selection process of participants was unclear in several studies. This was most notably the studies that utilised a case study/series design, in which inclusion and exclusion criteria were not reported and it was likely that these were retrospective accounts of a clinical case. The possibility of publication bias must be considered, as case studies are significantly more likely to be published in cases with positive outcomes (Nissen et al., 2014). Findings from these studies cannot be generalised, however they provide insight and direction for further research. To increase quality of evidence of case studies/series, multiple baseline designs are recommended to assess whether changes occur due to intervention.

The results of the studies must be considered in the context of the quality of evidence and methodology. Ten studies included in this review were high quality, three of which were RCTs examining the effectiveness of EMDR for pain and one RCT examining effectiveness for chronic subjective tinnitus. The remaining six high-quality studies were also examining effectiveness of EMDR for pain or tinnitus. Whilst comparisons between persistent physical symptoms cannot be drawn due to paucity of studies and differences in methodological quality, the evidence for pain and tinnitus is most compelling. Despite these promising findings, further research with sufficiently powered samples is needed. For other types of persistent physical symptoms (e.g., functional neurological disorder, chronic fatigue), quality of evidence was generally low (42.8%) and it was unclear whether some case study findings were substantiated in the data. High quality RCTs examining efficacy are recommended. The lack of validated measures for PPS is also highlighted in this review. Reliability and validity of current measures of PPS have not been established, although outcome measures specific to FND presentations are in development (Pick et al., 2020).

A strength of this review process was that scoping searches were not restricted to one study design, and all quantitative and qualitative studies were considered. This was deemed necessary due to the paucity of research in this area and allowed for a broad examination of the evidence. Quality appraisal was conducted prior to synthesis to reduce bias in data extraction, and no studies were excluded on this basis. However, quality of data was taken into account when reporting findings. Despite this, there are several limitations of this review. Firstly, due to the restricted scope of this review, PPS in which causal and maintaining mechanisms are considered to be largely biological were excluded. However, the authors acknowledge that there is an ongoing paradigm shift in this area of research with current debate on the differentiation between medically explained and unexplained symptoms. As a result of this, the breadth of this review is limited to symptoms in which aitiology or maintenance is considered “medically unexplained” and is not better explained by biological factors. In addition, this review was restricted to studies written in the English language with adult samples only and therefore other relevant studies may have been excluded. Although six databases were searched, the authors acknowledge that other relevant databases were not accessed and therefore other relevant studies may have been missed. The limitations of the review methodology must also be highlighted. Due to the heterogeneity of the studies in this area, meta-analysis was not appropriate and thus data was organised using narrative synthesis. Whilst this method allows for identification of relationships within the data, it does not provide a precise estimate of treatment effect.

In conclusion, there is promising emerging evidence for the effectiveness and acceptability of EMDR for a range of PPS. However, findings for pain and tinnitus are the most compelling due to methodological quality. Firm conclusions on efficacy cannot be made and further high-quality empirical research is warranted.

Appendices

Appendix A

Critical appraisal of the included studies based on the MMAT tool.

Study	Qualitative MMAT Item				
	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Kelley & Benbadis, (2007)	Unclear	No	Unclear	Unclear	No
Gupta & Gupta, (2002)	Unclear	No	Unclear	Unclear	No
Grant, (2000)	Unclear	No	Unclear	Unclear	No
Hughes, (2014)	Unclear	No	Unclear	Unclear	No
Proudlock, (2015)	Unclear	No	Unclear	Unclear	No
Royle, (2008)	Unclear	No	Unclear	Unclear	No

Study	Quantitative Randomised Controlled MMAT Item				
	2.1. Is randomization appropriately performed?	2.2. Are the groups comparable at baseline?	2.3. Are there complete outcome data?	2.4. Are outcome assessors blinded to the intervention provided?	2.5 Did the participants adhere to the assigned intervention?
Demirci et al. (2017)	Unclear	Yes	Unclear	Unclear	Yes
Gerhardt et al. (2016)	Yes	Yes	Yes	Yes	Yes
Luyten et al. (2020)	Yes	Yes	Yes	Yes	Yes
Marcus, (2008)	Unclear	Yes	Yes	No	Yes
Rostaminejad et al. (2017)	Yes	Yes	Yes	Unclear	Yes
Suárez et al. (2020)	Yes	Yes	Yes	Unclear	Yes

Study	Quantitative Non-Randomised MMAT Item				
	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
de Roos et al. (2010)	Yes	Yes	Yes	Unclear	Yes
Konuk et al. (2011)	No	Yes	Yes	No	Yes
Phillips et al. (2019)	Yes	Yes	Yes	Unclear	Yes
Mazzolla et al. (2002)	Yes	Yes	Yes	Unclear	Yes
Ray & Page, (2002)	Unclear	Unclear	Yes	Unclear	Yes
Rikkert et al. (2018)	Yes	Yes	Yes	Unclear	Yes

Study	Quantitative Descriptive MMAT Item				
	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 data complete?	4.5. Is the statistical analysis appropriate to answer the research question?
Altunbaş, (2018)	Unclear	Unclear	Yes	Unclear	Unclear
Brennstuhl et al. (2015)	Yes	Yes	Yes	Yes	Unclear
Chemali & Meadows, (2004)	Unclear	Unclear	Yes	No	Unclear
Cope, (2020)	Unclear	Unclear	Yes	Yes	Unclear
Grant & Threlfo, (2002)	No	No	Yes	Unclear	Yes
Russell, (2008)	Unclear	Yes	Yes	Yes	No
Schneider et al. (2008)	Unclear	Unclear	Yes	Yes	Yes
Silver, Rogers, & Russell, (2008)	Unclear	Unclear	Yes	Yes	No
Wilensky, (2008)	Yes	Unclear	Yes	No	Unclear

Appendix B

Characteristics and key findings of studies

N	Author (Year), Country	Design	Sample	Medically Unexplained Symptom	Comorbidities	Treatment (Protocol, number of sessions)	Outcome measures (primary and secondary)	Follow up	Key Findings	MMAT Quality Rating
1	Altunbas., (2018), Turkey	Case report Peer-reviewed	N = 1 Age: 35 Gender: Female White Turkish	Daytime blindness (hemeralopia)	PTSD	EMDR, 9 sessions	BAI; BDI; CAPS, IES-R	3-month	• Client reported improvement in vision clarity compared to pre-treatment. • Clinically significant and reliable change measured in IES-R, BAI, BDI at post-test. • Maintained at 3-month follow up.	Low
2	Andrea et al. (2021), France	Uncontrolled Clinical Trial	N = 38 Age: not reported Gender: Female (n = 17), Male (n = 21)	Tinnitus	Not reported	5 sessions	THI, VAS	No follow up	• Statistically significant reduction in tinnitus symptoms in 78.9% patients. • Significant improvement in reported quality of life and daily functioning. • 86.8% participant completed EMDR.	High
3	Brennstuhl et al. (2015), France	Case study	N = 2 Age range: 48-56 Gender: Female	Phantom Breast Syndrome	Chronic pain	9-12 sessions (standard and pain protocol)	STAI, CES-D, Pain and Sensation Intensity	3-6 months	• Significant decrease in phantom breast sensation and pain at post-test and maintained at follow-up.	High

									• Significant decrease in depression and anxiety scores at post-test and maintained at follow up.	
4	Chemali & Meadows, (2004) North America	Case report Peer-reviewed	N = 1 Age: 48 Gender: Female Not specified	Psychogenic seizures	PTSD, Borderline Personality Disorder	EMDR, 18 months (session number not specified)	N of seizures, DES, BDI, QUOLIE-31	3-month	• Client seizure free following 18 months of EMDR. • Clonazepam (prescribed for seizures) reduced (dosage information not provided). • Maintained at 3-month follow up.	Low
5	Cope., (2020) UK	Case report Peer-reviewed	N = 2 Age range: 20-50 Gender: Female (n = 1), Male (n = 1) Not specified	Functional non-epileptic attack Functional sensory symptoms	Complex trauma Health Anxiety	EMDR, 20 sessions	BES, BIPQ, GAD-7, HAI, IES-R, MDI, PHQ-9	3-month	• Reduction in frequency of FNEA and dissociative episodes. • Reduction in severity of functional sensory symptoms and associated distress. • Post-treatment scores in subclinical range for PHQ-9, GAD-7, IES-R. • Post treatment scores in subclinical range for all subtypes of dissociation (n = 1 remained in clinical range for “emotional constriction” subtype).	Low

6	Demirci et al. (2017), Turkey	Randomised Clinical Trial Peer-reviewed	N = 31 (EMDR arm) Mean age: 27.65 Gender: Female (n = 31) Not specified	Somatic Symptom Disorder General pain	Psychological Trauma	EMDR, 6 sessions (90 mins each)	SCL-90, BAI, BDI, SF-36	No follow up	• Significant improvement in somatic symptoms at post-test (n^2 = 0.94). • Both EMDR and TAU (Duloxetine) resulted in significant decreases in SF-36, BAI, BDI at post-test. • EMDR group reported larger effect size (n^2 = 0.94) compared to TAU (n^2 = 0.68).	Moderate
7	de Roos et al. (2010), Netherlands	Uncontrolled clinical trial (pre-test/post-test design) Peer-reviewed	N = 10 Mean age: 50.1 Gender: Female (n = 4), Male (n = 6) Not specified	Phantom limb pain	Psychological trauma, Obsessive Compulsive Disorder, Substance Use	EMDR, 3-10 sessions (90 mins each)	Pain rating, SCL-90, CIS-20R, IES, SIL, SF-36	26-40 month	• 80% of patients reported clinically significant reduction in pain at post-test (medium effect size; n^2 = 0.63). Maintained at follow up. • Four participants reported to be “pain free” at post-test and discontinued pain medication. • Significant reduction in trauma measures (IES, SIL) to subclinical range at post-test.	High

8	Gerhardt et al. (2016), Germany	Randomised controlled pilot study Peer-reviewed	N = 20 (EMDR arm) Mean age: 56.6 Gender: Female (n = 14), Male (n = 6) White German	Non-specific chronic back pain	“Experience of psychological trauma” (assessed by Structured Clinical Interview DSM-5)	EMDR standard procedure and pain protocols, 10 sessions (90 mins each)	N days with pain, NRS pain intensity, MPI-D, PGIC	6-month	• 45% of participants who received EMDR experienced significant reduction in pain intensity (d = 0.79) and disability (0.39) versus 0% in TAU control group. Follow up (d = 0.50). • 50% of participants who received EMDR rated their condition as “much improved” (n = 8) or “very much improved” (n = 2) compared to 0% in control group (d = 1.69).	High
9	Grant., (2000), Australia	Case series	N = 2 Age range: 28-40 Gender: Female	Chronic pain	Depression, PTSD	Chronic pain protocol – no. sessions not specified	Qualitative self-report	Not specified	• Both clients reported marked improvement in pain symptoms, functioning and associated distress.	Low

10	Grant and Threlfo (2002), Australia	Case series	N = 3* Age range: 27-54 Gender: Female	Chronic pain	Depression, Fatigue	Chronic pain protocol – 9 weekly sessions	SFMPQ, CSQ, VOC, Qualitative self-report	2 months	• Significant decrease in pain and distress for all participants. • Marked increase in perceived ability to cope with pain and reported daily functioning.	Low
11	Gupta & Gupta, (2002), Canada	Case series	N = 4 Age range: 22-43 Gender: Female (n = 3), Male (n = 1)	Dermatologic Disorders	Anxiety, Complex Trauma	3-6 sessions	VOC, Qualitative self-report	6-12 months	• All patients reported significant improvement in symptoms. Maintained at follow-up.	Low
12	Hughes., (2014), Canada	Case study	N = 1 Age: 35 years Gender: Female	Complex regional pain	Depression, Fatigue, Trauma	16 sessions	Qualitative Self-Report	8 months	• Client reported decreased pain, decreased substance use and improved mood at post-test. Maintained at follow up. • Client reported improvement in daily functioning and perceived ability to cope with chronic pain.	Low

13	Kelley & Benbadis, (2007) North America	Case series Peer-reviewed	N = 8 Mean age: 37.1 Gender: Female (n = 4), Male (n = 4) White American	Psychogenic non-epileptic seizures	PTSD, Complex Trauma, Depression, Obsessive Compulsive Disorder, Dissociative Disorder, Anxiety, Substance Use, Psychosis, Traumatic Brain Injury	Counselling sessions followed by EMDR, 0-7 sessions EMDR protocol	VOC, N of psychogenic seizures	18-month	• Two out of three participants who received EMDR were seizure free following 6-7 sessions of intervention. Maintained at follow up. • 12.5% reported being seizure free after consult only (n = 1) • 12.5% declined treatment after consult (n =1) • 25% dropped out after 2-3 counselling sessions prior to receiving EMDR (n = 2)	Low
14	Konuk et al. (2011), Turkey	Uncontrolled clinical trial	N = 11 Age range: 18-50 Gender: Female (n = 9), Male (n = 2)	Migraines	Trauma related to headaches	8 sessions	NRS, SA-45, WHQ	3 months	• Statistically significant decreases in frequency and duration of headaches. Frequency of headaches increased during intervention but decreased post-treatment. • No reductions in reported pain intensity. • Significant decrease in pain medication and number of medical visits. • Maintained at follow up.	Moderate

15	Luyten et al. (2020), Belgium	RCT	N = 46 (EMDR arm) Mean age: 47.87 Gender: Female (n = 26), Male (n = 63)	Chronic Subjective Tinnitus	Anxiety, Depression	5 sessions EMDR (plus Tinnitus Retraining Therapy)	TFI, VAS, TQ, HADS, HQ	3 months	• TRT/EMDR showed clinically significant reduction in tinnitus symptoms compared to TRT/CBT. • Both TRT/EMDR and TRT/CBT showed significant decrease in tinnitus complaints, hyperacusis, anxiety and depression. • Maintained at follow up.	High
16	Marcus., (2008), North America	RCT	N = 21 (Integrated EMDR arm) Mean age: 38.33 Gender: Female (n = 41), Male (n = 2)	Migraine	Not reported	1 session (60 minutes) EMDR with diaphragmatic breathing and cranial compression	SPL, MIDAS, HDI	1, 2, 7 days	• Both the integrated EMDR and TAU (pain medication) groups reported reduced migraine pain posttreatment. Integrated EMDR group showed significantly greater improvements in rapidity of pain reduction. • Maintained at follow up.	Moderate

17	Mazzola et al (2009), Argentina	Uncontrolled clinical trial	N = 38 Age: not specified Gender: Female (n = 32), Male (n = 6)	Chronic pain 30 (79%) headaches; 4 (10.5%) fibromyalgia; 4 (10.5%) neuropathic pain	Personality disorder, Depression, Anxiety	12 weekly sessions	SF-36, STAI, BDI, SCID-II, VAS	No follow-up	• Significant reduction in pain levels resulting in reduction of medication (e.g., benzodiazepines, opioids). • EMDR resulted in significant decrease in BDI and STAI at post-test. • Statistically significant positive change in perceptions of quality of life (SF-36).	High
18	Phillips et al (2019), UK	Uncontrolled clinical trial	N = 14 Mean age: 57.2 Gender: Female (n = 7), Male (n = 7)	Tinnitus	Anxiety, Depression	3-10 sessions	THI, BDI, BAI	6 months	• Statistically significant improvement in tinnitus symptoms in “majority of participants”. • Marked decrease in depression and anxiety at post-test. • Results maintained at 6 month follow up.	High
19	Proudlock, S., (2015) England	Case report, Peer-reviewed	N = 1 Age: “Late 50s” Gender: Male White British	Abdomen pain	Psychological trauma, Anxiety	EMDR plus “principles of SLT and CBT”, 20 sessions	IES	6-month	• Client reported reduction in frequency and severity of pain. • Client reported improvement in depressed mood. • At 6 month follow up, client required 6 additional sessions to manage pain associated with	Low

									recurrent bladder infections.	
20	Ray and Page, (2002), Australia	Non-randomised Trial	N = 17 Mean age: 36.8 Gender: Female (n = 7), Male (n = 10)	Chronic pain	PTSD, Depression	1 session of EMDR followed by 1 session hypnosis or 1 session hypnosis followed by EMDR (randomly assigned)	MPQ	<1 month	• Non-significant reduction in self-reported pain in EMDR condition. • Statistically significant pain reduction reported in hypnosis condition. • 86.7% reported preference for hypnosis over EMDR post-treatment.	Low
21	Rikkert et al. (2018), Netherlands	Within-groups design	N = 35 Mean age: 49.2 Gender: Female (n = 16), Male (n = 19)	Tinnitus	Sleeping difficulties, pain, trauma, other somatic complaint not otherwise specified	6 sessions	TFI, Mini TQ, SCL-90, SRIP	3 months	• Significant reduction in tinnitus distress at post-test compared to passive control condition. Medium effect size observed (d = .72). • Almost 1 in 2 participants reported benefiting from EMDR. • Results maintained at follow up.	High
22	Rostaminejad et al. (2017) Iran	Randomised controlled trial, Peer-reviewed	N = 30 (EMDR arm) Mean age: 42.8 Gender: Female (n	Phantom limb pain	Psychological trauma related to amputation	EMDR, 12 sessions (60 mins each)	VOC, Pain rating scale	24-month	• At post-test, 86% of participants who had received EMDR reported being “almost or completely pain free”. Maintained at follow up. • Statistically significant	High

			= 9), Male (n = 21) Not specified						reduction in pain intensity and associated distress at post-test (P<0.001). Effect size calculated for purpose of review (d = 3.23). • In comparison, 96.3% of control group (allocated to routine care) reported no reduction in pain in same period.	
23	Royle, L., (2008), UK	Case report, Peer reviewed	N = 1 Age: 49 Gender: Male Not specified	Chronic fatigue	Anxiety, depression, work related stress	EMDR, 9 sessions	VOC, Qualitative self-report	6, 12-month	• Significant decrease in fatigue which allowed client to return to employment and other daily activities. • Reduction in symptom-perpetuating maladaptive cognitions. • Maintained at 12 month follow up.	Low
24	Russell, M., (2008), Japan	Case report, Peer-reviewed	N = 1 Age: 40 Gender: Male Not specified	Exaggerated startle response, chronic pain, somatic symptoms	Combat related trauma	EMDR, 5 sessions	IES, BDI, Health Status	1, 3, 6-month	• Marked improvement in health status self-report at post-test. Maintained at 6 month follow up. • Clinically significant and reliable change in IES and BDI scores at post-test. Scores in non-clinical range. Maintained at follow up.	Low

25	Schneider et al., (2008), Germany	Case series, Peer-reviewed	N = 5 Mean age: 49.2 Gender: Female (n = 1), Male (n = 4) Not specified	Phantom limb pain	PTSD	EMDR, 3-15 sessions	IES, BDI, Faces pain scale	12-24 month	• Complete elimination of phantom limb pain in two cases. Maintained at follow up. • Reduction in pain in three cases. At follow up, one case (who did not complete full protocol due to relocation) reported “rebound in pain frequency”. • At post-test and follow up, two clients reduced pain medication (e.g., morphine) and discontinued Diazepam. • Average IES and BDI scores in subclinical range at post-test and follow up.	Moderate
26	Silver, Rogers, & Russell., (2008), North America & Japan	Case report, Peer-reviewed	N = 1 Age: 73 Gender: Male Not specified	Myoclonic movements (upper body shaking & jerking)	Combat related PTSD	EMDR, 2 sessions	IES, BDI, BHS	1, 6-month	• Clinically significant and reliable change in IES, BDI and BHS scores at post-test. No longer in clinical ranges. Maintained at follow up. • Client reported complete elimination of myoclonic movements. Maintained at 6 month follow up.	Moderate

27	Suárez et al. (2020), Spain	RCT Pilot	N = 14 (EMDR arm) Age range: 49-60 Gender: Female (n = 22), Male (n = 6)	Chronic Pain	Depression, Anxiety	12 sessions	VAS, PDI, EDQ-5D-5L, HADS	3 months	• EMDR+TAU group reported significant improvement in pain intensity, anxiety and depression scores at post-test when compared to TAU. • Results from EMDR maintained at follow up.	High
28	Wilensky, M., (2008), Canada	Case series, Peer-reviewed	N = 5 Mean age: 45.6 Gender: Female (n = 1), Male (n = 4) Not specified	Phantom limb pain	Psychological trauma	EMDR, 3-9 sessions	IES, BDI, PDI, TSI	1, 3- year (two clients only)	• Four of the five clients completed planned protocol and reported complete elimination or marked reduction in pain. • One client stopped treatment after reducing reported pain by 50%. • Significant reduction in BDI and PDI scores at post-test. • Significant reduction in IES scores at post-test. One client no longer scoring in clinical range. • Three clients lost to follow up.	Moderate

BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; CAPS = Clinician-Administered Post-traumatic stress disorder Scale; IES-R = Impact of Events Scale Revised; BES = Beliefs About Emotions Scale; BIPQ = Brief Illness Perception Questionnaire; GAD-7 = Generalized Anxiety Disorder Scale; HAI = Health Anxiety Inventory; IMDI = Multiscale Dissociation Inventory; PHQ-9 = Patient Health Questionnaire; CIS-R = Checklist Individual Strength Revised; SCL-90 = Symptom Checklist; SIL = Self-Inventory List; SF-36 = Short Form Health Survey; NRS Pain = Numeric Pain Rating Scale; MPI-D = Multi-dimensional Pain Inventory (Dutch Version); PGIC = Patient Global Impressions of Change; VOC = Validity of Cognition; BHS = Beck's Hopelessness Scale; PDI = Peters' Delusions Inventory; TSI = Trauma Symptom Inventory; SFMPQ = Short-Form McGill Melzack Pain Questionnaire; CSQ = Coping Skills Questionnaire; VAS = Visual Analog Score; WHQ = Weekly Headache Questionnaire; SA-45 = Symptom Assessment 45 Questionnaire; SCID = Structured Clinical Interview for DSM; STAI = State Trait Anxiety Inventory; CES-D = Centre for Epidemiologic Studies – Depression;

EQ-5D-5L = EuroQol 5 Dimensions Quality of Life; TFI = Tinnitus Functional Index; Mini TQ = Mini Tinnitus Questionnaire; SRIP = Self-Rating Inventory List for Post-Traumatic Stress Disorder; THI = Tinnitus Handicap Inventory; HQ - Hyperacusis Questionnaire; CTQ = Childhood Trauma Questionnaire; ADES = Adolescent Dissociative Experiences Scale; SPL = Subjective Pain Level; HDI = Headache Disability Inventory; MDAS = Migraine Disability Assessment Scale

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JOURNAL PAPER

Functional Neurological Disorder: A Qualitative Study Exploring Experiences of Psychological Services[1]

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[1] **Disclaimer:** Under supervision from Dr David Dawson, Amelia Staton developed and wrote a research protocol, parts of which are now included in the final thesis.

Abstract

Objectives: Individuals with a diagnosis of FND report experiencing stigma in medical settings, however there is a paucity of research exploring their experiences in psychological services. The aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with FND.

Methods: This study utilised a qualitative approach with data collected from semi-structured interviews (*n = 15*) and analysed using reflexive thematic analysis.

Results: One superordinate theme, '*the stigmatised self within the therapeutic relationship'*, and five interrelated subthemes were identified: '*internalised stigma and self-doubt', 'selective disclosure to professionals', 'perceptions of psychological explanations', 'having to educate the professionals'* and *'attunement and trust within the therapeutic relationship'.* Positive therapeutic relationships were perceived to mitigate the impact of these perceived barriers. The conceptualisation of FND and the perception of how this was responded to by services and professionals was a central tenet throughout the related themes.

Conclusions: Intra-personal, interpersonal and organisational stigma impact access and engagement to psychological treatment. The findings of this study highlight the need for increased training provision for practitioners with a focus on actively challenging FND stigma within services at both an individual and systemic level.

Practitioner Points

- Internalised stigma and perceptions of stigma within the therapeutic encounter are barriers to accessing and engaging with psychological services.
- Some individuals with FND experience psychological explanations of their symptoms as blaming. Psychological formulations that bridge the gap between mind-body dualism may be helpful in reducing perceptions of blame.
- Positive therapeutic relationships in services may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention.

Introduction

Functional Neurological Disorder (FND) is classified as a "disorder of the voluntary motor or sensory system with symptoms including paralysis, tremor, dystonia, sensory disturbance (including visual loss), speech symptoms, and seizures" (Stone et al., 2020, p.1). As outlined in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5; American Psychiatric Association, 2013) and the International Classification of Diseases 11th Edition (ICD-11; World Health Organisation, 2019), FND presentations may include motor, sensory and cognitive symptoms. Despite these symptoms, medical investigations (e.g., MRI and EEGs) do not show any structural abnormalities, indicating that symptoms may instead be the result of an issue with the functioning of the nervous system (Bennett et al., 2021)[2]. Whilst FND was previously a diagnosis of exclusion, current diagnostic criteria emphasise the need for a positive diagnosis to be based on signs and symptoms associated with the condition (Aybek & Perez, 2022).

Individuals with symptoms related to FND usually present to Neurology services in the first instance, with FND representing the second most common reason for new patient referrals in these settings (Stone et al., 2010). Although true prevalence is unknown, estimations of annual incidence are approximately 4-12 out of 100,000 (Carson et al., 2012; Stone & Carson, 2015). Although gender ratios vary dependent

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[2] See extended paper (section 1.1) for discussion around the historical context of FND.

on age of onset (Lidstone et al., 2022), women are two to three times more likely to receive a diagnosis of FND[3] (Matin et al., 2017), the reasons for this are currently poorly understood (Baizabal-Carvallo et al., 2019). There is some evidence to suggest FND is more prevalent in lower socioeconomic groups (Owen & Dein, 2006; Ali et al., 2015), although other demographic variables such as ethnicity are not considered to be a contributing factor (Ali et al., 2015). Chronic stress and psychological trauma have been consistently linked to an increased risk of developing the condition with a recent meta-analysis concluding that adverse life events were eight times more common in those with FND compared to non-clinical controls (Ludwig et al., 2018). However, it should be noted that epidemiological studies related to FND are in their infancy and thus must be considered in the context of their methodological limitations such as small sample sizes and retrospective data that increases the risk of selection bias. Furthermore, not all individuals with a diagnosis of FND report experiences of adversity or trauma (Ludwig et al., 2018).

The variance in diagnostic labels (e.g., FND, conversion disorder, psychogenic seizures, functional/dissociative seizures, non-epileptic seizures, functional movement disorder) highlight the etiologic uncertainty of this presentation (Garrett et al., 2020). FND was previously referenced under the umbrella term “medically unexplained” and more recently “persistent physical symptoms”[4]. Causal mechanisms for these types of presentations are complex and widely debated[5], although they are often considered through the lens of the biopsychosocial framework such as the interaction of biological and psychosocial etiological factors (Brown, 2007) and the stress-diathesis model (Keynejad et al., 2019). Thus, the recommended multi-disciplinary intervention involves both psychological treatment and physical rehabilitation (LaFaver et al., 2021). However, there is currently no National Institute of Health and Care Excellence (NICE) guideline for the treatment of FND, although reference is made in the quality standards that there should be “the offer of psychological support where appropriate” (NICE, 2021). Despite this recommendation, there is a lack of consensus on the most appropriate evidence-

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[3] See extended paper (section 1.2) for further discussion on FND and gender.

[4] See extended paper (section 1.3) for further discussion on changes to diagnostic criterion.

[5] See extended paper (section 1.4) for further discussion on theoretical models of FND.

based psychological treatments for FND. Systematic reviews of several treatment modalities[6] have found promising emerging evidence for the effectiveness of, cognitive behavioural therapy (Kleinstauber et al., 2011; Goldstein et al., 2020; Gutkin et al., 2021), psychodynamic therapy (Gutkin et al., 2021), acceptance and commitment therapy (Hughes et al., 2017) and EMDR (Staton et al., 2022), although firm conclusions on treatment efficacy cannot be drawn due to methodological limitations of the current research. As a result of this, psychological treatment provision in UK services can vary greatly. Whilst there are some specialist FND services within the National Health Service (NHS), a large portion of those with a diagnosis of FND will be referred to general psychological services due to limited specialist service provision and increasing waiting times (Walker, 2019)[7].

When considering the experiences of those accessing healthcare services for FND, current research has focused solely on medical settings. Individuals with FND report feeling dismissed in these settings (Burke, 2019), arguably due to the widely debated causal mechanisms, differences in professional and service-user perceptions, lack of treatment guidelines and limited specialist service provision. Within the qualitative research, interactions with medical professionals have been described as “offensive” and “disgraceful” (Robson & Lian, 2017). These experiences are hypothesised to relate to negative perceptions that professionals may hold about FND (MacDuffie et al., 2020). This is highlighted in studies comparing how individuals with different diagnoses perceive interactions with medical professionals. Individuals with epilepsy described medical professionals as “supportive”, whereas individuals with functional seizures perceived those involved in their care as “distrustful” and “lacking understanding” (Rawlings et al., 2018)[8]. Whilst there is a paucity of research exploring the perspectives of those with a diagnosis of FND, research from the perspective of healthcare professionals emphasise the negative perceptions that may be associated with the condition. Some healthcare professionals reported perceptions that FND symptoms were “voluntary” or “fake” (Shneker & Elliott, 2008) and that individuals had control over their symptoms (Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsley et al., 2011). It should be noted that these studies were limited to small sample sizes and thus the findings

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[6] See extended paper (section 1.7) for further discussion on psychological interventions for FND.

[7] See extended paper (section 1.6) for further discussion on current UK service provision for FND.

[8] See extended paper (section 1.5.3) for further discussion on FND and the associated stigma.

cannot be generalised to all healthcare professionals. However, it could be argued that stigmatised perceptions are influenced by the historical context of FND (e.g., “hysteria”) (Raynor & Baslet, 2021) and gaps in professionals’ knowledge and training (Hutchinson & Linden, 2021).

These negative interactions in services may be conceptualised as direct enactments of stigma (MacDuffie et al., 2020). Based on Goffman’s theory (Goffman, 1963), stigma[9] is considered a process of “labelling, othering, devaluation and discrimination” (Knaak et al., 2017). This can occur intra-personally (e.g., internalised stigma), interpersonally (e.g., interactions with others) and structurally (e.g., in organisations and systems) (Link & Phelan, 2001). In the context of FND, this may be viewed as perceptions of losing personal credibility (Dosanjh et al., 2021), negative experiences of healthcare professionals and lack of investment in specialist service provision and training. There is considerable research highlighting that broader mental health stigma impacts seeking and participating in mental health care (Corrigan et al., 2014). Although it is acknowledged that individuals with FND experience significant stigma, current research has focused predominantly on experiences in medical settings. The impact of stigma on engagement and treatment outcomes has been well-documented across a range of health conditions (Stangl et al., 2019). Although the relationship between FND and stigma has been highlighted (MacDuffie et al., 2020), little is known on whether this impacts the therapeutic encounter in psychological services. Despite individuals with FND regularly accessing psychological services, there is no published research on individuals’ experiences in these settings. The perspectives of those accessing services are essential in understanding and improving the quality of healthcare provision (Reader et al., 2014). This is particularly pertinent for individuals with FND, with recommendations for future research emphasising that those with a diagnosis of FND should be empowered to share their voices and to drive changes in care (Rommelfanger et al., 2017)[10].

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[9] See extended paper (section 1.5) for further discussion on explanatory models of stigma.

[10] See extended paper (section 1.8) for further details on the rationale for this study.

Research Aim

The aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with a diagnosis of FND.

Methods

Study Design

This study utilised a qualitative approach[11], with data collected from semi-structured interviews analysed using reflexive thematic analysis (RTA) (Braun & Clarke, 2006; 2019). This analysis is compatible with the researcher's epistemological position of critical realism[12]. The study received ethical approval from the University of Lincoln's Human Ethics Committee (ref: UoL2022_9139).

Participants

Between May 2022 and August 2022, participants (*n* = 15) were recruited via social media platforms and received a £20 high-street voucher following participation. A member of the Service User, Carer and Advisory Panel (SUCAP) who was an expert by experience of FND, supported study recruitment by advertising the research in online FND support groups. Relevant charities (e.g., FND Hope, FND Action) were contacted to discuss whether study advertisements could be displayed on their websites and social media. However, the sample was recruited prior to this agreement with the relevant charities and thus their support with recruitment was not necessary. Recruitment of participants did not conclude until the research team determined there was a richness and quality of data to meet the research aims. The demographic variables of the sample were also considered when deciding when to discontinue recruitment. For example, it was deemed important to the research aims that the sample consisted of both male and female participants. Inclusion criteria stipulated that participants must be aged 18 years or older, be able

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[11] See extended paper (section 2.2) for further discussion on rationale on qualitative methodology.

[12] See extended paper (section 2.1) for further discussion on epistemological position.

to speak and comprehend English, have received a diagnosis of Functional Neurological Disorder from a healthcare professional and have previously accessed support from UK psychological services due to their diagnosis. No exclusion criteria were applied[13].

Procedure[14]

Participants were provided with the participant information sheet and were required to provide informed consent in writing. A minimum of 24 hours was given between consent and participation in the study. Data was collected using semi-structured interviews and audio recorded using an encrypted Dictaphone. In accordance with the mixed inductive and deductive approach, the development of interview questions was considered in the context of the relevant theoretical and empirical evidence, whilst also including broad open-ended questions to facilitate novel insights. A member of the Service User, Carer and Advisory Panel (SUCAP) who was an expert by experience of FND, was consulted for further feedback. SUCAP feedback provided recommendations on the wording/phrasing of questions and the inclusion of a question on views of self. As a result of this, the question; “how did you think about/view yourself when seeking support from psychological services?”, was added to the schedule.

Thirteen interviews were completed via video calling platforms (e.g., Microsoft Teams, Zoom) and two were conducted via telephone. Each participant completed one interview, approximately 30-75 minutes in duration (average 55 minutes). The interviews were transcribed verbatim using an automated transcription service prior to data analysis. Interviews were transcribed approximately one week after being conducted to allow time for participants to exercise their right to completely withdraw their data from the study. Participants were informed that they were able to withdraw after this time period, however data already obtained may have been analysed and therefore may have been unable to be erased[15].

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[13] See extended paper (section 2.4.2) for further discussion on inclusion and exclusion criteria.

[14] See extended paper (section 2.4) for further discussion on study design.

[15] See extended paper (section 2.7) for further discussion on ethical considerations.

Analysis[16]

Reflexive thematic analysis (RTA) was used to analyse the data. RTA is flexible in its theoretical framework and views researcher subjectivity as a resource during theme development (Braun & Clarke, 2021). This study took a mixed deductive-inductive approach with codes generated at both a semantic and latent level to allow for exploration of the meaning associated with individuals' experiences (Braun & Clarke, 2013). This allowed themes to be data-driven whilst also providing an opportunity for exploration of relevant theoretical ideas reflected in the broader literature. Within thematic analysis, themes are considered as organised aspects of the data set that are pertinent to the aims of the proposed study (Braun & Clarke, 2006; 2019). The process of identifying themes begins with the re-reading and familiarisation of transcripts and initial codes are identified. These themes are then reviewed, and a "thematic map" is produced outlining the super-ordinate and subthemes and the relationships between them (Braun & Clarke, 2006, 2019).

Results

Participant Characteristics[17]

Participants were aged between 21-54 years old (mean age of 33.66), with 80% (*n* = 12) identifying their gender as female and 20% (*n* = 3) identifying as male. Further participant demographic information is presented in Table 1. The demographic information of participants was collected to provide context of individuals' experience and perspectives. In line with the theoretical underpinnings of qualitative research, "knowledge is situated" (Braun & Clarke, 2013 p67) and thus the findings of the research must be considered through the lens of the sample. The rationale for collecting this demographic data was to explore whether age, gender identity or ethnic/cultural identity influenced participants' experiences of accessing psychological services for FND. Participants were also asked what type of psychological service they had accessed, what professional they had worked with (e.g., psychologist, CBT therapist, mental health nurse) and the type of therapy they

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[16] See extended paper (section 2.3) for further discussion on rationale for thematic analysis.

[17] See extended paper (section 3) for further details on participant characteristics.

had received. However, it was noted that participants frequently reported they did not know what type of therapy or professional they had worked with and due to missing data this information could not be meaningfully compared across the dataset. Although ethnicity and employment status were collected, neither were indicated as relevant contextual factors in the results. However, the researcher acknowledged that due to their own ethnic/cultural background (White British), certain nuances relating to this contextual factor may have been missed in the data.

Table 1. Sample Demographic Information

Participant Pseudonym	**Age**	**Gender**	**Ethnicity**	**Employment Status**	**No. of months accessing UK psychological services**
Amy	41	Female	White British	Unemployed	3 years
Beth	26	Female	White Welsh	Part-time	2 years
Clara	38	Female	White European	Full-time	3.5 years
Danielle	30	Female	White Irish	Full-time	10 months
Elizabeth	26	Female	White British	Unemployed	2 months
Fran	24	Female	White British	Unemployed	3 months
Grace	23	Female	White British	Full-time student	4 months
Helen	37	Female	White British	Full-time	1 year

Isla	21	Female	White British	Full-time student	10 months
Joshua	30	Male	Black British Caribbean	Unemployed	2.5 years
Katherine	54	Female	White British	Unemployed	3 years
Liam	49	Male	White British	Unemployed	7 months
Michael	48	Male	White British	Full-time	2 weeks
Natalie	29	Female	White British	Part-time	18 months
Olivia	29	Female	White British	Full-time	16 months

Themes[18]

One superordinate theme and five interrelated main themes were identified. These themes are presented visually in a thematic map (Figure 2).

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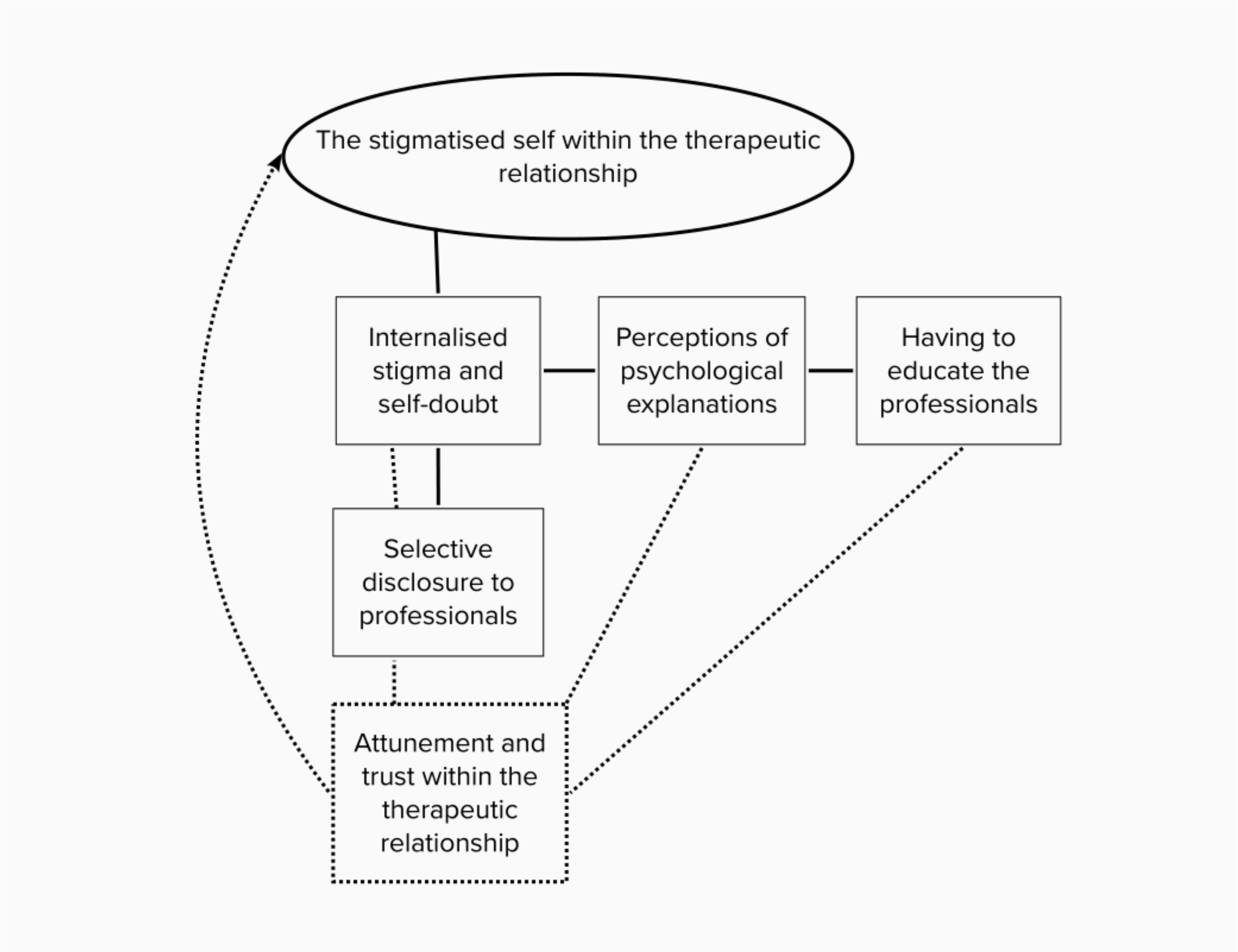
[18] See extended paper (section 3) for further discussion on identified themes and additional illustrative quotes.

Figure 2. Thematic Map



Superordinate theme: The stigmatised self within the therapeutic relationship

When discussing their experiences of UK psychological services, all participants alluded to the concept of their own self-identity and how this was impacted by their relationships with professionals. The conceptualisation of the self in this relational context highlighted how perceptions of stigma from healthcare professionals may be internalised by the individual. This process appeared to have far-reaching implications on engagement and highlighted the inherent power imbalance within the therapeutic relationship:

> *“It's difficult to take out those ingrained thoughts and experiences because they've been woven into the tapestry that is my life and it*

> *shows how important it is what the message is that professionals are saying because we hold on to them, don't we? And they can maybe impact whether we'd seek support or might just hold us back from seeking support for ourselves when it's really important" - Helen*

The conceptualisation of FND and the perception of how this was responded to by services and professionals was a central tenet throughout the related themes. These could be considered in the context of reciprocal roles, the relationship between 'doing' and 'done to'; the roles individuals are positioned in or actively adopted, in response to the perceived role that has been adopted by others (e.g., professionals/services). These reciprocal roles form the expectations of and responses to future interactions (Ryle & Kerr, 2002).

Internalised stigma and self-doubt

The concept of internalised stigma and the self-doubt that this propagated was discussed by all participants. They described the discrepancy between experiencing physical symptoms and being told these symptoms were "psychological" by professionals. This led to uncertainty about the validity of their own experiences, and subsequently impacted their sense of self. This was reflected in descriptions of self-blame and associated shame. For example, Danielle reported:

> *"It's like in your head and you kind of start doubting yourself. You kind of start questioning yourself a lot. Am I actually? Is it my fault that I'm having these seizures?" – Danielle*

These negative views of self and associated ruminations were discussed in the context of internalisations of previous interactions in medical settings. Grace reported, *"to be told that there's nothing wrong with you… it also plants a seed of doubt in your mind then as well".* Specific concerns around "*it all being in my head*" and the associated psychological distress were reported by the majority of participants:

> *“So I've always kind of struggled with that, that feeling that it's all in my head that I know why it's happening, but I still can't get past the fact that I can't control it” – Olivia*

Although for some participants this appeared to be a re-enactment of externalised stigma from healthcare professionals, others considered the impact of historical social stigma on their views of self. For example, *“you’re a mental health patient, it still does have that stigma of you’re a fruitcake”* [Liam]. Regardless of whether participants reported explicit experiences of stigma in psychological services, internalised stigma appeared to permeate participants’ sense of self identity. For example, Beth reported an inner conflict around internalisations of malingering, despite knowing her symptoms were real:

> *“You know, I know I'm not faking my symptoms but there's always that little voice of doubt in my head that says what if you are? What if you are?” - Beth*

For most participants, these internalisations appeared to present barriers to accessing and engaging with services. Regardless of participants perspectives of where the internalised stigma and self-doubt originated, this theme appeared to capture the reciprocal nature of stigma. Further, there was evidence that individual’s stigmatised views of self impacted their relationships with professionals in psychological services.

Selective disclosure to professionals

Participants identified a sense of feeling unable to share information with professionals due to a fear of negative judgement:

> *“I feel like I was gonna be in that situation again where I couldn't really say what I wanted to because it’s almost feeling like you might be judged in a certain way” – Joshua*

These anticipated interactions appeared to be framed and experienced through the lens of internalised stigma which manifested as feelings of self-doubt. These internalisations were seemingly underpinned by previous negative experiences of healthcare professionals and the historical stigma associated with FND (e.g., malingering, feigned illness to elicit attention):

> *"When I first started talking therapy, I didn't talk about all of the symptoms … because I just thought no one's going to believe me. No one's going to believe what it is. I held back certain symptoms or I wouldn't say the whole truth … I think I was just worried that they would think I was making it up and that I was just doing it for attention" – Isla*

In response to anticipated interpersonal stigma, participants adopted a position of 'being on the defence'. They described withholding information about their personal history based on a belief that some professionals may be unable to contain and integrate this with the professionals' own perspective or understanding. For example, Olivia stated:

> *"The other thing you kind of realise is that you stopped telling the full story of your life to certain professionals because you know they're just not going to take it" - Olivia*

Individual differences between professionals were highlighted, with participants reflecting that their levels of disclosure could be influenced by their perception of the professional. For example:

> *"You categorise professionals a little bit like, well, you're one when I'm not going to speak to completely honestly. You're one that I know I need to not say certain things to you or someone I can speak completely openly with, and because it's like you don't want to hear the lecture" - Danielle*

The experience of being '*lectured*' and how this impacted disclosure appeared to highlight how individual professionals managed the inherent power imbalance within the therapeutic relationship. One participant described the power professionals held, describing them as *"like God"* and reflected on how difficult it felt to challenge a professional as a result of this dynamic. There was a sense of disempowerment shared by several of the participants, with individuals appearing to use selective disclosure as a way of managing their relationships with professionals and avoiding potential conflict.

Perceptions of psychological explanations

Perceptions of psychological explanations was one of the most salient factors influencing all participants' experiences of psychological services. Wariness around psychological explanations appeared to be linked to their levels of disclosure in sessions, with participants describing a worry that aspects of their life would be seized upon and used as an explanation for their symptoms. Most participants described perceiving these explanations as blaming based on previous experiences of enacted and internalised stigma which became a lens through which psychological formulations were viewed. For example, Katherine reported:

> "*It felt like they were thinking I'm doing it to myself but the whole time I couldn't understand. Why why why? I can't make it up. This is the thing what I kept saying to them, I can't make it up".*

Participants' assumptions about which services they would be referred to based on the physicality of their symptoms appeared to be a complicating factor. This dissonance between anticipating a medical explanation and receiving a psychological formulation was described by several participants as *'difficult to accept'*:

> *"It was strange being referred to a psychological service when I've got very, very physical symptoms. It's strange to be told to go to counselling because I can't walk" – Grace*

Difficulties assimilating their own understanding of the problem with that of the psychological professional's further reinforced these negative perceptions. However, this process was seemingly reciprocal, with one participant highlighting that professionals may also hold rigid preconceptions and have difficulty assimilating a client's contrasting narrative or personal history:

> *"They kept saying to me things about like psychological triggers, that certain things trigger it, and I could not for the life of me … I could not think of any reason, any logical explanation as to why one minute I could walk and the next minute I couldn't. They were like 'have you been through any stress, any trauma, any like car accident, have you witnessed anything happening like a death or anything?' I was like no, absolutely nothing" – Katherine*

The idea of trauma and its proposed link to FND was discussed by several participants. Two participants rejected this link but highlighted their perception that professionals were heavily invested in this narrative. Others considered this relevant but acknowledged that this was a difficult explanation to accept and process due to feelings of shame and defectiveness:

> *"It felt like they were saying my body's reaction to trauma was not to deal with it how a normal person would deal with it, my reaction had been to just shut down" - Isla*

A barrier to accepting a psychological explanation appeared to be the perception of how their difficulties had been conceptualised by professionals. Whilst links to other mental health difficulties may have been developed as part of the professional's wider formulation, this was perceived as placing the 'fault' within the individual. There was also an implicit aversion to FND being categorised as or compared to mental health conditions, perhaps reflecting experiences of enacted or internalised stigma. However, this also perhaps reflected broader hierarchical views of physical health as 'less stigmatised' compared to mental health conditions:

> *"Yeah, I did feel not great about it being almost blamed on the anxiety because again, it's sort of comes back to the whole thing of it's your fault, which is the stigma that's attached to loads of mental health issues" – Beth*

Similarly, different psychological models were considered by some to perpetuate this sense of blame and stigma:

> *"I think if I'd have had CBT again I might have become quite disillusioned quite quickly. I think CBT aligns with the stigma of FND in a way. I'm a bit sceptical but it feels like it can align itself with some other mental health conditions and that you can just think your way out of it as though it's a logical process" – Natalie*

However, not all participants perceived the psychological formulation of their difficulties as blaming. Conversely, Michael described feeling 'understood' and 'heard', but acknowledged that this was a sensitive process that required consideration of individual need:

> *"When I first started, I did not think I was anxious and I think the psychologist realised that, so instead he would say burned out. I suppose using language to engage people… and the pace of it so it's right for the person at that particular time… I think it needs very careful language and I think just gauging the level of what people will understand or want to understand at that time" - Michael*

This highlighted the importance of professionals "*meeting the [client] where they are*" [Michael] and developing psychological formulations collaboratively to minimise individuals' perceptions of blame.

Having to educate the professionals

Some professionals were perceived as lacking knowledge and experience of working with FND and thus the patient found themselves occupying the role of 'educator'. Several participants appeared to have become accepting of this role, *"I think you just have to educate them because they just don't know about FND, by their own admission"* [Katherine]. For others, the dynamic between the patient and the professional was not as they had reasonably expected. These blurred boundaries within the therapeutic relationship increased anxiety in those accessing services:

> *"That makes me very wary because I feel strange being the patient and having to explain what's wrong with me, especially when it's something so complex and I am not fully understanding it myself' – Elizabeth*

There was an implicit reference that these dynamics with professionals resulted in a loss of trust in services and this had significant implications on individual well-being:

> *"The more uneducated [professionals] that you meet, the more that affects your FND symptoms and the more you spiral down because you're not getting that support" – Beth*

This lack of knowledge in services appeared to reinforce perceptions of stigma and the sense of feeling dismissed and doubted by professionals. It was also suggested that participants could experience professionals as 'distancing themselves' from patients with FND. For some this had been perceived as a direct enactment of stigma, for others this had been understood as professionals' own uncertainty and anxiety when working with individuals with FND:

> *"I've found there's less stigma in mental health services [compared to medical settings] and more absolute terror on the faces of people who didn't know what to do with me. In hindsight, I think some of it was just complete uncertainty about what to do with this [FND]. Just complete*

> *lack of awareness of the condition or what to do with someone with it' - Natalie*

The perceived responsibility of having to educate the professionals appeared to strengthen narratives around being 'misunderstood' and 'othered' by services. These views of self impacted how individuals related to professionals and perhaps had the potential to impact how professionals related to those accessing services. For example, Katherine reported *"they either don't know what to think about it or what they do know is a very closed view... they don't understand the complexities of it".* An individual's anticipation of these interactions was a barrier to sharing information and contributed to early ruptures in the therapeutic alliance. If not resolved, these ruptures had a significant impact on the development of the professional relationship; "*you don't feel believed, you don't feel supported, you don't feel validated"* [Beth].

Attunement and trust within the therapeutic relationship

For all participants, experiences of 'services' were synonymous with the experiences of the interactions they had with professionals. Those that had experienced a positive therapeutic relationship in services described this as having mitigated the impact of other perceived barriers such as anticipations of enacted stigma. Attunement (the process of the therapist being aware of the client's emotional state and responding to this appropriately) was highlighted as a crucial component in developing a sense of safety and trust:

> *"And I think there's a massive sense of her knowing where I'm at and being able to say the right things at the right time that help me through those difficult moments" - Olivia*

This attunement appeared to be both explicit and implicit. Psychological explanations of FND communicated from a position of curiosity and compassion facilitated a sense of feeling understood. For example, Michael reported, *"he completely understood me and got me and he said this has occurred for a number of reasons... [you're] not a failure, this is a normal reaction".* Implicit communication within the therapeutic relationship also nurtured a sense of being understood. Natalie explained, *“[the psychologist] could read my body language in a way that I can’t convey”.* The healthcare professional's perceived ability to recognise emotional and physical shifts in the session also appeared to foster trust and a sense of containment:

> *“There was a moment where I was getting a severe symptom and she could see it even before I could and she could help me, and not many professionals have actually been able to help me. I do have a lot of trust in her” - Clara*

A positive therapeutic relationship in services appeared to increase participant disclosure and thus the development of a shared perception of the difficulties. This intersubjectivity aided the collaborative process of psychological formulation and arguably lessened the inherent power imbalance between therapist and client. For example, Michael reported *“[the psychologist] does it in a very gentle way, but I’m starting to see the patterns with how particular things had happened and I can now say to him, can we think a bit about this?”.* This attunement and trust also appeared to support individuals to tolerate and become more accepting of psychological explanations:

> *“I feel like what I've been offered has been brilliant in that it’s been factual and useful for me to actually understand what was going on in my body and mind. The one to one session I’ve been able to dive in to more about me, personally, why certain things might be happening and just the general feeling of like that support and that knowledge, that acknowledgement” - Michael*

Professionals’ knowledge of FND was considered integral to the development of the therapeutic alliance. This appeared to provide a sense of containment for individuals and supported feelings of trust in services. This process could be considered in the context of a reciprocal role, with perceptions of a professional as understanding and accepting challenging an individual's internalised stigma and negative views of self. Furthermore, a positive therapeutic relationship was described as increasing engagement and future help-seeking behaviours. For example, Isla reported, *"because of that relationship, I would ask for support again if I needed it, just because I'd feel like maybe they could help me too".*

Discussion[19]

This qualitative study aimed to explore the experiences of psychological services from the perspective of those with a diagnosis of FND. One superordinate theme, '*the stigmatised self within the therapeutic relationship'*, and five interrelated main themes were identified: '*internalised stigma and self-doubt', 'selective disclosure to professionals', 'perceptions of psychological explanations', 'having to educate the professionals'* and *'attunement and trust within the therapeutic relationship'.*

Experiences of psychological 'services' appeared to be synonymous with experiences of interactions and relationships with professionals. The patterns of interactions between individuals and professionals, referred to as reciprocal roles are underpinned by the "radically social concept of self" (Ryle & Kerr, 2002). This relational context appeared to impact how participants viewed their own self-identity, with individuals' describing how their sense of self was influenced by the perceived meanings conveyed by others (e.g., professionals) (Vygotsky et al., 1978). This highlighted the inherent power dynamic within the patient/professional relationship which appeared to influence participants levels of disclosure, with selective disclosure used to manage perceived ruptures or conflict. These perceived conflicts were also underpinned by perceptions of, and anticipation of, enacted stigma. Stigma appeared to function across three levels: intra-personally, interpersonally and structurally (Goffman, 1963). In the intra-personal domain, experiences of perceived stigma appeared to negatively impact how individuals conceptualised themselves and their condition. This appeared particularly pertinent when considering how participants understood their referral to a psychological service. Participants described a sense of 'not being believed', alluded to social stigma around mental health conditions (compared to physical health conditions) and referenced historical stigma associated with medically unexplained presentations e.g., "malingering", "hysteria". Whilst this study did not explore the perspectives of professionals, the findings are consistent with research exploring medical clinician's negative

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[19] See extended paper (section 4) for further discussion on findings in relation to previous literature and theory.

perceptions of FND (Rommelfanger, 2013; Scneker & Elliott, 2008; Whitehead et al., 2013; Whitehead & Reuber, 2012; Worsley et al., 2011).

Due to the study's qualitative approach, direction of effect regarding stigma and its impact cannot be identified. However, perceptions of stigma in mental health services may be viewed in the context of personal-level barriers (internalised stigma, perceptions of ineffective service) and system-level barriers (lack of FND knowledge and training, service development constraints) (Corrigan et al., 2014). The interaction of these perceived barriers were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services (Ryle & Kerr, 2002). For example, individuals with FND may anticipate stigmatised interactions with healthcare professionals due to previous negative experiences in these settings and awareness of historical social stigma. In response to this anticipated stigma, individuals may be selective in their disclosure due to mistrust of professionals. It could be suggested that professionals may interpret selective disclosure as 'emotional avoidance', a perception that is widely cited within the wider literature (Raynor & Baslet, 2021). However, consistent with Goffman's theory (1963), enactments of stigma become internalised and impact the conceptualisation of the self. Thus, individuals with FND may find it difficult to accept referrals to psychological services due to experiences of intra-personal (self-stigma) and perceived interpersonal stigma (enacted by others).

These multi-layered experiences of stigma has the potential to impact the therapeutic encounter during the formulation process, with the majority of participants perceiving psychological perspectives as 'blaming'. Whilst proposed links to psychological trauma were accepted by all but two of the participants, it was highlighted that individuals held narrow views of what constituted psychological trauma. This is perhaps due to understandings of trauma being based on specific diagnostic criterion (DSM-5; American Psychiatric Association [APA], 2013; ICD-11; World Health Organisation [WHO], 2019), rather than broader psychological theories on experiences that impact the autonomic nervous system (Porges, 2007; 2009). Regardless of participants' perspectives on trauma and its proposed link to FND, there was an acknowledgment that this needed to be communicated sensitively, as to not reinforce ideas of 'fault'. Some participants referenced the importance of adopting the client's language to support engagement and overcome resistance.

This is consistent with conversational analysis studies that have found mirroring of client language can facilitate a shared understanding of client experiences and presenting difficulties (Knol et al., 2020). Furthermore, language style matching by the therapist has been found to increase perceptions of empathy (Lord et al., 2015) and foster development of the therapeutic alliance with clients who may be hypervigilant to rejection (Borelli et al., 2019). This appears to be particularly important for individuals with FND who may anticipate rejection and dismissal from healthcare professionals due to multi-layered stigma.

The perception that professionals lacked knowledge about FND was consistent with previous research that concluded that medical professionals did not feel adequately trained with FND-type presentations (Hutchinson & Linden, 2021). Although, it should be noted that this research did not consider the perspectives of other healthcare professionals and thus cannot be generalised across disciplines. Despite this, some participants acknowledged that whilst there was less explicit stigma in psychological services (compared to medical settings), there was a perception of professionals 'distancing themselves'. Whilst this study did not explore perspectives of professionals, findings from a recent meta-synthesis identified that professionals may be anxious of 'saying the wrong thing', 'offending patients' and thus avoid patients with FND (Barnett et al., 2022). These findings are strikingly similar to conclusions drawn from a systemic review of professionals' experiences of working with psychogenic non-epileptic seizures (Rawlings & Reuber, 2018), suggesting that uncertainty around causal and maintaining factors of presentations may influence these patient/professional relational patterns. These perceptions of enacted stigma may also be viewed through the lens of organisational stigma (Goffman, 1963). The lack of specialist provision for FND results in individuals accessing general mental health services that are not resourced to meet their needs. This may highlight more fundamental issues regarding the false mind-body dualism that underpins service provision e.g., the separation of physical and mental health services. When considering the relational impact of this, participants described that 'having to educate the professional' led to the dynamic between patient and professional not being as they had reasonably expected, blurring the boundaries of the therapeutic relationship.

The process between relating to others, how others related to individuals and how individuals related to themselves was a central tenet throughout the themes.

This emphasised the therapeutic relationship as a key component to positive and helpful experiences of services. Those that had experienced a positive therapeutic relationship in services described that this had mitigated the impact of other perceived barriers and had the potential to increase future help-seeking behaviours. These qualitative findings were consistent with previous research in medical settings that highlighted the integral role of the therapeutic relationship on outcomes for those with a diagnosis of FND (Hutchinson & Linden, 2021). These findings are also consistent within the wider literature on the link between the therapeutic relationship, engagement and clinical outcomes (Horvath & Symonds, 1991; Klein et al., 2003). In the context of stigma and its impact on the therapeutic encounter, participants referenced that the therapeutic relationship had the potential to revise internalisations of enacted stigma and thus improve engagement with psychological services.

Strengths and limitations[20]

This research adds to the growing literature on patient experience of psychological therapy for FND and highlights how perceived stigma impacts the therapeutic encounter. A strength of this study was the contribution of an expert of experience who provided consultation during the development of the interview schedule and supported recruitment of participants. Furthermore, the study also addresses aims of a recent research agenda (MacDuffie et al., 2020) and provides a basis for understanding how perceived stigma impacts how individuals with FND conceptualise themselves and the condition. However, the research must be considered in light of several methodological limitations. Due to the nature of the qualitative approach, the findings of this study cannot be generalised to the wider population. However, despite the small sample size, the sample was potentially representative of the FND population in terms of gender ratio and varied age of onset (Lidstone et al., 2020). Although the focus of the study was limited to UK psychological provision, there was a range of diversity in the localities of participants, and thus experiences were not solely reflective of one service or NHS Trust.

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[20] See extended paper (section 4.2) for further critique of the study's limitations and recommendations for future research.

Additionally, although participants where asked contextual information (e.g., type of psychological service accessed, type of professional they had worked with and the type of therapy), several participants did not know this information. Due to missing data this information could not be meaningfully compared across the dataset and therefore was not considered during analysis. However, this contextual data may have aided interpretation and informed the recommendations for clinical practice.

Whilst the study provided rich data on the experiences of individuals with FND, it does not consider how this may compare to other stakeholder perspectives (e.g., therapists, clinical psychologists, mental health practitioners). Within the wider literature, there is research exploring medical professionals' perspectives, however it remains unclear how psychological practitioners experience this therapeutic encounter. Future qualitative research is needed to understand these perspectives, specifically the barriers and facilitators to engagement and to the development of the therapeutic relationship. Given the higher prevalence of women diagnosed with FND and existing research highlighting impacts of gender-based stigma in healthcare (Appignanesi, 2011), further research should also consider intersectional stigma and FND (MacDuffie et al., 2020).

Clinical Recommendations[21]

Professionals should be mindful of how experiences of stigma may impact an individual’s perception of explanations pertaining to FND. This should be considered when referring individuals to psychological services through to formulation and intervention. It should be explicitly discussed that ‘psychological factors’ are not synonymous with faked symptoms, with reference made to the biopsychosocial framework (Brown, 2007; Engel, 1977). Similarly, whilst psychological formulation should be tailored to the individual and integrative in its approach, theories that bridge the gap between mind-body dualism may be helpful to reduce feelings of shame e.g., Polyvagal Theory (Porges, 2007), the impact of psychological trauma on the autonomic nervous system (Sherin & Nemeroff, 2011). Practitioners should be mindful that any specific event or experience is likely to be insufficient in explaining

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[21] See extended paper (section 4.3.1) for further discussion on communication psychological explanations, the development of the therapeutic relationship and organisational and systemic change.

the onset of FND, and therefore the formulation should be held tentatively. Psychological formulations should be paced appropriately as to not overwhelm the client (Dawson & Moghaddam, 2016) with language style matching used to support a shared understanding (Knol et al., 2020). When considering the impact of enacted and internalised stigma, the formulation process may be particularly important in fostering feelings of validation, acceptance, and compassion. Furthermore, practitioners should explicitly address perceptions of blame and provide psychoeducation on coping responses to trauma/stressors and the impact of this on the nervous system. Experiences of stigma and how this may influence perceptions of psychological models (e.g., CBT) should also be considered. Given organisational constraints such as the limited specialist FND services (Walker, 2019), psychological services and clinical training providers may benefit from increasing training provision for clinicians. The findings of this study suggest that training for practitioners should aim to develop knowledge and awareness of FND, with consideration of how stigma may impact the therapeutic relationship. This training should be co-produced and co-delivered with experts by experience, to minimise the risk of stigmatised ideas being further embedded in services. It is recommended that this training is evaluated from multiple perspectives, with a focus on the impact on clinical practice.

Conclusion

To our knowledge, this is the first study exploring the experiences of psychological services and highlights the impact of perceived stigma on the therapeutic encounter from the perspective of those with a diagnosis of FND. Our findings provide a nuanced understanding of how intra-personal, interpersonal, and organisational stigma impact access and engagement to psychological treatment. These findings were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services. Positive therapeutic relationships were perceived to mitigate the impact of perceived barriers. Furthermore, the therapeutic alliance may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention. The findings of this study highlight the need for increased training provision for practitioners with a focus on actively challenging FND stigma within services, at both an individual and systemic level.

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EXTENDED PAPER

Extended Introduction

1.1 Historical Context of Functional Neurological Disorder

Functional Neurological Disorder (FND) has been known by several different names throughout history, arguably due to the etiological uncertainty that surrounds the condition (Raynor & Baslet, 2021). One of the first names for presentations now referred to as FND, was "hysteria" (Madva et al., 2019). The ancient Egyptians coined the term to describe medically unexplained symptoms in women due to the belief that this was caused by movement of the female reproductive organs (Madva et al., 2019). In the 19th century, the concept of "hysteria" was widely debated and there was a growing view that medically unexplained presentations originated in the mind (Raynor & Baslet, 2021). These presentations were labelled as a "nervous illness" that had resulted as a dissociation from painful emotion or as a feigned illness for secondary gain (e.g., malingering) (Bass, 2016; Madva et al., 2019). During the turn of the 20th century, Freud (1912) built on the concept of "hysteria" and medically unexplained symptoms by hypothesising that repressed psychological trauma manifested as physical symptoms ("hysterical conversion"). Despite the rejection of hysteria in modern times, Freud's theoretical framework continued to underpin diagnostic labels such as conversion disorder. Furthermore, treatment for these types of presentations often occurred in mental asylums and included "ovarian compression" (Massey & McHenry, 1986), highlighting the link between FND and gender throughout history (Madva et al., 2019). However, this was challenged by the rise of medically unexplained symptoms in male soldiers in the First World War; a presentation coined "shell shock" (Linden & Jones, 2014). Attempts to explain these presentations in men in the context of war appeared to lend support for theories around dissociation from psychological trauma (Myers, 1915). Although ideas related to "malingering" persisted, with suggestions that these symptoms were feigned by soldiers to avoid active duty (Jones & Stone, 2020). It could be argued that this historical context, plus the widely debated causal and maintaining factors, have resulted in the FND label being associated with negative and stigmatised connotations. Whilst the medical and psychiatric field has moved past historical explanations, it should be noted that the term "hysteria" is still used colloquially to refer to "uncontrollable emotions" (Madva et al., 2019; Raynor & Baslet, 2021).

1.2 Functional Neurological Disorder and Gender

There is evidence to suggest that gender ratios vary dependent on age of onset (Lidstone et al., 2022) but highlight that women are two to three times more likely to receive a diagnosis of FND (Matin et al., 2017). Furthermore, the research suggests that gender may impact the type of FND presentation; with women more likely to experience functional dystonia (muscle spasms and contractions) and men more likely to present with difficulties pertaining to movement and gait (Baizabal-Carvallo & Jankovic, 2019). The reasons for this gender difference are currently poorly understood (Baizabal-Carvallo et al., 2019). Given that the literature proposes psychological trauma as a risk factor for the development of FND (Ludwig et al., 2018) it is hypothesised that sexual abuse may explain the gender differences observed in FND (Kletenik et al., 2020, 2022). This hypothesis is based on research highlighting higher rates of reported sexual abuse in women compared to men (Basile et al., 2011; Smith et al., 2018). However, it is widely acknowledged that men are less likely to report sexual abuse (Sabe et al., 2006) and thus may be underrepresented in the data. Research comparing lifetime prevalence of sexual abuse in FND and control populations found that sexual abuse was reported more in those with a diagnosis of FND (Kletenik et al., 2019). Kletenik and colleagues (2019) concluded that the risk of developing FND following sexual abuse was higher in women than men. Despite this, due to the methodological limitations (e.g., small sample size, self-report data) the research is unable to explain the gender differences observed in FND or whether abuse plays a causal mechanistic role (Edwards & Aybek, 2020). In addition, it should be noted that not all individuals with a diagnosis of FND report experiences of adverse life events or trauma (Espay et al., 2018; Ludwig et al., 2018), suggesting that the link with FND and gender is not solely underpinned by experiences of abuse. It could be argued that these gender differences can be understood through the lens of FND’s historical context. As a result of this, clinicians may be more likely to diagnose FND in women and more likely to consider other diagnoses for men presenting with the same symptoms (Edwards & Aybek, 2020). However, there is a paucity of research exploring these hypotheses and thus the relationship between FND and gender remains unknown.

1.3 Changes to Diagnostic Criterion

Although FND has previously been considered a medically unexplained presentation, there has been a shift in the literature with the umbrella term “persistent physical symptoms” increasingly used. This changing language arguably reflects an ongoing paradigm shift in this area with the aim of destigmatising these types of presentations. In line with this, the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013) removed two requirements for diagnosis of FND; ‘recent psychological stressor’ and ‘exclusion of feigning’ (Lehn et al., 2016). This is reflected more broadly in diagnostic frameworks that no longer differentiate between somatic and medically explained symptoms, instead there is a focus on levels of distress. Despite the intentions of this paradigm shift, it has been criticised for assuming that both medically explained and unexplained presentations are underpinned by the same causal mechanisms (Rief & Martin, 2014). Given there is no empirical evidence or consensus within the literature on this topic, this arguably has concerning implications on both clinical practice and research (Rief & Martin, 2014). Therefore, further research on the similarities and differences between presentations with and without a medical explanation is needed (Rief & Martin, 2014).

1.4 Theoretical Models of Functional Neurological Disorder

1.4.1 Cognitive Behavioural Model

Cognitive behavioural theory (CBT) postulates that our life experiences shape our beliefs of self, others, and the future (Beck, 1970). These fundamental beliefs underpin our appraisals and interpretations of events, and thus influence our emotions and behavioural responses (Beck, 1970; 2011, 2020). These behavioural responses are developed and maintained through classic and operant conditioning processes (Skinner, 1971). Beck (1970) proposed that ‘dysfunctional thinking’ is a common feature to all forms of psychological distress. In the context of Functional Neurological Disorder, the CBT model emphasises that the onset and maintenance of the condition is a “self-perpetuating” cycle that is influenced by several factors (van Ravenzwaajj et al., 2010). These cognitive, emotional, and behavioural (e.g., symptom vigilance, safety behaviours, monitoring, avoidance) processes result in physical symptoms and thus may be categorised as predisposing, precipitating and/or perpetuating factors. Although aspects of the model are well-validated within the empirical literature, it should be noted that these studies were cross-sectional studies using self-report data (Rief & Broadbent, 2007). In light of the methodological limitations of the research, the studies only suggest an association, and not causation. Furthermore, the model was originally developed to explain the maintenance of health anxiety and has been criticised for over-simplifying the complexity of FND presentations (Rief & Broadbent, 2007). The CBT model of FND is considered a meta-model, as it incorporates several different theories of the condition:

1.4.1.1 Cognitive Perceptual Theories

Cognitive perceptual theories propose that individuals with FND have an increased proprioception (the body's ability to sense its movement and location) (van Ravenzwaajj et al., 2010). As a result of this, individuals are more sensitive to the perception of their body and thus slight physiological changes may be experienced as abnormal. Somatosensory amplification is a process in which an individual's attention is focused to a benign physical symptom (Barsky et al., 1988). The individual develops cognitions and appraisals that further amplify their perception of the physical sensation. For example, an individual may attribute these innocuous sensations as a signal of threat and thus increase their attentional awareness to monitor for further symptoms. This leads to a self-perpetuating cycle with physical sensations being reinforced by an individual's cognitions and behavioural responses. Furthermore, these cognitions result in feelings of anxiety and distress, which may increase experiences of unpleasant physical sensations (van Ravenzwaajj et al., 2010). The empirical literature highlights symptom appraisal, attentional processes, and perception as important factors in the maintenance of FND (Petrie & Weinman, 2003). However, this theory does not consider other factors supported by empirical evidence and may therefore only partially explain how FND is maintained (Duddu et al., 2006).

1.4.1.2 Illness Behaviour Model

The illness behaviour theory postulates that an individual’s beliefs impact their behavioural response and subsequently their emotional and physiological experiences (Mechanic, 1962). This is further maintained by the behavioural response to the physical sensations, resulting in a maintaining cycle of the difficulties. In the context of FND, an individual may avoid activities to manage symptoms, however this leads to increased attentional awareness to physical sensations, increased anxiety and physical deconditioning that further maintain the condition (van Ravenzwaajj et al., 2010). In addition, the theory proposes to address key questions around why some individuals may develop FND and others may not (Pilowsky, 1969), highlighting that illness behaviours are influenced by previous illness experience and cultural and social factors (Mechanic, 1977). Pilowsky (1969) suggested that individuals with ‘functional symptoms’ demonstrated ‘abnormal’ illness behaviours. This has faced criticism for being paternalistic in nature (Carson et al., 2016) and for placing blame within the individual rather than acknowledging the inadequacy of medical explanations of the condition (Armstrong, 1986). Despite illness behaviours being regularly cited as a maintaining process in FND presentations, there is a paucity of empirical research examining this theory (Deary et al., 2007; Rief & Broadbent, 2007). Furthermore, the theory can be applied to both medically explained and unexplained presentations which arguably undermines the theory’s explanation of the onset of FND type presentations (Carson et al., 2016).

1.4.1.3 Sensitisation Theory

Individuals with FND may experience a heightened somatic response due to previous experiences of these physical sensations (van Ravenzwaajj et al., 2010). It is postulated that repeated experiences of sensations (e.g., pain) can result in neuronal level somatic memories. These somatic memory traces may increase sensitivity leading to benign sensations being perceived and experienced as pain. This process suggests a neural and psychological interaction, with sensations attached to distressing or negative memories activating further physiological and emotional responses (Deary et al., 2007). The concept of somatic memories has been supported within the wider literature with neural plasticity studies concluding that repeated experiences of pain can heighten future symptom perception (Arnstein, 1997). These perceptions of physical sensations and the associated cognitive appraisals may hinder the process of habituation, and thus individuals experience increased psychological distress (Rief & Barksy, 2005).

1.4.2 Bayesian Inference Model

Edwards and colleagues (2012) propose a neurobiological model of FND: the Bayesian Inference Model. The theory outlines that motor and sensory symptoms can be explained by changes in perception and behaviour based on prior predictions and sensory information. These active inferences are mediated by beliefs about illness, emotional experiences, expectations of symptoms and increased attentional focus to physiological sensations. The brain receives information through ‘top down’ (predications) or ‘bottom-up’ (sensory data) processes. Failures of inference, such as when top-down processes are relied on more heavily, can result in the initiation or absence of movement. Increased bodily attention and focus on the prediction and expectations of the symptom increase the likelihood of the ‘abnormal’ prediction overriding the sensory data, thus maintaining the difficulty. This theory is supported by research findings whereby when an individual with FND is distracted there is a temporary reduction in their functional motor symptoms (Nielsen et al., 2015).

1.4.3 Psychodynamic Theories

1.4.3.1 Somatization

Somatization is conceptualised as a physical and somatic expression of psychological distress (Robbins et al, 1997; Lipowski, 1988). It is considered an umbrella term to describe the following two psychodynamic theories:

1.4.3.2 Conversion

Freud and Breuer (1895) proposed that repressed stress and psychological trauma are converted into physical symptoms. The emotional reaction may be inhibited due to an inner conflict and a belief that the hidden feeling is “unacceptable”. For example, an individual may repress feelings of anger towards their parent. This physical manifestation is considered a defence mechanism, allowing for the release of emotional tension whilst reducing the anxiety associated with the inner conflict. This reduction in anxiety is considered a ‘primary gain’ of the conversion process, with secondary gains (e.g., avoidance of other stressful situations) also hypothesised (Cretton et al., 2020). However, it should be noted that qualitative research has highlighted that individuals with FND may not support these explanations of their condition (Nielsen et al., 2020). Although the conversion defence may be considered as protective in function, it likely becomes a maladaptive mechanism as the individual remains unable to acknowledge and address the underlying conflict. In the context of FND, conversion is a proposed defence that results in chronic physical symptoms and an inability to recognise one’s emotional state (Cretton et al., 2020). The link between psychological trauma, stress and FND is widely cited within the broader literature (Ludwig et al., 2018), with antecedent stressors varying in nature (Stone, 2009). It should be noted that not all patients with FND report experiences of stress or psychological trauma (Ludwig et al., 2018). However, this may be due to individuals’ understanding of what constitutes ‘trauma’, with more subtle psychological stressors underreported, not viewed as relevant by the patient or not identified with life event checklists (Cretton et al., 2020). Despite supporting evidence (e.g., link with psychological trauma and stress) in the wider literature, conversion theory’s proposed causal mechanism is not based on empirical evidence (Brown, 2004). Furthermore, it has been suggested that due to the dominance of the theory, alternate explanations are ignored in both clinical and research settings (Roelofs & Spinhoven, 2007).

1.4.3.3 Dissociation

The dissociation model posits that distressing memories of a traumatic event are not fully integrated due to overwhelming emotion and deficits in attention (Janet, 1907). These memories are not processed in the usual manner and thus can be activated by internal or external triggers following the event. The theory assumes that this is a subconscious process, with the individual re-experiencing the memory as a current reality. In the context of FND, medically unexplained presentations occur when the dissociated memory involves a somatic element (e.g., physical sensation). Although, this model has not been empirically validated due to difficulty operationalising ‘dissociation’, it is partially supported by research that indicates individuals with FND have different forms of cognitive processing compared to controls (Brown, 2006).

1.4.4 Polyvagal Theory

Polyvagal theory (Porges, 2009) is underpinned by psychological, evolutionary, and neurobiological theories of the role of the vagus nerve in social functioning, threat response and emotion regulation. The vagus nerve is intrinsically linked to the autonomic nervous system which controls unconscious bodily processes such as breathing, reflexes and digestion (Johnson & Wilson, 2018). Polyvagal theory proposes that chronic stress and adverse life events (e.g., psychological trauma) have a profound effect on the nervous system (Porges, 2009), and subsequently our emotional, physiological, and behavioural responses (Hudson, 2020). According to the theory, the autonomic nervous system evolved into three different branches. The most primitive system (dorsal vagal) is activated in response to overwhelming fear and life-threatening events. As the amygdala activates, higher cortical systems in the brain become overridden and thus the body enters a state of immobilisation. This immobilisation may be understood as an attempt to survive (e.g., anti-predator adaptive behaviour such as death feigning observed in animals). In clinical settings, activation of the dorsal vagal system may be observed as vasovagal syncope (fainting), catatonic states or dissociative episodes related to FND presentations. As the nervous system moves out of immobilisation into the fight or flight response, it begins to process and evaluate the level of threat. In this second branch of the nervous system (sympathetic), the body is flooded with the stress hormone cortisol and adrenaline is released into the bloodstream to prepare the body to respond to the threat. Individuals who remain in this state chronically may be hypervigilant to threat cues, misinterpret signs of threat in others and find it difficult to regulate their emotions. Finally, the third branch of the nervous system (ventral vagal), proposed to only exist in mammals, is responsible for social engagement. During this neurobiological state, an individual can self-regulate and co-regulate their emotions through interaction with others. The parasympathetic nervous system is activated due to appraisals of the environment as safe and thus neuro-endocrine responses (e.g., cortisol and adrenaline) are inhibited. If an individual remains in the ventral vagal state, they are able to respond and recover from threat quickly, without becoming stuck in the dorsal vagal or sympathetic systems (Hudson, 2020).

The theory posits that an individual's response to threat and the functioning of their nervous system is dependent on their prior experiences (Porges, 2009). The responses to threat that were once adaptive may be unconsciously adopted by default process. For example, an individual who has survived childhood sexual abuse by "shutting down" and dissociating may subsequently respond to perceived threat by becoming immobilised (dorsal vagal system) (van Der Kolk, 2014). Similarly, individuals who have experienced prolonged and chronic stress may remain within the fight-flight response (sympathetic nervous system). Over time, these experiences impact the nervous system and may result in physical symptoms that attract the diagnosis of FND (Hudson, 2020). Although Polyvagal theory has faced criticism for its lack of empirical evidence (Grossman & Taylor, 2007), recent meta-analysis highlighted the link between psychological trauma and autonomic nervous system dysfunction (Scheider & Schwerdtfeger, 2020). In the context of FND, individuals with medically unexplained symptoms have been found to have reduced heart rate variability (indicating increased sympathetic nervous system activity) compared to "healthy" controls (Ruschil et al., 2021). These findings are consistent with research that found that individuals with FND had an impaired resting state vagal tone which may increase their vulnerability to stress (Maurer et al., 2016).

1.4.5 Endocrine Dysregulation Theory

The hypothalamic pituitary gland (HPA) axis involves interaction between the hypothalamus and pituitary gland (located above the brainstem) and the adrenal glands (located above the kidneys). The HPA axis uses a feedback loop system to regulate the body's reaction to stress (Kinlein & Karatsoreos, 2015). The theory posits that chronic stress and psychological trauma results in reduced HPA activity (Binder et al., 2008). This dysregulation of the HPA axis has also been found in those with a diagnosis of FND (Apazoglou et al., 2018) suggesting a link between these mechanisms. However, direction of effect has not been established and therefore it is unclear whether dysregulation of the HPA axis causes FND presentations or occurs as a result of the stress associated with living with the condition (Rief and Barsky, 2005). Furthermore, endocrine dysregulation has been linked to other psychiatric conditions such as Anorexia Nervosa (Miller, 2011) and neurodevelopmental conditions such as Autism (Swierczynski, 2019). Thus, this theory is unlikely to provide a singular and comprehensive explanation of the development and maintenance of FND.

1.4.6 Stress-Diathesis Model

The stress-diathesis model (Monroe & Simons, 1991) proposes that environmental factors (e.g., adverse events, trauma, stressors) may trigger onset of symptoms in individuals who are biologically predisposed to the condition. In the context of FND, it is postulated that several risk factors influence susceptibility to developing the condition. These risk factors range from endocrine regulation (Kinlein & Karatsoreos, 2015), cognitive perceptual processes (Barsky et al., 1988), neurobiological processes (Edwards et al., 2012) and psychological responses to perceived threat (Cretton et al., 2020; Porges, 2009). It is hypothesised that individuals with a strong biological predisposition to FND may develop the condition following a ‘mild’ environmental trigger (e.g., work stress). Whereas an individual with a low biological susceptibility may only develop FND following significant psychological trauma and a moderate to severe precipitating stressor (Keynejad et al., 2019). This theory may explain why individuals with FND develop the condition despite differences in environmental factors, and why not all individuals who have experienced psychological trauma present with these symptoms. It should be noted that individuals with FND are less likely to link stress to their symptoms compared to matched controls (Stone et al., 2010). However, in a study using the Life Events and Difficulties Schedule (LEDS), 91% of individuals with FND endorsed statements related to significant life stressors. Interestingly, 88% of these stressors were not recorded in the patients' clinical notes, suggesting that these had not been mentioned or deemed relevant by the patient or practitioner (Brown et al., 1973). Although this study used a sample from a distinct geographical location and thus may not be generalisable to all individuals with FND (Cretton et al., 2020). Furthermore, the findings of this study may be outdated, as there is now a greater awareness of ‘trauma informed care’ embedded within current services as outlined by the inclusion of trauma informed approaches in local, regional, and national UK policy (Emsley et al., 2022). It is unclear whether the findings of Brown and colleagues (1973) study would be replicated if repeated in current times. Although, it is outlined in the current empirical literature that a proportion of those with a diagnosis of FND either do not report or explicitly deny experiences of trauma (Ludwig et al., 2018).

1.4.7 Biopsychosocial Framework

The biopsychosocial model assumes that all illness comprises of both physical and psychological components that interrelate with one another (Engel, 1977). This involves a complex interaction between psychological factors (beliefs, emotions, behaviour), biological factors (genetic predispositions, biochemical processes) and social factors (cultural and socioeconomic background) (Engel, 1981). An example of this in the context of FND may be, an individual has a high biological susceptibility for the condition which is triggered by significant psychological stressors. The condition may then be maintained by illness behaviours influenced by social and cultural factors and personal factors such as emotional avoidance. Akin to the stress-diathesis model, this theory postulates that an individual's genetic predisposition is triggered by psychological and social factors.

Given the heterogeneity of FND presentations (Espay et al., 2018), it is unlikely that one singular theory is adequate in explaining the onset and maintenance of the condition. Therefore, frameworks that allow for the integration of several theories appear to be the most appropriate in understanding the causal and maintaining mechanisms that may underpin FND.

1.5 Stigma

The word stigma has Greek origins and describes an ancient process in which 'criminals' would be physically marked to alert others of their 'immoral' character (Goffman, 1963). In contemporary times, it is acknowledged that stigma occurs without the presence of a physical mark but as an appraisal that an individual is "socially different" (Bos et al., 2013). This recognition of difference leads to social devaluation and disapproval from others (Dovidio et al., 2000). The process of stigma occurs within interpersonal interactions and thus stigma exists within the social sphere (Hebl & Dovidio, 2005). The stigmatisation of a person or group may be overt (e.g., avoidance, dehumanisation, marginalisation, and discrediting) or more covert (e.g., implicit communications of discomfort during interactions) (Hebl et al., 2000; Herek, 1999; Knaak et al., 2017). Experiences of stigma are associated with increased risk of poverty, poor mental and physical health and social isolation, which subsequently reinforce perceptions of stigma (Elliot & Masters, 2009). The correlation with poor mental and physical health may be explained by research highlighting the link between experiences of stigma and poor engagement with healthcare services (Stangl et al., 2019). This has far-reaching implications on treatment outcomes across a range of health conditions (Stangl et al., 2019).

1.5.1 Explanatory Models of Stigma

Based on Goffman's model (1963), it is proposed that stigma can occur interpersonally (e.g., interactions with others), intra-personally (e.g., internalised stigma) and structurally (e.g., in organisations and systems) (Link & Phelan, 2001). In interpersonal stigma (stigma enacted by others), it is proposed that these interactions are underpinned by the cognitive representations that are held about the stigmatised group (Bos et al., 2013). Negative cognitive representations result in a subsequent negative emotional and behavioural response (Dijker & Koomen, 2003). These cognitive representations may involve concepts such as 'onset controllability' (e.g., attributed personal responsibility), in which individuals perceived to have 'high levels of personal responsibility' for the development of their condition experience higher levels of social disapproval (Bos et al., 2013). The 'perceived severity' of the condition (e.g., whether the condition is viewed as life threatening), the 'perceived dangerousness' of the condition (e.g., group viewed as unpredictable and harmful) and the 'perceptions of violated norms' (e.g., condition associated with 'deviant' activities) all impact the levels of enacted stigma an individual may experience (Bos et al., 2013; Dijker & Koomen, 2003; Feldman & Crandall, 2007). When applying this to FND, it could be suggested that the historical context of the condition (e.g., associations with hysteria, malingering and mental illness) result in perceptions that individuals have control of their symptoms (Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsley et al., 2011) and that the perceived severity of the condition is low. Furthermore, given the conditions historical association with "mental illness" and ‘malingering’, it could be argued that FND may be perceived as ‘dangerous’ and a violation of social norms.

Intrapersonal stigma (self-stigma) is considered to be the result of an individual’s awareness of social stigma on an implicit and explicit level (Bos et al., 2013). Similar to interpersonal stigma, negative cognitive representations of the self impact the emotional and behavioural responses of the individual (Mak & Cheung, 2010). A stigmatised individual may anticipate stigma in their interactions with others as a result of previous enacted stigma or experience an internalisation of this stigma leading to low self-worth (Herek, 2009). In response to this multi-layered stigma, individuals may attempt to conceal the stigmatised attribute/condition, with research suggesting worries around disclosing this information to colleagues/friends leads to significant psychological distress (Pachankis, 2007). When this information is disclosed or discovered, individuals report fears of their character being ‘discredited’ by others (Stutterheim et al., 2011).

Finally, structural stigma is a term to describe how institutions and societal beliefs further reinforce and maintain stigma (Corrigan & Lam, 2007). Economic, political and social power highlight and perpetuate social inequalities (Link & Phelan, 2001; Scambler & Paoli, 2008) dependent on the historical and social context. As a result of this, the societal structures perpetuating stigma may vary dependent on the cultural and social context in which the stigma exists (Foucault, 1977). In the context of FND, this may be viewed as the lack of investment in specialist service provision and the inadequate levels of staff training on the condition.

1.5.2 Stigma and Chronic Illness

The link between stigma and chronic illnesses is widely recognised (Engebretson, 2013; Fitzpatrick, 1984). It is proposed that there are four categories of illness: mental illness, acute illness, chronic non-stigmatising and chronic stigmatising (Fields, 1976). The differentiation between stigmatising and non-stigmatising illness may depend on several factors such as the perceived difficulty in understanding the symptoms and the perception of social consequences associated with the condition. Consistent with general theories of stigma (Goffman, 1963; Link & Phelan, 2001), it is hypothesised that the level of stigma is influenced by perceptions of responsibility for the illness and the impact of the illness on social interactions (e.g., perceived discomfort of others) (Albrecht et al., 1982). This theory outlines why physical illness may be considered less stigmatising than conditions believed to be psychological in nature (Jacoby et al., 2005). When viewing this through the lens of FND, it could be suggested that the stigma associated with the condition is partially the result of the widely debated causal and maintaining factors. The unknown aetiology of the condition exists within the social and historical context, perpetuating negative and stigmatised connotations.

1.5.3 Stigma and Functional Neurological Disorder

The relationship between FND and experiences of stigma have been highlighted within the literature, with a recent international survey concluding that 81% of participants had experienced stigma related to the condition (Butler et al., 2021). Furthermore, participants reported perceptions that their medical care had been negatively impacted by experiences of stigma and this led to worries about accessing healthcare in the future (Butler et al., 2021).

Whilst there is a paucity of research exploring the perspectives of those with a diagnosis of FND, research from the perspective of healthcare professionals emphasise the negative perceptions that may be associated with the condition. Some healthcare professionals reported perceptions that FND symptoms were “voluntary” or “fake” (Shneker & Elliott, 2008) and that individuals had control over their symptoms (Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsley et al., 2011). It should be noted that these studies were limited to small sample sizes and thus the findings cannot be generalised to all healthcare professionals. However, it could be argued that stigmatised perceptions are influenced by the historical context of FND (e.g., “hysteria”) (Raynor & Baslet, 2021) and gaps in professional’s knowledge and training (Hutchinson & Linden, 2021). In addition, findings from a recent meta-synthesis highlighted that medical professionals may feel overwhelmed by the complexity of the condition and “pass the buck” to another discipline or service (Barnett et al., 2022). This may be understood through the lens of psychodynamic defences in which clinicians avoid contact or depersonalise patients that evoke feelings of anxiety (Menzies Lyth, 1961). Arguably, medical professionals’ attempts to manage feelings of uncertainty further perpetuate experiences of stigma for those with a diagnosis of FND. A meta-ethnographic synthesis of experiences of stigma amongst people with FND identified that individuals feel abandoned and excluded by medical services (Foley et al., 2022). In response to these perceptions of enacted stigma, individuals reported avoiding interactions with medical professionals, concealing their illness from others and withdrawing from social activities in a bid to protect themselves from further anticipated stigma (Foley et al., 2022).

1.6 Current UK Service Provision for Functional Neurological Disorder

Gold standard multi-disciplinary intervention for FND involves both psychological treatment and physical rehabilitation (LaFaver et al., 2021). A stepped model of care proposed by Carson and Stone (Health Improvement Scotland, 2012) emphasises that treatment should be tailored to the individual based on their psychological and physical presentation. Step 1 of the model involves brief psychoeducation and signposting for management with primary care services; this approach is appropriate for individuals with mild presentations (e.g., transient symptoms, minimal disruption to functioning). For patients presenting with severe physical symptoms but without complex mental health needs, brief psychological or neuro-rehabilitative intervention should be offered (Step 2). Step 3 is therefore focused on the treatment of the most complex cases (e.g., severe and enduring physical and psychological symptoms, impact on daily functioning, previous treatment deemed ineffective) and recommends multidisciplinary input from a specialist FND service (outpatient or inpatient). These multidisciplinary services may include a neurologist, clinical psychologist, psychiatrist, occupational therapist, physical therapist and speech and language therapist (La Faver et al., 2021). It is recommended that the intervention provided is systemic in nature, involving family and carers to reduce the likelihood of future relapse (La Faver et al., 2021).

Despite the recommended stepped care approach (NHS Scotland, 2012), there is currently no National Institute of Health and Care Excellence (NICE) guideline for the treatment of FND, although reference is made in the quality standards for FND that there should be “the offer of psychological support where appropriate” (NICE, 2021). Clinical audit of NHS services against these quality standards has concluded that these standards are regularly not met and thus individuals with FND are failed by services (Houston & Cooper, 2022). Whilst there are some specialist FND services within the National Health Service (NHS), a large portion of those with a diagnosis of FND will be referred to general psychological services due to limited specialist service provision and increased waiting times (Walker, 2019). Some services have proposed the development of FND psychological assessment and formulation pathways within general services (Jones, 2020), however these are in the initial stages and thus long-term data on the effectiveness of these pathways is unknown.

1.7 Psychological Interventions for Functional Neurological Disorder

1.7.1 Cognitive Behavioural Therapy

Cognitive behavioural therapy (CBT) for FND aims to target cognitive (e.g., attentional focus to symptoms, catastrophic appraisals) and behavioural (e.g., avoidance, symptom monitoring) factors that are hypothesised to maintain the condition (Brown & Reuber, 2016). Through collaborative empiricism, the individual is supported to challenge unhelpful illness behaviours and cognitions through behavioural experiments, graded exposure and cognitive restructuring techniques (Beck, 1970). Whilst this can be tailored to the individual, structured CBT-informed interventions have been developed specifically for FND (LaFrance et al., 2009, 2014). Meta-analysis of CBT studies showed statistically significant improvement of physical symptoms with moderate to large effect (Gutkin et al., 2021). Effect sizes for measures of mental health, functioning and quality of life were small to moderate (Gutkin et al., 2021). Median pooled pre-post effect size was calculated at 0.49 at the end of treatment and 0.33 at follow up (Gutkin et al., 2021). Although a strength of this systematic review was the inclusion of high-quality studies, the effect sizes were calculated without distinction of the primary and secondary endpoints which may have introduced statistical error (Gutkin et al., 2021).

1.7.2 Acceptance and Commitment Therapy

Acceptance and Commitment Therapy (ACT) is a third wave CBT approach which focuses on changing an individual’s response to distressing thoughts and emotions with the aim of living a value-led life (Hayes et al., 2004, 2006). The approach is underpinned by the philosophy that life is a “process to be lived, not a problem to be solved" (Hayes, 2019 p.10). Furthermore, it is proposed that all behaviour (including thoughts and emotions) serve a purpose and function within context (e.g., functional contextualism). However, individuals experiencing psychological distress are considered to be responding to life's challenges in unhelpful or inflexible ways (Harris, 2019). This may be due to cognitive fusion (e.g., difficulty separating from one's cognitions) or experiential avoidance (e.g., attempts to avoid experiencing unpleasant or distressing internal events) (Curvis & Methley, 2021). The evidence base examining the effectiveness of ACT for FND is in its infancy, however, there have been several studies highlighting mixed results. Reliable change in the improvement of psychological flexibility, FND symptom interference and mood was reported in one case study (Graham et al., 2017), and reduction in self-reported frequency of seizures was observed in a non-concurrent case series (Barrett-Naylor et al., 2018). However, Graham and colleagues (2018) consecutive case series found no reliable change in symptom interference or mood. These findings should be considered in light of several methodological limitations and thus it is difficult to determine whether the therapeutic changes identified are a result of the intervention or other common factors (e.g., the therapeutic relationship) (Barrett-Naylor et al., 2018). Despite this, ACT is a widely used intervention for persistent physical health conditions (Cope et al., 2017; Hughes, 2017) and therefore may be a promising treatment for FND presentations.

1.7.3 Brief Psychodynamic Therapies

Psychodynamic therapies (PDT) focus on the emotional and interpersonal domains with the aim of locating the "central pain" and associated affect (Blagys & Hilsenroth, 2000). There are several hypothesised mechanisms of change within PDT; interpersonal interactions (past and present), the recognition of reoccurring patterns and themes, and the therapeutic relationship (transference and countertransference) (Luborsky et al., 1990). It is proposed that change occurs through the recognition and understanding of these unconscious processes (Luborsky et al., 1990). Meta-analysis of PDT showed statistically significant improvement of physical symptoms with moderate to large effect (Gutkin et al., 2021). Median pooled pre-post effect size was calculated at 0.69 at the end of treatment and 0.49 at follow up (Gutkin et al., 2021). Comparison of CBT and PDT found higher pre-post median pooled effect sizes for PDT at both treatment end and follow-up (Gutkin et al., 2021). However, these findings should be interpreted in the context of several methodological limitations; the inclusion of poor-quality studies with small sample sizes. Furthermore, the effect sizes were calculated without distinction of the primary and secondary endpoints which may have introduced statistical error (Gutkin et al., 2021).

1.7.4 Eye Movement Desensitisation and Reprocessing Therapy

Eye movement desensitisation and reprocessing (EMDR) therapy is an eight phased protocol that targets and reintegrates psychologically distressing memories by utilising bilateral eye movements (Shapiro, 2001). The intervention is underpinned by the Adaptive Information Processing model (AIP) which proposes that physical symptoms are the result of unprocessed traumatic memories (Shapiro, 2001). When these memories are triggered, the individual re-experiences the somatic sensations and emotions associated with this memory (Shapiro, 2014). It is proposed that the reprocessing of these memories reduces the somatic and emotional arousal, and thus the physical re-experiencing of symptoms decreases (Shapiro, 2001). In addition, EMDR has been found to reduce autonomic nervous system arousal (Voitova & Hasto, 2009). Through this lens, FND type presentations are hypothesised to be a physical re-experience of traumatic memories that are maintained by cognitive, emotional and neurobiological factors (Van der Kolk & Fisler, 1995; Van Rood & De Roos, 2009). Systematic review of the effectiveness of EMDR for medically unexplained presentations concluded that there was promising emerging evidence that warranted further high-quality sufficiently powered research (Staton et al., 2022). Effect sizes could not be calculated due to heterogeneity of study design. Whilst all 28 studies included in the narrative synthesis reported reduction in the frequency and severity of medically unexplained symptoms, only five of these studies included participants with a diagnosis of FND. The majority of these studies utilised a case study design and were deemed low quality and thus cannot be generalised to a wider population. However, the findings of this review provide direction for future research (Staton et al., 2022).

1.8 Extended Rationale

Individuals with FND are regularly referred to psychological services following diagnosis, however there is no published research on individuals' experiences in these settings. Furthermore, although it is acknowledged that individuals with FND experience significant stigma, current research has focused predominately on experiences in medical settings. Recent meta-synthesis exploring experiences of stigma emphasised that included papers described individuals' experiences of stigma in medical settings and wider society (Foley et al., 2022), however this highlighted that little is known on the perceptions of stigma in psychological services. The devastating impact of stigma on engagement and treatment outcomes has been well-documented across a range of other health conditions (Stangl et al., 2019). Whilst the association with stigma has been documented, due to the lack of research on experiences in psychological services, it was deemed important to broaden the aim of this research to ensure opportunity for different perspectives. The perspectives of those accessing services are essential in understanding and improving the quality of healthcare provision (Reader et al., 2014). This is particularly pertinent for individuals with FND, with recommendations for future research emphasising that those with a diagnosis of FND should be empowered to share their voices and to drive changes in care (Rommelfanger et al., 2017). As the current research was the first study to explore experiences of UK psychological services from the perspective of those with FND, an inductive-deductive analytic approach allowed for novel insights to be developed from the data whilst allowing for relevant theories to inform interpretation.

Extended Methodology

2.1 Epistemological Position

The study is grounded within the epistemological position of critical realism. Critical realism assumes ontological realism; "the intransitive objects of knowledge are invariant to our knowledge of them" (Bhaskar, 1979, p.12). Whilst acknowledging epistemic relativism; our measurements are biased, and our understanding tentative and influenced by context (Ponterotto, 2005). Critical realism also highlights judgmental rationalism as a central tenet within its position. This assumes that multiple perspectives should be sought, compared and evaluated, in order to reach a consensus of “truth” (Barker, Pistrang & Elliott, 2002). As a result of this, a critical realist position lends itself to qualitative research that seeks to identify and explore tentative causal explanations of unobservable phenomena (Lund, 2005).

By adopting this epistemological position, it is accepted that the aim of research is to develop “the best explanation of reality through engagement with existing (fallible) theories about that reality” (Carter & New, p. 166) whilst also allowing for the emergence of new information (Fletcher, 2017). With this in mind, the position is compatible with inductive-deductive thematic analysis. Within this study, the critical realist position and compatible methodology allows for the development of an integrated yet tentative understanding of experiences of UK psychological services from the perspective of those with a diagnosis of Functional Neurological Disorder.

2.2 Rationale for Qualitative Methodology

Qualitative methodologies are appropriate for exploratory research that aims to understand experiences of a particular phenomenon (Braun & Clarke, 2013). Due to the focus on an individual meaning and context-bound experiences, qualitative analysis allows for the identification of patterns and contradictions within the data. This multi-faceted understanding provides a rich insight into the complexity and nuanced experiences of the individual, situated in partial or socially influenced truth (Braun & Clarke, 2021). Unlike quantitative approaches which are grounded in positivist or post-positivist epistemologies, qualitative approaches value the subjectivity of the researcher (e.g., ‘the interpreter of meaning’) (Braun & Clarke, 2021). Given the aims of this research and the paucity of research on this topic, quantitative methodologies which seek to identify relationships between variables and establish cause and effect, would not be appropriate. In line with the research aims, a qualitative approach, allowing for the generation of ‘contextualised and situated knowledge’ was adopted (Braun & Clarke, 2021).

2.3 Selecting a Qualitative Methodology

Qualitative analysis can be separated into two groups: descriptive/exploratory and interrogative/interpretative (Braun & Clarke, 2013). These groups align with the orientation adopted by the researcher. Experiential qualitative approaches view language as a tool to communicate the meaning an individual has made based on their worldview. The philosophy of interpretation is a *'hermeneutics of empathy',* in which analysis seeks to make sense of the reality portrayed in the data. Conversely, critical qualitative approaches view language as creating meaning and reality, rather than reflecting and communicating this meaning. This analytic orientation is informed by a '*hermeneutics of suspicion'* in which analysis "interrogates and asks critical questions of the meanings in the data" (Braun & Clarke, 2021 p.160). When considering the analytic orientation of the researcher, there must also be consideration of the theories of language that underpin qualitative methodologies. Realist positions view language as reflective of truth that can be revealed through communication, often referred to as mind-independent truths (Sealey, 2007). Constructionist positions view language as symbolic with meaning actively constructed through language (Galbin, 2014). Finally, consistent with the researcher's epistemological position of critical realism, mind-dependent truth views language as intentional (Braun & Clarke, 2021; Fletcher, 2017). This position asserts that language is used to convey an individual's reality and unique perspective. Intentional language is associated with 'standpoint theory', a theoretical perspective that argues an individual's perspective is influenced by their social position (Naples & Gurr, 2013). In the context of Functional Neurological Disorder, feminist standpoint theory would assume that the historical stigma and associated inherent power imbalance shapes an individual's experiences and perceptions. Thus, it is essential to understand the experiences of those who have experienced oppression, as their insights are likely to differ from other stakeholders that hold different positions within the system.

With the above analytic orientations in mind, several qualitative approaches were considered to address the research aims. Based on extant literature (Braune & Clarke, 2013; Braun & Clarke, 2021; Starks & Trinidad, 2007), the rationale for reflexive thematic analysis is discussed below.

2.3.1 Grounded Theory

Grounded theory is an approach that is focused on developing theory from the data (Bryant & Charmaz, 2007; Charmaz & Henwood, 2017; Glaser & Strauss, 1967). This approach varies depending on the epistemological position: contextualist (Charmaz & Henwood, 2017); positivist (Glaser, 1992); and constructionist (Madill et al., 2000). However, in its broad application, grounded theory constructs theory by conducting interviews, analysing initial data and then altering the interview schedule to pursue prevalent codes (Sbaraini et al., 2011; Strauss & Corbin, 1997). Unlike reflexive thematic analysis that can be applied flexibly (mixed inductive and deductive), grounded theory is a solely inductive approach, with the researcher remaining independent from the wider literature (Bryant & Charmaz, 2007; Glaser & Strauss, 1967). However, whilst the researcher does not explicitly code the data deductively, it is widely debated that the researcher can remain independent from the wider theoretical literature (Charmaz, 2014). Due to the researcher's clinical and research practice, the wider relevant literature had been reviewed extensively and thus the researcher could not remain independent from the data. Furthermore, the current study did not aim to generate a theory from the data, but rather sought to take an inductive and deductive approach to explore perceptions and experiences of psychological services. Therefore, grounded theory was not a suitable approach for this study.

2.3.2 Discourse Analysis

Discourse analysis is not solely a qualitative method, but a school of thought that assumes the function of language is to construct reality, rather than representing reality itself (Galbin, 2014; Georgaca & Avdi, 2011; Willig, 2016). Thus, discourse analysis is grounded within a social constructionist epistemological position (Braun & Clarke, 2013; Potter & Wetherell, 1987) which is inconsistent with the researcher's own epistemological stance and analytic orientation (see selecting a qualitative methodology subsection). In addition, discourse analysis is preferably used with naturalistic and interactive datasets (Potter & Hepburn, 2005). Whilst discourse analysis can be applied to a number of research questions and topics, it is not always suitable for research which aims to elicit understanding that can be used to facilitate clinical or social change (Potter & Wetherell, 1995). The current study sought to understand personal experiences of psychological services (as opposed to how these experiences were constructed through language). Thus, the aim of this was to consider the clinical implications for practitioners to facilitate improvement of service experience. As a result of this, discourse analysis was not considered to be a suitable methodology.

2.3.3 Interpretative Phenomenological Analysis (IPA)

With a focus on the meanings individuals give to their experiences, IPA is considered a ‘contextualist’ approach (Braun & Clarke, 2021; Smith, 2011). There is an assumption that an individual cannot be removed from their context (Larkin et al., 2011). As such, IPA considers this the double hermeneutic, the researcher cannot directly access the worldview of the participant and thus makes sense of them through their own interpretation, which is based on their own context (Smith, 2011). In essence, “the researcher is trying to make sense of the participant trying to make sense of their experience” (Smith et al., 2009). IPA is often referenced as idiographic in its analysis, focusing on understanding patterns of meaning and the unique characteristics of a specific group. As a result of this, IPA tends to be used when aiming to understand the impact of life events on an individual's self-identity (Smith, 1999). However, IPA has been criticised as being ‘simply descriptive’ (Larkin et al., 2006) with limited interpretation within its analysis (Brocki & Wearden, 2006).

Whilst IPA is suited to this project’s research aim (e.g., exploration of experience) and is consistent with the researcher’s epistemological position, the method lacks the theoretical flexibility of reflexive thematic analysis (Braun & Clarke, 2021). Whilst IPA gives focus to psychological interpretations, it has been criticised for neglecting the influence of socio-cultural factors during analysis (Fox et al., 2009). Although this may be due to IPA’s commitment to ‘stay close’ to participant perspective, it does not allow for more in-depth interpretation that draws from the wider social and cultural context. Given the historical stigma associated with FND, it was paramount that participant accounts were considered in the context of broader frameworks of understanding. Thus, IPA would not be considered the most appropriate methodology to address this aim. Furthermore, IPA is designed to focus on small (4-6 participants) homogeneous groups (e.g., women’s experiences of transitioning to motherhood) (Braun & Clarke, 2013; Noon, 2018). The current study sought to provide a broader understanding of the experiences of psychological services by using a more heterogenous sample of participants. This is particularly pertinent when considering differences in experiences based on demographic characteristics (e.g., gender, culture, racial background, socio-economic background, age).

2.3.4 Reflexive Thematic Analysis

Unlike other qualitative approaches, reflexive thematic analysis is considered a qualitative method, rather than a methodology that prescribes a theoretical and epistemological position (Braun & Clarke, 2013). As a result of this, reflexive thematic analysis can be used with both experiential and critical analytic orientations and critical realist or constructionist epistemological positions. It can be used flexibly to answer an array of research questions in which qualitative data is analysed to identify and interpret patterns of meaning (Braun & Clarke, 2006, 2019). These patterns of meaning are referred to as 'themes' (Braun & Clarke, 2006). Themes can be developed inductively (e.g., data-driven) in a 'bottom-up approach' or deductively in a 'top-down approach' (Braun & Clarke, 2013). Whilst an inductive thematic analysis allows the researcher to be led by the data, deductive analysis is guided by the wider theoretical literature (Braun & Clarke, 2006, 2021). These approaches can be used in conjunction with the data analysed inductively before being analysed through the lens of the relevant theoretical and empirical frameworks (Joffe, 2011). A strength of reflexive thematic analysis is that mixed inductive-deductive approaches allow for data to be analysed in the context of whether it supports or contradicts existing theory (Braun & Clarke, 2013).

In addition, reflexive thematic analysis can be coded across two levels: semantic or latent (Willig, 2013). Semantic coding involves the researcher viewing the focus of meaning on the surface level (e.g., what is explicitly being said). Conversely, latent coding involves the researcher exploring meaning at a more implicit level (e.g., interpreting the underlying meaning) (Braun & Clarke, 2021; Willig, 2013). Due to the flexibility of this qualitative method, analysis can be both inductive/deductive and semantic/latent (Braun & Clarke, 2013). Although the method has received criticism for being 'descriptive' in its analysis, inclusion of deductive and latent level coding increases interpretation (Braun & Clarke, 2013). As the current research was the first study to explore experiences of UK psychological services from the perspective of those with FND, this approach allowed for novel insights to be developed from the data whilst allowing for relevant theories to inform interpretation. Furthermore, the reflexive thematic analysis method is coherent with the researcher's analytic orientation and epistemological position.

Unlike other qualitative approaches (such as IPA), reflexive thematic analysis focuses on identifying patterns across the dataset (Braun & Clarke, 2013). Thus, it has been criticised for its inability to highlight contradictions within individual accounts (Braun & Clarke, 2013). However, due to the current study's research aims, it was deemed appropriate to prioritise the identification of patterns across the dataset, as opposed to contradictions within individual accounts. Furthermore, reflexive thematic analysis views subjectivity as an essential component of analysis (Braun & Clarke, 2021). The concept of knowledge being situated and shaped by individual process (Luttrell, 2019) underpins this qualitative method (Braun & Clarke, 2021). Thus, researcher subjectivity and reflexive practice is integral to the analysis process and is viewed as a resource rather than a problem. Reflexivity can be viewed across three domains; personal (how researcher experiences and values shape analysis), functional (how the methods used influence interpretation) and disciplinary (how professional membership shapes the knowledge produced) (Wilkinson, 1988). As a result of the above rationale, reflexive thematic analysis was considered the most appropriate method to meet the research aims.

2.4 Study Design

2.4.1 Semi-structured interviews

Semi-structured interviews were used to collect data, as this method is compatible with reflexive thematic analysis (Braun & Clarke, 2006, 2019). Whilst other methods of data collection are compatible with this qualitative approach (e.g., focus groups), semi-structured interviews were considered most appropriate for the research aims. Due to the sensitive nature of the research, it was acknowledged that participants may find it difficult to share personal experiences in a focus group. Furthermore, focus groups may have complicated the analysis process as it may have been difficult to untangle multiple disjointed perspectives from within the data (Barbour, 2008). Conversely, the flexible and conversational nature of a semi-structured interview allows for exploration of participant perspectives and experiences, whilst allowing for participants to discuss unexpected topics/issues (Braun & Clarke, 2013, 2021). As per the semi-structured aspect of the interview, there were a mixture of planned open-ended questions included in the schedule (Appendix H), as well as opportunities to elicit novel insights relevant to the research aims (Braun & Clarke, 2013, 2021; Crompton et al., 2022). Participant responses were checked for clarity and understanding, and additional information was elicited through follow-up questions (Coolican, 2017). The researcher/interviewer had significant experience of conducting semi-structured interviews (e.g., assessment, information gathering) and had good knowledge of the topic area due to previous research projects. Thus, interviews were able to remain focused with the researcher aiming to capture participant responses whilst pursuing areas that appeared to warrant further exploration (e.g., links with the wider research literature).

Due to the COVID-19 pandemic and the large geographical spread of participants (across the UK), interviews were conducted remotely via telephone, Microsoft Teams or Zoom. The rationale for this was 1), to reduce the spread of infection and to protect participants who may be immuno-compromised, and 2), to capture experiences of service across the UK. Although face to face interviews are considered best practice (McCoyd & Kerson, 2006), there is growing research evidence for the efficacy of telephone (Cachia & Millward, 2011) and online video platform interviews (Gray et al., 2020). There was a total of fifteen semi-structured interviews conducted, all completed remotely. Thirteen interviews were completed via video calling platforms (e.g., Microsoft Teams, Zoom) (*n* = 13) and two were conducted via telephone (*n* = 2). Participants each completed one interview, approximately 30-75 minutes in duration (average 55 minutes).

2.4.2 Inclusion and Exclusion Criteria

Participants were screened against the inclusion criteria during initial discussions and via the web-link prior to receiving the participant information sheet and consent form. Inclusion criteria stipulated that participants must be:

- Aged 18 years or older and able to provide informed consent.

- Be able to speak and understand English.
  Justification: Due to financial constraints, translator services were not available. Language barriers may result in participant and investigator's misinterpretation of meaning during interview which would likely impact quality of data.

- Have received a diagnosis of Functional Neurological Disorder from a healthcare professional.

- Previously or currently accessing support from UK psychological services due to their diagnosis.
  Justification: Due to nature of the research aims, participants were required to have experience of accessing and engaging with UK psychological services for difficulties related to FND.

- No exclusion criteria were applied.

The studies broad inclusion criterion was adopted with the aim of capturing a range of participants to reflect the heterogeneity of individuals with a diagnosis of Functional Neurological disorder.

2.4.3 Recruitment Procedure

Purposive sampling is one of the most common recruitment strategies used in qualitative research that aims to explore experiences of a specific topic of interest (Emmel, 2015; Patton, 2002). In purposive sampling, participants are recruited based on their ability to provide rich data of the aforementioned area of interest (Patton, 2002). The current study was experiential, and thus participants were eligible if they had a diagnosis of Functional Neurological Disorder and had accessed UK psychological services. Maximum variation/heterogeneity is considered best practice in qualitative approaches (Fassinger, 2005) in which researchers aim for a diversity of perspectives (Braun & Clarke, 2013). This can be achieved through adopting broad inclusion criteria (see inclusion/exclusion criteria subsection).

Participants were recruited from across the UK to ensure that findings were not solely reflective of experiences of one service or NHS Trust.

The study was advertised on social media platforms (e.g., Twitter, Instagram, Facebook and Reddit). Relevant hashtags (e.g., #FND, #FunctionalNeurologicalDisorder) were used to ensure the research advert reached the relevant audience. The administrators of Facebook support groups for FND were contacted by the researcher to request that study information was shared on the group's page. Prospective participants were invited to access the participant information sheet via a web-link or to contact the researcher over email to discuss further. Relevant charities (e.g., FND Hope, FND Action) were contacted to discuss whether study advertisements could be displayed on their websites and social media. However, the sample was recruited prior to this agreement with the relevant charities and thus their support with recruitment was not necessary.

2.4.4 Sample Size

Due to the nature of qualitative approaches, sample sizes in this type of research tend to be smaller than in quantitative studies (Vasileiou et al., 2018). Although there is no standardised sample size (Patton, 2002), it is acknowledged that the sample consists of participants that are appropriate to answer the research aims and there is enough data to adequately draw conclusions (Morse et al., 2002). Although the concept of saturation (e.g., the process of recruiting participants until no further themes 'emerged' from the data) was previously supported (Braun & Clarke, 2013; Fusch & Ness, 2015). Saturation is now considered problematic in reflexive thematic analysis and generally in qualitative research (Thorne, 2020) as it assumes that an objective understanding of the data has been achieved, which is theoretically inconsistent with this qualitative approach (Braun & Clarke, 2021). Instead of aiming for 'saturation', there is a current movement towards 'information power' (Malterud et al., 2016) in which the researcher reflects on the richness of the data and considers whether this is adequate in answering the research aims (Braun & Clarke, 2021). Thus, recruitment of participants did not conclude until the research team determined there was a richness and quality of data to meet the research aims. The demographic variables of the sample were also considered when deciding when to discontinue recruitment. For example, it was deemed important to the research aims that the sample consisted of both male and female participants. Although individuals identifying as female are overrepresented in FND populations, if only females were recruited and interviewed it would be unclear whether experiences of services were different for other groups (e.g., see extended background literature). The final sample size consisted of fifteen participants.

2.4.5 Data Collection

2.4.5.1 Demographic Information

The demographic information of participants was collected to provide context of individuals' experience and perspectives. In line with the theoretical underpinnings of qualitative research, "knowledge is situated" (Braun & Clarke, 2013 p67) and thus the findings of the research must be considered through the lens of the sample. Participants were asked to provide information on; *gender identity, age, ethnic/cultural identity, employment status and number of months/years accessing UK psychological services.* The rationale for collecting this demographic data was to explore whether age, gender identity or ethnic/cultural identity influenced participants' experiences of accessing psychological services for FND. Employment status was also collected for this reason and was based on the historical context of FND (e.g., stigmatised connotations of 'malingering'). Participants were also asked what type of psychological service they had accessed, what professional they had worked with (e.g., psychologist, CBT therapist, mental health nurse) and the type of therapy they had received. However, it was noted that participants frequently reported they did not know what type of therapy or professional they had worked with and due to missing data this information could not be meaningfully compared across the dataset. In addition, neither ethnicity nor employment status were indicated as relevant contextual factors in the results. However, the researcher acknowledged that due to their own ethnic/cultural background (White British), certain nuances relating to this contextual factor may have been missed in the data.

2.4.5.2 Development of interview schedules

In accordance with the mixed inductive and deductive approach, the development of interview questions was considered in the context of the relevant theoretical and empirical evidence, whilst also including broad open-ended questions to facilitate novel insights. Once the initial draft interview schedule had been developed, feedback was sought from research supervisors and amendments were made based on their advice. These changes were focused on reducing the number of questions to ensure a conversational style, changing the chronology of questions and rephrasing questions to be open-ended (Smith, 1995). In addition, follow-up questions were added to encourage reflection of the emotional impact of experiences.

Rapport building is one of the key focuses when developing an interview guide as this facilitates a sense of safety that allows participants to share their personal experiences (Reinharz, 1993). The interview schedule included ‘opening and closing questions’ to orient the participant (Kvale & Brinkmann, 2009). For example, the first question individuals were asked (after demographic questions) was “why don’t we start by you telling me about your experiences of receiving the diagnosis of FND?”. The interview was ended by offering the participant to ask any questions or share any reflections. The chronology of the questions was also considered to ensure that the questions flowed in a logical sequence. Concepts such as “funnelling” were utilised, with earlier questions being more general and less direct, whereas later questions were more specific and sensitive in nature (Braun & Clarke, 2013). Following feedback from research supervisors, a member of the Service User, Carer and Advisory Panel (SUCAP) who was an expert by experience of FND, was consulted for further feedback. SUCAP feedback provided recommendations on the wording/phrasing of questions and the inclusion of a question on views of self. As a result of this, the question; “how did you think about/view yourself when seeking support from psychological services?”, was added to the schedule.

2.4.5.3 Recording and transcription

Interviews were digitally audio recorded using a university encrypted Dictaphone. The audio recording was held for one week prior to being sent for transcription to allow participants sufficient time to withdraw their data. Audio recordings were transcribed using the University of Nottingham's automated transcription service. Transcriptions were checked at least once to ensure veracity prior to data familiarisation and analysis.

2.4.6 Analysis

2.4.6.1 Reflexive Thematic Analysis Process

The six phases proposed by Braun and Clarke (2006) were followed during analysis of the data. The process of identifying themes begins with the re-reading and familiarisation of transcripts and initial codes are identified. These themes are then reviewed, and a "thematic map" is produced outlining the super-ordinate and subthemes and the relationships between them (Braun & Clarke, 2006, 2019). Table 2 outlines the phases of thematic analysis as proposed by Braun & Clarke (2006).

Analysis was a recursive, rather than linear process, with the researcher moving between phases and themes reviewed and refined (Braun & Clarke, 2006, 2019). The data was initially analysed inductively and later analysed deductively, in which existing theoretical literature was used to interpret the data (Braun & Clarke, 2021). Initial coding was reviewed by research supervisors to facilitate reflections on assumptions being made and to identify any areas that may have been overlooked (Braun & Clarke, 2021).

Phase one: Familiarisation with the dataset. During this initial stage, it is paramount that the researcher becomes intimately familiar with the data. This is achieved through rereading the transcripts and listening to the audio-recording at least once. The reflexive journal entries completed after the completion of each interview were also reviewed. Brief notes and initial reflections were noted during this phase, with consideration of the researcher's personal values and the influence of personal, functional and professional subjectivity.

Phase two: Coding. Initial codes were generated by working through the dataset in a systematic manner. Aspects of the data that were considered interesting and meaningful to the research aims were labelled (code labels). These code labels were both semantic (explicit) and latent (implicit) within their interpretation. Although coding was aimed to summarise the data, the focus was on developing the researcher's analysis and interpretation of meaning. Initial codes were data-driven (inductive), before deductive analysis was used to view the data through the lens of existing theoretical frameworks. Once the entire dataset had been coded, the code labels were collated and organised with the supporting data.

Phase three: Generating initial themes. The aim of this phase is to identify patterns of meaning across the dataset. Codes that appeared to share a core concept and that were considered important in relation to answering the research aims (Braun & Clarke, 2006), were clustered together. Theme development was an active process, with interpretation and meaning constructed by the researcher. Unlike codes, themes are considered to be patterns of meaning that are underpinned by analytic observations. Initial/potential themes were organised and collated with the relevant supporting data.

Phase four: Developing and reviewing themes. Initial themes were reviewed in relation to the research aims and to the overall dataset. Visual thematic maps were developed to support reflections on how well the themes described the patterns of shared meaning. In addition, this process allowed for consideration of how the themes related and linked to one another. Themes were revised during this phase, with two themes collapsed together and another three discarded. The focus and scope of each theme was considered, as well as its relationship with existing knowledge and the wider literature. This was achieved by referring back to the entire dataset and using supervision to ensure that themes were grounded within the data and reflective of participants perspectives.

Phase five: Refining and naming themes. The researcher reflected on the ‘story’ each theme told in the context of the research aims. Each theme was summarised and then organised to develop the overall narrative of the data. Themes are then provided a name that is concise, informative and reflective of participants’ own language. For example, the theme “internalised stigma” was expanded to include “self-blame” as this term was heavily referenced by participants in the data.

Phase six: Writing up. The final phase involved producing the final report. Although Braun and Clarke (2006, 2019) recommend that the writing process starts during phase three, in phase six, the focus is on developing a nuanced and compelling narrative of the data. Data extracts (e.g., participant quotes) with pseudonyms are used to support the themes. The findings from the analysis were then considered in the context of the existing theory and extant literature.

Table 2. Phases of Thematic Analysis (Braun & Clarke, 2006, p.87)

Phases of thematic analysis	Description of process
1. Familiarisation of data	Re-reading transcribed data and making initial notes as foundation for subsequent phases
2. Generating initial codes	Identification of preliminary codes that appear relevant and meaningful in the context of research aim
3. Searching for themes	Interpretive analysis of the collated codes. Researcher will begin organising data into codes, sub-themes and themes.
4. Reviewing themes	Researcher will begin process of refining themes, ensuring themes reflect initial coding (level 1) and the entire data set (level 2). A thematic map is produced outlining the super-ordinate and subthemes and the relationships between them.
5. Defining and naming themes	Researcher will continue process of refining themes and the “story these themes tell” about the data set. Names and definitions of themes are clearly defined.
6. Producing report	Researcher will use “vivid and compelling extract examples” that clearly reflect the themes, aims of study and wider research literature. The final report will provide the reader with an understanding of the data and an in-

	depth interpretation that addresses the study’s aim and objectives.

2.4.6.2 Deductive Analysis

The deductive coding framework was used during the deductive analysis phase. This took place after initial themes had been developed (phase three) but before the themes were reviewed (phase four). The deductive analysis allowed for the data to be viewed through the lens of the relevant theoretical literature (Braun & Clarke, 2013). The data was reviewed with consideration of how well it supported or contradicted the relevant theory. It should be noted that the deductive coding framework was not used to ask participants explicit questions. Instead, the deductive coding framework was used to develop a nuanced understanding of the data.

2.4.6.3 Deductive Coding Framework

Table 3. Deductive Coding Framework

Deductive Coding Framework	**Theory**	**Considerations during analysis**	**Code**
How does this support or contradict the data?			

Intrapersonal Stigma	Goffman's Theory of Stigma	*Do participants describe experiences of self-stigma and internalised shame? How does this intrapersonal stigma impact their experiences in psychological services? How does this impact the therapeutic encounter?*	A
Interpersonal Stigma	Goffman's Theory of Stigma	*Do participants describe a perception of being treated negatively by healthcare professionals? How do perceptions of enacted stigma impact experiences of psychological services? How does this impact the therapeutic encounter?*	B
Structural Stigma	Goffman's Theory of Stigma	*Do participants perceive there to be systemic-level barriers to receiving quality care in psychological services?*	C

2.5 Reflexivity and Quality Assurance

Consistent with the epistemological position of critical realism, the generation of themes from the data is influenced and shaped by the researcher's personal and professional context (DeForge & Shaw, 2012; Ponterotto, 2005). Thus, it is essential that researcher biases are explicitly considered and reflected upon throughout the analysis, a process that is aided with the use of reflexive logs (Braun & Clarke, 2006). These reflexive logs are considered a way of enhancing the interpretative quality of analysis (Ortlipp, 2015) as they allow the researcher to consider their position in relation to the data. For example, the completion of these logs facilitated reflections on the researcher's own assumptions (e.g., the assumption that stigma may impact the therapeutic encounter) during supervision.

Unlike quantitative research, there is no standardised criteria for monitoring quality and evaluating bias in qualitative research (Braun & Clarke, 2013). The concept of ‘reliability’ and ‘validity’ are theoretically inconsistent with the underpinnings of this method, which assumes that meaning is situated in context and is influenced by the researcher (McLeod, 2001). Thus, processes such as ‘inter-coder reliability’ which presume that analysis of the data is objective are arguably not appropriate methods of quality monitoring in qualitative research (Braun & Clarke, 2013). The demonstration of inter-coder reliability to limit bias is rooted within neopositivist approaches and therefore considered to be incoherent with reflexive TA (Braun & Clarke, 2021). However, to ensure quality assurance, the researcher’s codes were shared with the research team to facilitate reflection on how the data has been coded, the assumptions underpinning the development of the themes and to highlight any parts of the data that may have been overlooked (Braun & Clarke, 2021). Similarly, ‘validity’ measures which aim to assert whether the research has captured the objective reality are incoherent with epistemological positions that underpin qualitative research (Braun & Clarke, 2013). Instead, it has been proposed that quality monitoring should focus on the ‘trustworthiness’ and ‘dependability’ of the data and analysis (McLeod, 2001). This can be assessed through the use of a qualitative quality checklist. The Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative studies (Appendix I) aims to assess the quality of qualitative research. This checklist was completed and reflected on with members of the research team throughout the research process, with all quality criteria met. However, it is acknowledged that due to the subjective nature of this checklist (e.g., completed by the researcher), it is essential that the checklist is applied appropriately, and additional perspectives are sought (Long et al., 2020). Research supervision records were maintained in line with local policy and as part of the audit trail.

2.6 Service user involvement

Research that includes meaningful involvement of service users has been suggested to have a positive impact on the quality of research, the participants, and the associated wider community (Beresford, 2007; Minogue et al., 2005; Staley et al., 2013). It was deemed important to include consultation from experts by experience during the development of this research given the historical context of FND (see extended background). Due to the researcher's research aims being derived from the position that the perspectives of those accessing services should be empowered to drive changes in care (Rommelfanger et al., 2017), it was essential that this also extended throughout other stages of the research process. Consultation with an expert by experience was sought to consider the development of the research aims, recruitment and the development of the interview schedule.

2.7 Ethical Considerations

Ethical approval was granted by the University of Lincoln's Human Ethics Research Committee (Appendix C) on the 6th May 2022. An amendment was submitted on the 6th May 2022 and approval was granted on the same day. The amendments were as follows:

1. Initially, the research procedure included a pre-interview meeting with the participant to discuss their participation in the study and answer any questions. The ethics committee recommended that participants also had the option to ask any questions via email, or if they did not have any questions that they could be invited for the interview directly. This inclusion/additional option was aimed to minimise burden on the participant.
2. The ethics committee recommended that the data collection end date was extended (from October 2022 to February 2023) to account for any issues that may prolong data collection.
3. In the participant information sheets, one of the inclusion criteria was worded "can communicate verbally in the English language". The ethics committee requested that this was simplified and rephrased to support participant understanding. Subsequently this was rephrased to, "can speak and understand English".
4. It was requested that the ethics reference was added to any recruitment materials, the participant information, consent and debrief sheets.
5. Information signposting to support organisations were provided at the end of the participant information sheet and separate debrief sheet. The ethics committee recommended that this was explicitly referenced in the section

“what are the potential benefits and risks of taking part” section of the participant information sheet.

This qualitative study was conducted in adherence to ethical recommendations proposed by the British Psychological Society (BPS, 2014) and UK Policy Framework for Health and Social Care Research (2020). The relevant ethical considerations are discussed below.

2.7.1 Incentives and Reimbursement

Members of the Service User, Carer and Advisory Panel (SUCAP) who were experts by experience of Functional Neurological Disorder, were provided with a £16.66 per hour reimbursement for their consultancy (in line with university policy). Participants were provided with a £20 high-street voucher in recognition of their time and contribution to the research. This was offered to express gratitude to participants for their involvement, with the literature highlighting that adequate reimbursement is linked to participants feeling valued (Breeze & Repper, 2007). Furthermore, participants may need to arrange childcare, and spend up to two hours participating in research and thus should be reimbursed for this time. However, participation payments in research are widely debated due to concerns that incentives could “coerce” participants (Braun & Clarke, 2013). In response to this, the British Psychological Society (BPS, 2014) guidelines were adhered to; the financial reimbursement was written in a small font at the bottom of online recruitment materials and participants were informed they would still receive the £20 voucher if they chose to withdraw after completion of the interview. A high-street multi-store voucher was chosen so that participants were able to have choice on where they spent the reimbursement. In addition, high-street vouchers were provided so that this was not considered “income” that could affect participants who were in receipt of benefits. Due to interviews being conducted virtually (e.g., via telephone, Microsoft Teams or Zoom), no travel expenses were incurred by the researcher, experts by experience or research participants.

2.7.2 Informed Consent

The participant information sheet and consent forms could be accessed by email or through a web-link which was referenced on recruitment materials (Appendix G) Participants were required to read the participant information sheet prior to providing informed consent. The participant information sheet included information about the study, the study procedure, the potential benefits and risks of taking part, withdrawal information and contact details of the research team (Appendix E). If participants accessed this via a web-link, participants were required to tick a box to confirm that they had read and understood the information before they were able to provide e-consent. If the participant requested the participant information sheet and consent form over email, they were asked to sign this electronically and return prior to the interview. All participants were required to sign and date the consent form prior to interview, with a minimum of 24 hours between providing consent and participation. Signed consent forms were stored securely in the study records on a dedicated secure University of Nottingham and University of Lincoln webserver (e.g., OneDrive). Participants were provided with a copy of this consent form via email or were able to download a copy through the web-link.

2.7.3 Participant Withdrawal

The right to withdraw from the research was explicitly stated in the participant information sheet and consent form. Participants were informed that they could withdraw all of their data (without having to give a reason) during the interview or up to a week after completion of the interview. Participants were informed that if they withdrew up to one week after the interview, then their data would be withdrawn and would not be used in the analysis. Participants were informed of their right to withdraw at any time, however, should they have withdrawn after the one-week time period, the information collected so far could not be erased and may still have been used in the analysis. The rationale for this was that after one-week the interviews were sent to the transcription service to be transcribed. This was explained in the participant information sheet and consent form. No participants withdrew from the study after completion of their interview.

2.7.4 Risk of Harm and Debriefing

The occurrence of an adverse event as a result of participation within this study was considered minimal. In the event that participants became distressed during the research process, it was agreed that they would be offered the chance to take a break or end the interview and would be signposted to support organisations. All participants were provided with a de-brief upon completion of the interview. Prior to participation, participants were informed of the limits to confidentiality. In the event that risk or safeguarding concerns (risk to self, risk to and from others) were disclosed or identified during participation, confidentiality would be breached in accordance to safeguarding policy, and relevant agencies would be informed. If immediate risk was identified, the researcher would adhere to local risk management policy and contact emergency services. Any concerns or disclosures regarding professional misconduct would be reported in line with local NHS policy and participants would be signposted to Patient Advice and Liaison Service Concerns (PALS). No participants reported experiences of distress or discomfort during the research process, and no information pertaining to risk or safeguarding concerns were reported or identified. Participants were informed at the start of the interview that they were not inclined to answer any question they did not wish to, and this would not be questioned by the researcher. However, all participants answered all questions asked. Whilst all participants were provided with a debrief information sheet (Appendix F) and opportunity to talk with the researcher following completion of the interview, no participants requested further support.

2.7.5 Confidentiality

The concept of confidentiality was explained to all participants prior to participation. Individual participant medical or personal information obtained as a result of this study was considered confidential and disclosure to third parties was prohibited with the exceptions noted above. Additionally, any personal identifiable information related to third parties/locations provided during interviews were omitted. Participant confidentiality was further ensured by utilising identification code numbers and pseudonyms to correspond to study data in the computer files. Pseudonyms were used when transcribing, analysing and reporting the data in the research paper. It was agreed that if information was disclosed during the study that could pose a risk of harm to the participant or others, the researcher would discuss this with the research team and where appropriate report accordingly. The transcription service used held a confidentially contract and Data Protection agreement with the university.

2.8 Data Protection and Storage

The data collected and stored as a result of this study was done so in accordance with the Data Protection Act (2018), and Data Protection Regulation (2018). All study staff and investigators endeavoured to protect the rights of the study's participants to privacy and informed consent. Only the minimum required information for the purposes of the study was collected and stored. Personal identifiable information (e.g., signed consent forms, participant information and contact information) were stored on a secure, password-protected university webserver (e.g., OneDrive). Interviews were audio-recorded using an encrypted Dictaphone and this audio file was deleted after transcription and veracity checks. Anonymised interview transcriptions were stored on the main researcher's university OneDrive account.

2.9 Research and Dissemination Policy

This research portfolio was submitted to the Trent Doctorate in Clinical Psychology course in February 2023. The journal paper was submitted for publication in a peer-reviewed journal in December 2022 and may be presented at relevant conferences. It is intended that the findings from this research will be disseminated to participants and experts by experience who requested this.

Extended Results

The extended results section provides further detail and description of the themes. Pseudonyms are used throughout to protect the anonymity of the study participants.

3.1 The stigmatised self within the therapeutic relationship

The way in which participants conceptualised themselves and their condition appeared to be heavily influenced by their experiences of the therapeutic relationships. This theme also captured how the concept of stigma interacted with perceptions of and the meaning made of interactions with professionals:

> *“They need to be really careful, the professionals, how they speak to people because their actions and their words have a lasting impact. An impact that lasts longer than you know. For them they see so many people, they see so many patients and they don't think about what it's doing, or the impact you know, because in the next 30 minutes, they're going to have another patient in their room so to them they forget about it. They see so many people that they just forget about us, whereas for us we can't forget about it” – Grace*

Participants alluded to feeling dehumanised within the relational and systemic context of services. For example, Amy stated *“I felt at the time like I was getting passed from pillar to post”*. Similarly, Helen described the sense of *“going around the houses”* and that *“no professional wanted to take responsibility of [her]”*. For the majority of participants, this was conceptualised as professionals “not being interested”; Danielle reported, *“I never felt any bit of investment from any NHS doctor or any other member of staff, you can feel that they don’t have faith that you’ll get better”*. These perceptions appeared to be formed through the lens of being stigmatised as a result of the condition. Participants described a sense of being dismissed and *“not listened to”* by professionals (Michael). Participants also heavily referenced the stigma associated with FND and how this led to a *“need to advocate for themselves”* within these professional relationships:

> *“Why do we have to go through that? Why do we always have to be the one standing up for ourselves and kind of saying, well, we can't be treated this way… we just feel like we're numbers on the list and not actual people” – Clara*

The perception of being stigmatised within the therapeutic relationship had the potential to impact access and engagement with services. Natalie shared, *“people are very reluctant to access services because they've been stigmatised, because they've not had good experiences with professionals”.*

3.2 Internalised stigma and self-doubt

All participants described the concept of internalising experiences of stigma which subsequently led to feelings of self-doubt despite their physical symptoms being real. Participants described blaming themselves, leading to feelings of guilt. Internalised stigma was apparent in participant narratives around mental health:

> *“Are you mad? You're making yourself feel this way. You know there’s nothing wrong with you. I felt guilty. I mean, I was feeling massively guilty” - Liam*

The majority of participants described their perception that the interpersonal stigma experienced in healthcare settings had been internalised over time. Participants described experiences of overt acts of stigma associated with FND; *“[the medical professional] went ‘stop walking like that, stop making it up and walk properly’”* (Natalie). The historical associations with FND, hysteria and gender also appeared to underpin experiences of stigmatised interactions in medical settings:

> *“[Medical professional] thought he knew better and for him I'm just a woman so you know I get oversensitive probably I don't know but probably I wasn't. He asked me if I was on my period and I was around that time, so for him all of that meant, you know I was just over-reacting and I kept thinking am I?” - Clara*

Participants described these experiences as ‘planting a seed of doubt’ in their minds:

> *“Initially I had many professionals telling me it was my period. I had all sorts of different trips out of hours over the course of probably about a month and then I was admitted to hospital for one night, but they didn't know what was wrong, so they released me and then literally less than a week later I was admitted again to a different hospital, and then I stayed there for six weeks and I was initially in the gynaecology ward because they didn't know what was wrong with me and that plants a seed of doubt in your own mind then” – Helen*

One participant made an explicit link between the stigma she had experienced in healthcare settings and the historical context of FND and considered how this led to feelings of self-doubt:

> *“They’re uneducated, ignorant, dismissive. They just don't want to hear anything else, they're very closed minded and I think there's too much of a stigma attached to it as in its hysteria or it's all made-up. Even if you Google it, it still makes a reference to it being hysteria. That’s the main thing that gives it a negative view. When people look at it, they'll go ‘oh yeah, so really she hasn't got anything actually wrong with her’ and that can make yourself start thinking like that too” - Isla*

Other participants referenced historical literature pertaining to FND and how this led to internalisations of stigma:

> *“The literature, particularly the old literature, is very stigmatising. It makes out that you are a scrounger, you want the easy way out, you're putting it on, you’re malingering. There is quite heavy bias towards that and that has a huge impact on how you see yourself” - Natalie*

One participant shared that although she had not experienced interpersonal stigma within healthcare settings, her self-identity had been negatively impacted by the stigma around mental health perpetuated within social and cultural contexts:

> *“It's not something I've had a professional actually say to me, which is really cool cause I think that I would have definitely internalised that very deeply. It's an internalised thing that I think I've sort of picked up from general society and how people respond to people with mental illnesses and that kind of thing is basically the cultural things we need to work through as a society to make sure we understand mental illness better. I think a lot of my feelings of doubting myself were from that, rather than one person directly saying ‘it's all in your head’” - Beth*

Over time, these direct enactments and perceptions of stigma led to negative conceptualisations of the self and the condition. For example, Isla reported, *“I did really feel a bit of a fraud because it wasn't epilepsy”.* This appeared to highlight the broader hierarchical views of physical health as ‘less stigmatised’ compared to conditions labelled as mental health conditions. The impact of this internalised stigma was profound, with participants sharing perceptions of being isolated and marginalised:

> *“I felt like I had nowhere to go, you're basically stuck. You're basically stuck is how you feel and this is how I felt at a crossroads with a big fog over you and everywhere you look. You feel like you can't talk to anybody about it” - Grace*

Whilst feelings of shame appeared to underpin many of the participants’ internal experiences, one participant explicitly said:

> *“My experience isn't a great one, but there is way worse, but also because most people that get this like the ones I've talked to and what I've seen, people are really, really, ashamed. That doesn't matter if it's a conclusion of how you got it, but because it's not really acknowledged even now as a real condition” – Clara*

Internalisations of stigma and the associated shame, negative conceptualisations of self and social isolation had a devastating impact on participants’ psychological and physical health:

> *“I was suicidal thinking I'm useless, I'm hopeless. They're saying ‘it's all in the head’, maybe it is all in the head and you just end up spiralling. I ended up not eating, I was barely drinking. You know I just thought well, what's the point? There's no point in me being here... I was really suicidal, really suicidal. I was so depressed. I shut myself off. I didn't want to go out. I didn't want to socialise. I didn't want anybody to look at me”* - Grace

These internalisations of stigma and profound feelings of shame created barriers to seeking, accessing and engaging with support from psychological services:

> *“I think my experience of having FND as a whole has just been stigma and a disregard for the effect it has on your life, and a disregard to the scariness of it and being made to feel that you're just being stupid, which makes it very difficult to keep seeking help and to keep advocating for yourself”* - Natalie

For some this appeared to be due to anticipation of further stigma in psychological services, and for others negative conceptualisations of the self resulted in perceptions that they may be undeserving of care:

> *“A big part of accessing services for me was feeling valid enough to ask for the help”* – Natalie

3.3 Selective disclosure to professionals

Participants described finding it difficult to disclose information to professionals due to worries that they would not be believed or would be judged negatively. These worries appeared to be underpinned by the historical stigma associated with FND (e.g., malingering, eliciting care). Participants also discussed feeling overwhelmed and confused by their symptoms which appeared to reinforce perceptions that professionals would not understand:

> *"I don't think when I first started talking therapy, I didn't talk about all of the symptoms that I had, for example because I wasn't really sure what was sort of going on. I was having dissociative seizures but I didn't know that's what it was at the time, so I didn't talk about that for a while. I just thought no one's going to believe me because I've got no idea what it is. No one's going to believe what it is so I held back certain symptoms or I wouldn't say the whole truth, maybe to begin with, just cause I was worried about not being believed and I think I was just worried that they would think I was making it up and that I was just doing it for attention" - Isla*

Most participants felt unable to disclose information due to anticipated judgement or disbelief and linked this to previous negative experiences of services. Katherine described how previous experiences of interpersonal stigma in services led to loss of trust of professionals. Thus, participants appeared to limit the sharing of information in a bid to protect themselves from further stigmatised interactions:

> *"It's just as important as when you actually speak to someone, because if you're spoken to in an understanding or compassionate way then you're more likely to respond better to the services that are offered to you. If you're treated like, 'she's crazy', 'she's making it all up' then you're not going to get the best out of that service because you're not going to open up to that system. And I think because I've been bashed by all the other services, my expectations have become so low" – Katherine*

Whilst selective disclosure appeared to be used to protect against anticipated stigma in services, in the long-term participants described feeling isolated and alone. Katherine reported, *"it makes it the most isolating, painful and lonely condition".* One participant reflected his perception that he had not experienced stigma 'aimed at him' but had experienced indirect stigma associated with FND. These experiences of indirect stigma had the potential to impact levels of disclosure due to worries about how information would be perceived and appraised by professionals:

> *“They didn't direct at me, but they took me through the video from FND Hope and said that ‘there's going to be one or two that's put it on’, so that makes you worry about how much to say to professionals” – Liam*

Other participants referenced the inherent power imbalance within the therapeutic relationship and how these dynamics influenced levels of disclosure. Selective disclosure in this context appeared to be a strategy to avoid perceived ruptures within the therapeutic relationship:

> *“It wasn't so much a discussion between us, but it was more just her directing facts at me, about me, that she'd learned. I just think if it was more of a general conversation, it would have just flowed a bit easier. I just didn't feel like I could raise any issues with her because I thought maybe I would say the wrong thing” - Olivia*

Two participants described the process of overcoming the barriers to disclosing information to professionals. For Danielle, selective disclosure in psychological services also extended to worries about disclosing to family and friends. Attending a support group had been integral in overcoming these worries which appeared to highlight the importance of feeling understood and connected with others:

> *“I went to a support group that happened to be two days later and before that I’d felt worried [about telling professionals] but after I felt better straightaway. I called my mum and I felt able to tell everyone which I hadn’t before” - Danielle*

For Isla, developing trust in the professionals’ knowledge and experience supported levels of disclosure:

> *“But then I mean it literally took a week or so before I realised, like all these people are actually the FND experts basically so they know exactly what they're doing. After that I sort of got over that initial hurdle”* - Isla

3.4 Perceptions of psychological explanations

All participants described initially perceiving psychological explanations of their symptoms as blaming. For some participants, the way in which physical health professionals explained the referral to psychological services was experienced as a stigmatising interaction. Natalie reflected that this created a barrier to accessing and engaging with psychological services:

> *“The way services are communicated by physical health professionals can make people reluctant to engage in them because it feels quite blaming, quite stigmatising. It's the badging of it and I think you see a letter with psychological services written over the top and I think that's an issue for people”* – Natalie

Participants alluded to referrals to psychological services being poorly explained which further reinforced perceptions of stigma. Natalie shared her thoughts on more helpful ways in which referrals to psychological services could be discussed with individuals:

> *“It's like when they send you to endocrinology for chronic fatigue syndrome and you need someone to explain to you that a lot of people have fatigue because of hormone related issues and that's why it sits here. It's just where the service sits. It doesn't mean that's what we think is causing your condition, it doesn’t mean we think you’re making it up”* - Natalie

Similarly, participants described their difficulty understanding why a referral to psychological services had been made, given the physical nature of their symptoms.

Some participants appeared to view their condition through the lens of the medical model and thus psychological explanations were perceived to be synonymous with “not genuine”:

> *“It was quite difficult to get my head around at first, I think because obviously the symptoms felt very, very real and very very physical to me so I thought that there should be like a cure in the same way you'd cure a broken leg or whatever. I felt a bit confused because it was so real to me” – Helen*

These perceptions of psychological explanations appeared to be underpinned by internalisations of stigma, perhaps perpetuated by historical and interpersonal stigma. This self-stigma appeared to be highlighted in the language used to describe psychological services:

> *“A very, very strange feeling being told to go to a mental service” – Fran*

As a result of these internalisations of stigma, referrals to psychological services appeared to evoke feelings of shame:

> *“I’m not nuts, the only reason being is that I didn't think I was stressed or mad, I mean that in a nice way because when they said it was a mental health issue, I thought well I don't feel stressed, I don't feel barking mad so why do I need a psychologist. That upset me in the first instance” - Liam*

For other participants, perceptions of enacted stigma from healthcare professionals appeared to be compounded by hypervigilance to perceived stigma and internalisations of stigma pertaining to mental health, with psychological explanations viewed through this lens:

> *“I was told people that suffer from this condition are people that are basically cuckoo and that's basically what he was trying to say*

> *without saying it because [the professionals] are clever and know what to say and how to word it but that's basically what he was trying to say to me is that people that get it are cuckoo, they've got mental problems... they've got mental illness"* - Grace

These perceptions of being blamed led to a loss of trust in professionals and appeared to be a significant barrier to the development of the therapeutic relationship:

> *"I just thought I'm gonna show up there being blamed from the beginning it's not right and I don't think I should be treated the way they're treating me right now. I don't trust them. I'm sorry, but the way things went, she's the therapist. Why on Earth would she go and blame me at the start of the conversation? I know she was blaming me and I noticed it"* - Clara

Similarly, perceptions of being blamed made it difficult for participants to access psychological services in the first instance:

> *"Initially when it was sort of blamed on the anxiety it... I think that might have been why it took me a little while to contact the service because it partly felt like it might be my fault, that I was thinking about things wrong so therefore making my brain work wrong"* - Beth

Once engaging with psychological services, psychological formulations of FND were considered to be "difficult to accept":

> *"It was hard, it was a hard pill to swallow for them to be kind of putting this all on a mental health issue"* – Danielle

Consistent with perceptions about referrals to psychological services, psychological formulations were experienced as blaming. One participant explicitly referenced diagnoses such as conversion disorder and reflected on how this may perpetuate this cycle of blame:

> *"It's so important that we're just not whitewashed with people having conversion disorder, and that's completely unhelpful. It just goes into that cycle of blaming that you've done it to yourself" - Danielle*

For other participants, psychological explanations of their difficulties appeared to reinforce/activate negative beliefs of self:

> *"It just left me feeling like the symptoms that I was feeling, I shouldn't be feeling that way. The fact that I couldn't walk when there was no reason for not being able to walk it made me feel I was a failure" – Olivia*

One participant highlighted that professionals appeared to hold rigid preconceptions that did not fit with the client's narrative or personal history:

> *"When you're told that your FND is stress related and then you say well I'm not actually feeling stressed and then someone's saying 'maybe it's something that you've closed in the back of your mind' and it's like, well no, I'm not stressed. I was happy so I don't understand, it feels like you're screaming at a wall and you're not getting anything back" – Amy*

All participants referenced the focus on psychological trauma during assessment and formulation. Whilst the majority of participants supported the link between trauma and their symptoms, there was a perception that professionals appeared to be heavily invested in these narratives:

> *"I do support the link with the trauma alongside it, because yeah, I have experienced trauma, but I don't want that to be the main focus. I think the minute you say about trauma they say to you*

> *'ohh, you know, have you? You know what was your childhood like? What was this like? What was that like?' As soon as they pick up on the slightest bit of a hint that you've not had the best childhood or whatever they're like 'ohh well that's it'" - Katherine*

Some participants reflected that psychological trauma appeared to be the main focus of their formulation, with other factors not considered. Danielle described experiencing this formulation as blaming, reinforcing internalisations of stigma associated with the condition:

> *"She heard that I've had a rough life and was like 'that's why you have FND now'. I completely accept that has a big factor in why I got it, but it's not the only factor and you can't go blaming someone's life on why they got this condition within one second. Those words just made me feel like she was saying you did this to yourself" - Danielle*

The perception that psychological professionals heavily focused on trauma led to feelings of worry prior to attending sessions. For some participants this reinforced the appraisal that psychological services were inappropriate for their presentation:

> *"It was my worries about them talking about trauma and I just kept thinking well I've been referred to something from this thing that hasn't happened to me. I mean, as it turned out it was very helpful and it wasn't focusing on things like that, but that was what I was that was stuck in my head when I was first referred. That first of all, they just really put the focus on trauma" - Fran*

Some participants alluded to how trauma was explained and discussed being a barrier to accepting psychological formulations. Natalie reflected that prior to therapy she had not believed her experiences "counted" as trauma. However, during therapy she started to acknowledge these experiences as "valid":

> *“I'm still not comfortable using the trauma label, but trauma experiences are part of my experience so I compare my trauma experiences to other people that I know and I go ‘I didn't think that those memories counted’ but all were valid enough and so how trauma is discussed also is a barrier” - Natalie*

One participant explicitly linked their acceptance of trauma explanations with the Polyvagal Theory. This theory appeared to bridge the gap between the physical and psychological aspects of the condition in a way that encouraged a compassionate understanding:

> *“I believe one of the biggest reasons why I've gotten better is because I consider polyvagal theory to be a very important theory to help understand why I experienced dissociation and FND because that theory talks about how it is a neurological condition and neuro means nerves and my nervous system. My nervous system is so dysregulated now and that caused this because I was chronically stressed and dysregulated. I couldn't sleep, I couldn't relax” - Danielle*

Similarly, Fran reflected on how explanations that considered the link between the body and brain had been helpful in accepting psychological formulation and intervention:

> *“Then when I saw other professionals, they have explained how what's going on in my brain can affect my physical symptoms. They've talked about more it not being just mental health as a whole but it’s way that my brain works as well, and how looking at the psychology of it can help in that” – Fran*

One participant highlighted the importance of professionals explicitly acknowledging the symptoms as real. This appeared to reduce perceptions of blame:

> *“It really helped that he made sure to say like your symptoms are real because I think with conditions like FND and also with fibromyalgia, the way they're sometimes described can leave you feeling like it's your fault, like it's something your brain has made up like you're choosing to have these symptoms so the way he described it really helped in that it wasn't my fault, it's not something I'm choosing to do. It's not all in my head. Yeah, you know, it's an actual thing that's happening and there are potentially treatments that can help it to stop happening” - Beth*

3.5 Having to educate the professionals

Most participants shared their perception that psychological professionals lacked knowledge and clinical experience of FND. For some this appeared to be understood as a direct enactment of interpersonal stigma:

> *“Everyone just seems in the dark about it. They either don't know what to think about it or what they do know is a very closed view, as in oh it's all in your head and they don't seem to understand the complexities of it” - Katherine*

Lack of knowledge about FND had the potential to further reinforce unhelpful narratives around the condition *“just being a mental health condition”*:

> *“I had a seizure and I remember one of the people that were working there saying to me oh you're just having a panic attack” - Amy*

Being pulled into the role of having to educate the professional also activated internalisations of stigma:

> *“They've had very little experience or knowledge of it, and they've admitted that, other than the handouts and information that I've given them. One [psychological professional] said “one*

> *of my colleagues, she said I think she treated someone that had that thing that you've got". So again, you know you're made to feel like you're like some weirdo that's got this weird condition" - Katherine*

Participants described the dynamic between patient and professional not being as they had reasonably expected:

> *"It's a bit shit that the person that I'm trying to talk to doesn't really get it so they're having to research and learn about FND as they support you and offer you sessions around it" - Elizabeth*

These blurred boundaries had a significant impact on psychological well-being, with Katherine describing feelings of despair:

> *"Well, I'm just I'm in despair and I'm also like quite often I'm on the verge of tears because you know if they haven't heard of it, what hope do you have of trying to educate them?" - Katherine*

Other participants reflected that these dynamics resulted in losing trust in the professionals' ability to support them:

> *"I still don't hold a lot of trust with professionals in actually understanding what FND is. You don't get it until you're in our shoes, and so I don't hold a lot of trust unfortunately but I have read so widely that I trust myself and that I can advocate for myself" – Danielle*

A lack of knowledge and experience appeared to impact participants' perceptions of being 'understood' by professionals. For example, Beth reported "*I needed some understanding. Like I say, it goes back to education potentially".* A limited understanding of FND was also perceived to result in professionals avoiding giving explanations of the condition:

> *“I don't remember them offering an explanation for it, it was very much more focused on my thoughts and my feelings rather than ever discussing my physical symptoms” - Beth*

Due to having to educate the professional, the burden of learning about their diagnosis became the participant’s responsibility:

> *“That could have been done better and with explaining it to me rather than having me teach myself about it all, I think there should be more knowledge within the NHS” – Amy*

Conversely, two participants reflected that whilst the professional they had worked with did not have an in-depth knowledge of FND, this had been mitigated by the professionals’ commitment to learning more about the condition:

> *“Even my CBT therapist didn't know about it but she did her research and she was absolutely brilliant, she really looked into it for me and yeah she was amazing” - Amy*

Similarly, professionals’ limited understanding of FND may not be perceived as dismissive and unsupportive if the professional explained the rationale for signposting to other services:

> *“He didn't understand it fully, but he wasn't dismissive, but he was like I don't fully understand it, so I don't wanna give false information, but he was also very supportive on my journey. He helped me look for these clinics and do the referral but it wasn’t like he was passing me off to someone else either but that he thought I’d benefit more from someone who knows about FND rather than him trying to treat me when he's not fully understanding of it” - Olivia*

3.6 Attunement and trust within the therapeutic relationship

Participants that had experienced a positive therapeutic relationship in services described that this had mitigated the impact of other perceived barriers such as anticipations of interpersonal stigma. The sense of being ‘understood’ and ‘believed’ also had the potential to revise internalisations of stigma:

> *“She said I believe you and I understand and then we went through my history and we've gone through different events in my life and thought about how that might have led through to this. That just changed the way I understood things that had happened throughout my life, and it was like oh my God, it was almost like I became a different person. It was massive, like a light bulb moment. She is somebody that understands” – Liam*

A trusting therapeutic relationship had the potential to reduce feelings of shame and perceptions of blame associated with psychological explanations. Furthermore, this relationship appeared to revise negative internal representations of healthcare professionals:

> *“Psychology is not transactional. It's not like going to a GP and getting some medicine and it's not just about rapport either, it's about 100% trust. I feel comfortable and able to trust him [psychologist] but if I couldn’t then it’s failed because I wouldn’t be able to open up. I was anxious beforehand because of previous experiences but with him it was very different, and I wasn’t expecting that. Having listened to me talk for a short while he played it back to me. He completely understood me and got me and he said this has occurred for a number of reasons, you’re not a failure, this is a normal reaction” - Michael*

It was acknowledged that establishing relational safety was integral to engaging in therapy. For one participant, this allowed for an explicit focus on experiences of interpersonal and internalised stigma:

> *"We did like a section that focused on stigma and that helps people to notice stigma in themselves. I think that might help for other people as well"* - Beth

Attunement (the process of the therapist being aware of the client's emotional state and responding to this appropriately) was highlighted as a crucial component in developing a sense of safety and trust. For example, Joshua reported *"he seemed to know when I just needed to talk, and he would then just listen to me".* Some participants described that this was developed through co-regulation, in which the therapist supported the client to recognise their own emotional state:

> *"People expected me to know if I was anxious to know if I was depressed to know to be able to put a label on my own emotional state, and my experience was that I couldn't. In the therapy that I've had, I think a lot of it has been about going back to basics and learning that I didn't actually know what feelings were. So actually a lot of my therapy has been learning to label feelings through my therapist"* - Natalie

Attunement and trust within this therapeutic relationship appeared to foster feelings of being "cared for":

> *"She looks like she cares, even if she doesn't, but it looks like she does and that's kind of the only one where I've felt that way"* - Clara

Whilst attunement could be developed through the therapist's implicit and explicit communication, one participant reflected that an important part of this process was individually tailored assessment, formulation and assessment:

> *“If you've got FND or other similar conditions, this is one of those conditions where it does need to be tailored and I think it's so important in the assessment stages to understand the physical, the emotional, the history, and the experiences and you know everything that's going on in there that that shapes the way you think. And everybody's different, it’s not one size fits all” - Fran*

Upcoming endings were identified as a difficult aspect of a positive therapeutic relationship, evoking feelings of sadness:

> *“It was quite upsetting when it came to an end because she was such a support, and I didn't want to not go anymore. You know it was a good hour of my week” – Amy*

However, preparation for endings appeared to reassure participants that they were still ‘held in mind’ and allowed for positive revisions of relational templates with healthcare professionals:

> *“It was a really good relationship. We've got to the point where we've agreed that it’s time to start thinking about endings because we don't want me to be constantly relying on him every week. He said that the aim is for me to end up going off into the world and being able to look after myself, which I really like so we're now having a catch up every three months now instead of seeing each other every week. It's very much that he gives me that reassurance because he said, if at any point in our catch up that you've got worse, we can just restart the weekly session. I think that helps as well, because it's not like they just want to get the sessions done and discharge you, they’re actually putting the effort in and they care about me which makes the difference” – Fran*

Extended Discussion and Reflection

The extended discussion and reflection section expands on the journal article discussion. The study findings are considered in context to extant literature and psychological theory. The study's strengths and limitations are discussed before expanding on the clinical implications of the findings and recommendations for future research.

4.1 Findings in relation to previous literature and theory

Experiences of psychological 'services' appeared to be synonymous with experiences of interactions and relationships with professionals, with positive therapeutic relationships appearing to increase the acceptability of psychological formulation and treatment. These qualitative findings are consistent with previous literature highlighting the link between the quality of the therapeutic alliance and clinical outcomes regardless of psychotherapeutic approach (Ardito & Rabellino, 2011; Horvath & Bedi, 2002; Horvath & Luborsky, 1993; Horvath & Symonds, 1991). However, the findings from this study suggest that there may be several barriers to the development of the therapeutic relationship. Individuals with FND may feel distrustful of professionals due to previous experiences of enacted stigma and may find it difficult to engage due to internalisations of stigma associated with the condition. In services this may present as selective disclosure of information with participants describing feeling unable to speak openly due to fear of judgement. Whilst professionals' perspectives were not considered within this study, a previous meta-synthesis concluded that professionals may be anxious of 'saying the wrong thing', 'offending patients' and breaking the therapeutic relationship (Barnett et al., 2020). In addition, previous research suggests that professionals' preconceptions about FND may lead to 'defensive' interactions or conversely, professionals may be perceived as 'vague' and 'confusing' by patients (Monzoni et al., 2011). Arguably, these relational patterns appear to be a reciprocal process; professional's strategies to manage feelings of uncertainty may be perceived by individuals as 'dismissive' or as enactments of stigma. These patterns may be further perpetuated by the strategies used by individuals to avoid perceived conflict (e.g., selective disclosure), with professionals' perceptions of individuals with FND as 'emotionally avoidant' widely cited within the literature (Raynor & Baslet, 2021).

These therapist-client interpersonal dynamics may be compounded by the individuals' own relational and attachment patterns. A recent meta-synthesis of case studies highlighted that individuals' with FND perceived others as 'unreliable and unavailable' (Krivzov et al., 2021). Thus, it could be suggested that individuals' hypervigilance to perceived rejection may become a lens in which therapeutic relationships are viewed. This appears to be consistent with the findings of this qualitative study which highlights that previous relational experiences may influence perceptions of interactions in services. However, the conclusions from this meta-synthesis should be considered in light of several methodological limitations. The meta-synthesis involved secondary analysis of published case studies and therefore it is unlikely to be representative of the heterogeneous FND population. Furthermore, it is unclear whether these interpersonal patterns are specific to FND or are also evident in other presentations (Krivzov et al., 2021). Despite the literature pertaining to the interpersonal patterns of individuals with FND, the role of professionals and services cannot be ignored. Research from the perspective of healthcare professionals emphasise the negative perceptions that may be associated with the condition (Shneker & Elliott, 2008; Whitehead et al., 2013; Whitehead & Reuber, 2011; Worsley et al., 2011) which may contribute to individuals with FND feeling abandoned and excluded by medical services (Foley et al., 2022).

The process between relating to others, perceptions of how others related to individuals and how individuals related to themselves was a central tenet throughout the themes. These relational processes appeared to be heavily influenced by experiences and perceptions of interpersonal stigma. These experiences of enacted stigma resulted in intrapersonal stigma, with individuals referencing their awareness of social stigma on an implicit and explicit level. The findings of this study were consistent with theories of stigma, with participants perceptions of stigma associated with 'onset controllability' (e.g., attributed personal responsibility) (Bos et al., 2013) which was evident in participant statements such as "is it all in my head" and "am I doing this to myself". Furthermore, these findings support previous literature suggesting that stigmatised individuals anticipate stigma in their interactions with others or experience an internalisation of this stigma leading to negative conceptualisations of the self (Herek, 2009; Mak & Cheung, 2010). When considering the broader literature, the experiences of individuals with FND may be conceptualised as internalisations that have been assigned social meaning based on cultural context (Vygotsky & Cole, 1978).

4.2 Strengths, limitations, and future research

A strength of this research is that it included individuals who were currently accessing psychological services and those who had previously engaged in these services. Furthermore, the duration of engagement with psychological services ranged from 2 weeks to 3.5 years and included participants who had experienced services/professionals both positively and negatively. Thus, the findings of this study provide a novel and nuanced understanding of participants' perspectives such as how attunement within the therapeutic relationship may revise internalisations of stigma associated with FND. Previous research has focused on individuals' experiences in medical settings and thus the findings from this study (e.g., how participants perceive psychological explanations) were not possible to highlight in the existing literature.

Based on the demographic information collected, there was a skew towards younger working age participants, with a mean age of 33.66 years. Whilst there was a reasonable range in participant ages (21-54 years), nine of the fifteen participants were aged 30 years or below. Thus, the findings of this research must be considered in light of cohort effects potentially impacting participant experiences and perceptions. Future research is needed to explore whether this skew is representative of individuals accessing psychological services for difficulties pertaining to FND. Furthermore, further research exploring the perceptions of those under-represented in this study may be needed to understand whether age may influence experiences of services. Future research may wish to also consider the impact of age on how participants conceptualise themselves and the condition.

The cross-sectional nature of the design allowed for participants perspectives to be captured at one point, however this does not allow for exploration of whether their perceptions change during their time in services. Arguably, given the range of participants time in services, the study captures perceptions of participants who are at different stages in their treatment journey. However, future research adopting a longitudinal design would allow for participants perspectives to be captured at different time-points, from initial referral through to discharge. This may offer further insights into the factors that influence experiences of services from the perspective of those with a diagnosis of FND.

The findings of this study should be interpreted with consideration of the researcher’s professional membership. The researcher does not have a diagnosis of FND and although consultation and supervision were provided by an expert of experience, these sessions were limited due to financial constraints and availability. Whilst the findings of this study are important in understanding how perceptions of stigma impact the therapeutic encounter, there is a possibility that these conclusions do not align with the participants interpretations or priorities. The researcher acknowledges that there is a possibility that certain aspects of the data may have been highlighted based on their professional membership and clinical interests. Future research may wish to increase expert by experience involvement through all stages of the research process: conceptualisation through to data analysis.

This research was the first qualitative study to explore how individuals with a diagnosis of FND experience psychological services in the UK and highlighted how perceived stigma impacts different aspects of the therapeutic encounter. Although qualitative interviews allowed for an in-depth exploration of participant experiences and perspectives, due to the small sample size these findings cannot be generalised to the broader FND population. Future research adopting a mixed-methods sequential exploratory design would allow for the findings from the qualitative phase of the research to be condensed into a survey, to investigate how well endorsed these themes are within a larger sample.

Whilst the study provided rich data on the experiences of individuals with FND, it does not consider how this may compare to other stakeholder perspectives. Within the wider literature, there is research exploring medical professionals' perspectives, however it remains unclear how psychological practitioners experience this therapeutic encounter. Future qualitative research is needed to understand these perspectives, specifically the barriers and facilitators to engagement and to the development of the therapeutic relationship. A dyadic case design could be adopted to compare the perspectives of individuals with a diagnosis of FND with the perspectives of professionals working within psychological services.

Intersectional stigma is defined as “total synchronistic influence of various forms of oppression which combine and overlap to form a distinct positionality” (Berger, 2010 p.24). Given the higher prevalence of women diagnosed with FND, the historical context associated with gender and existing research highlighting the impact of gender-based stigma in healthcare (Appignanesi, 2011), further research should also consider intersectional stigma and FND (MacDuffie et al., 2021). Whilst the majority of participants identified as female (80%), it was noted during data collection and analysis that the participants who identified as male (20%) appeared to report less stigmatised experiences within services. Due to the small sample size and qualitative methodology of the research, conclusions on this difference in experiences cannot be made. However, future research exploring how gender and other demographic characteristics impact experiences of FND-related stigma in services is warranted. Furthermore, structural racism in healthcare settings has been highlighted extensively in the literature and is linked to poor health outcomes and negative service user experiences (Williams et al., 2019). In the current study, only one participant identified as Black British, with the remaining 14 participants identifying as White British/Irish/Welsh/European. As a result of this, it was unclear how ethnic background influenced experiences for those accessing psychological services for FND. Although this demographic information was not highlighted as a relevant contextual factor in the data, it is acknowledged that the researcher may have missed nuances in the data due to their own ethnic background (White British) and the small sample size. Further research exploring how ethnicity and cultural identity impact experiences of FND-related stigma in services is warranted.

4.3 Clinical implications

4.3.1 Communicating psychological explanations

The findings of this research have several implications on clinical practice in psychological services. Practitioners should be mindful of how individuals’ previous experiences of enacted and internalised stigma may impact perceptions of psychological explanations of FND. This should be considered from the point of assessment whereby practitioners should explicitly acknowledge symptoms as real and where appropriate address any concerns regarding the referral to psychological services. It may be helpful to explain to individuals that referral to psychological services does not imply symptoms have been ‘feigned’ or are ‘all in the mind’, but that the evidence-base currently recommends psychological intervention as part of treatment. There may be consideration of how psychological explanations of FND-type presentations may be perceived, particularly for individuals’ who are heavily invested in medical explanations. As highlighted by the participants in this study, theories that bridge the gap between mind-body dualism (e.g., polyvagal theory, autonomic nervous system dysfunction theories) and consider multiples factors (e.g., stress-diathesis model and biopsychosocial frameworks) may support understanding. Overcoming perceptions of false dualism may be an integral aspect of the assessment and formulation process. These explanations should aim to highlight how environmental factors (e.g., stress, trauma) impact the nervous system, resulting in physical symptoms. However, practitioners should be mindful of how psychological concepts such as trauma are discussed with individuals, with explicit conversations addressing perceptions of blame and shame, where clinically appropriate. Although the link between trauma, stress and FND is documented within the literature, some participants described finding these links difficult to accept. Therefore, practitioners should aim to communicate psychological explanations using the language of the client and pacing these formulations in line with the client’s zone of proximal development. Formulations may also benefit from consideration of how interpersonal and internalised stigma may impact how individuals conceptualise themselves and the condition.

It is important that practitioners acknowledge the gaps in the current theoretical and clinical understanding of FND, and that psychological formulations are held tentatively. Given the heterogeneity and complexity of the condition, it is unlikely that one theory can adequately explain symptom onset and maintenance. Thus, practitioners should explicitly acknowledge this and integrate theories and models based on individual presentation and personal history.

Furthermore, there should be consideration throughout the formulation process of how certain psychological models may be perceived by individuals. For example, cognitive models may be experienced as reinforcing ideas that FND is a rational and conscious process or that symptoms are “all in the mind”. As such, the practitioner should ensure to introduce psychological explanations whilst acknowledging that symptoms are real and believed by professionals. It is essential that practitioners reflect on their own preconceptions and do not inadvertently force these onto individuals, particularly if these do not fit with the client’s narrative or personal history. Psychological formulations should be developed collaboratively, with meaning co-constructed through the practitioners’ knowledge of theory and research and the individuals’ expertise of experience (Butler, 1998; DCP, 2011; Johnstone, 2018). The formulation will provide a foundation and rationale for intervention, and as such should be tailored to the individuals’ needs. As outlined by Stone and colleagues (2016), formulation of FND may be a therapeutic intervention in addition to facilitating engagement with therapy. Further research exploring the impact of different models of psychological formulations for FND is warranted.

4.3.2 Development of the therapeutic relationship

As highlighted by the results of this research, practitioners should be mindful of how previous experiences with healthcare professionals may impact the development of the therapeutic relationship. Perceptions and anticipations of interpersonal stigma are likely to be a barrier to developing meaningful rapport, and thus there should be an initial focus on establishing relational safety within therapy. This may be achieved through utilising Rogerian principles (Rogers, 1965), with a focus on intersubjectivity; developing a shared perception of the client’s reality. As described by participants, attunement and trust had the potential to mitigate against barriers to engagement and the perceptions of interpersonal stigma. Participants highlighted that attunement could be communicated both explicitly and implicitly. For example, practitioners drawing attention to shifts in the session and communicating recognition of the client’s emotional state. This joint attention and awareness may also support the individual to recognise their own emotional and physical cues. Arguably, this relational process demonstrates co-regulation, whereby the practitioner acknowledges the client’s distress, models self-regulation and provides containment that supports emotional safety (Hughes, 2017). The findings of this study suggest that a positive therapeutic relationship lowers perceptions of relational threat which increases the acceptability of psychological explanations.

The therapeutic relationship has the potential to revise internalisations of stigma associated with FND through a reciprocal process; the therapist demonstrates unconditional positive regard, understanding and acceptance and thus the client is more able to be accepting and understanding of themselves. However, an integral aspect of this process is the congruence of the therapist-client intentions which may be supported through development of the formulation. Given this client group may have had previous experiences of feeling ‘dismissed’ and ‘ignored’ by professionals, practitioners should consider how to support the client to feel ‘held in mind’. This may be through use of therapeutic letters (Hamill et al., 2008), demonstrating attunement within sessions (Rocco et al., 2017) and planning contained endings (Joyce et al., 2007). During sessions, it may be helpful to consider how selective disclosure may be used by participants to manage or avoid perceived ruptures, and the impact of this on relational dynamics. Practitioners should also be aware of parallel processes that may impact on the development of the therapeutic relationship. For example, practitioners’ own uncertainty around working with FND type presentations may be perceived by individuals as ‘dismissing’. To account for this, it is important that clients are given space and opportunity to share their personal narratives associated with FND, and that their experiences are validated by professionals.

4.3.3 Organisational and systemic change

The findings of this research suggest that professionals’ limited knowledge pertaining to FND may be perceived to perpetuate experiences of stigma in services. The perceived responsibility of having to educate the professionals appeared to strengthen participant narratives around being ‘misunderstood’ and ‘othered’ by services. Although the perspectives of professionals were not considered in this study, participants described a perception that professionals may distance themselves from individuals with FND due to lack of training. These findings highlight the need for further training in psychological services and clinical training programmes, with a particular focus on appropriate formulation models and evidence-based intervention. In addition, participants described professionals’ lack of knowledge around relevant specialist FND services and thus there should be a focus on improving links with specialist services and increasing access to signposting information.

Arguably, the findings of this study appear to lend support for wider arguments around the need for specially commissioned FND services. Participants described perceptions that they did not fit into general psychological/mental health services unless there were relevant co-morbid psychological needs. In addition, medical services also do not appear to be resourced to meet the needs of clients with functional presentations (Walker, 2019). Although there is a paucity of literature around FND service development, participants' experiences of psychological services in the UK support the need for services that bridge the gap between medical and psychological models. Whilst approximately 23 specialist services exist within the UK (https://www.fndaction.org.uk/specialist-care/), many individuals with FND will be referred to general psychological services (Bennett et al., 2021), perhaps due to increasing waiting times for specialist services and professionals' limited knowledge of referral pathways. This results in individuals with FND accessing services that may not be best resourced to meet their needs with research suggesting that quality standards are regularly not met for these patients' care (Houston & Cooper, 2022). Thus, future service development is needed to improve access to specialist provision and provide FND pathways within general psychological services. Furthermore, as highlighted by German Centres of Somatic Medicine, integration of medical and psychological services may be most effective for FND-type presentations (Zipfel et al., 2016).

4.4 Critical Reflection

The critical reflection section considers personal reflections on the process of the research, including any issues and challenges raised. Reflexive diary extracts are included throughout.

4.4.1 Conceptualising the research

My interest in Functional Neurological Disorder initially developed from an interest in the link between trauma and medically unexplained presentations. Prior to clinical psychology doctoral training, I worked predominantly with young people and families who had experienced significant adversity e.g., homelessness, abuse, poverty, mental health difficulties. Although based on anecdotal observations, I noted that many of these individuals experienced distressing physical symptoms that were considered “medically unexplained”. After working as a support worker in a Teenage Parent Homeless service and as a mental health practitioner in community and inpatient Children and Adolescent Mental Health services, I started to review the theoretical and empirical literature around medically unexplained presentations. During my first year of training, I completed a placement in an adult Step 4 Psychological Therapies service. Whilst on this placement I worked with an individual that had recently received a diagnosis of FND. Through working with this client, I became aware of how perceptions of psychological services impacted the therapeutic encounter. My clinical interest expanded to research, and I completed and published a systematic literature review on the effectiveness of EMDR for medically unexplained presentations (Staton et al., 2022). Following a comprehensive review of the literature, I was surprised on the paucity of research on individuals’ experiences of services from the perspective of those with a diagnosis of FND. As a result of this I became interested in understanding how individuals with FND experienced psychological services and how this may impact the therapeutic encounter. During the development of the research project, I consulted with a SUCAP member/expert by experience. This helped widen my thinking around the research aims to ensure that I did not inadvertently lead participants with the interview schedule or only recruit participants who had negative experiences of services.

4.4.2 Deciding on the qualitative methodology

Prior to training I appeared to hold a more positivist stance towards knowledge, with a view that there was an ‘absolute truth’ to be uncovered. During training I experienced a shift in my epistemological position, perhaps due to my exposure to different people’s perspectives and a recognition that a person’s ‘reality’ was influenced by their context and prior experiences. Consistent with this view, I started to endorse a critical realist stance towards knowledge. On reflection, this paradigm shift heavily influenced my choice of qualitative methodology, as reflexive thematic analysis allowed for the exploration of the individuals’ perceptions of reality within social and cultural contexts. Whilst I was initially drawn to the flexibility of reflexive thematic analysis, I started to note feelings of anxiety which appeared to be underpinned by cognitions such as *“what if I don’t do it the right way?”.* These worries were apparent in my reflexive diary in which I wrote, *“I’m starting to ruminate on my lack of research experience. I’ve never used reflexive thematic analysis and there’s so many different interpretations of the approach. I wonder whether anxiety around my research competency is manifesting as a preference for a more prescriptive methodology as this would certainly feel more containing!”.* To manage these feelings of anxiety, I adopted to use Braun and Clarke’s (2006, 2019) principles to guide my analysis, which still allowed for a flexibility in its approach.

4.4.3 Reflections on sample size

During the recruitment phase of the research, I found myself becoming fixated on what constituted an appropriate sample size. These concerns appeared to be related to the lack of guidance in this area and thus a worry about how I would justify this decision. I used research supervision to consider my research aims in addition to current thinking in the qualitative literature. As a result of this I noted a shift towards concepts such as ‘information power’ (Malterud et al., 2016) whereby the researcher considers the richness of the data and its adequacy in meeting the research aims. On reflection, my anxiety around determining a ‘large enough’ sample size appeared to be influenced by my own personal narrative around the ‘meaningfulness’ of the research. The idea of how ‘meaningful’ the research would be was noted several times throughout my reflexive diary, perhaps underpinned by academic pressures and personal striving patterns. However, I considered my critical realist epistemological position and reflected that I was not aiming to uncover an absolute reality, but rather exploring the perceptions of an individual's reality. As such, the richness and quality of the data was more important than merely the quantity of participants. Furthermore, given the qualitative methodology I was not aiming to represent the views of all individuals with a diagnosis of FND and misguided attempts to do so would likely have led to poor representation of participants within the themes.

4.4.4 Interview process

During the conceptualisation phase of the research, I had reflected on my professional role and how this may impact the disclosure of participants during interviews. However, this became more apparent as I started to conduct the research interviews. The increased awareness of my professional identity in the context of the research was reflected upon in my reflexive diary:

> *"In the last interview a participant stated "I know it's not all psychological professionals" after sharing a negative interaction with a healthcare professional. This made me aware of the dual position I hold; a researcher exploring experiences of psychological services and a professional working within these very systems. I wonder how my professional identity impacts participant disclosure during interviews?"*

Although participants appeared very open in the information they shared about their experiences, I reflected on how the way participants shared their perspectives may have differed had I not worked within psychological services. This may be viewed through the application of social identity theory (Tajfel, 1979), in which due to my professional identity participants may have conceptualised me as part of the "out group". During the interviews I ensured to adopt a position of curiosity to encourage participants to share their experiences. I was also mindful of the importance of validating participants experiences through my explicit and implicit communication. Although it is impossible to know the extent to which my dual roles (e.g., researcher and trainee clinical psychologist) affected participant disclosure, it may have been helpful to have an interviewer who did not currently work in psychological services.

The relational process during interviews was a reoccurring theme throughout my reflexive diary. I became acutely aware of the inherent power imbalance between myself as the researcher and the position of the participant:

> “I’ve noticed that several participants have made comments about feeling anxious prior to interviews or worrying that they may not be sharing “helpful information”. This has made me reflect on how my role as ‘researcher’ is perceived by participants”.

I attempted to address these inherent power imbalances by prefacing interviews with a conversation about how the meeting was a chance for the participant to share their experiences. I reflected with participants on how formal the term ‘interview’ was (and the connotations of this word) and reassured them that the meeting would feel more like an informal discussion. I informed participants at the start of each interview that there was no ‘right’ answer to the questions and the research was interested in understanding individual perceptions and experiences. Following this, I noted that participants made less statements pertaining to worries about sharing ‘helpful’ information.

During six of the fifteen interviews, I noticed that I often allowed participants to stray away from the interview schedule onto unrelated tangents. This resulted in longer than anticipated interview durations. I reflected on this in a research supervision and considered how reoccurring themes arising in interviews such as participants sharing experiences of being dismissed, made me wary of ‘re-enacting’ these patterns. As such, on occasion I became wary of redirecting participants back to the interview schedule:

> *“There’s been a number of occasions where I find myself avoiding steering the participant back on topic during interviews. I suppose my worry is that this may be experienced as ‘dismissive’ or ‘critical’ by participants. Given their previous experiences of healthcare professionals, I feel acutely aware of accidentally re-enacting these same patterns. I also wonder whether I perceive some participants to be hypervigilant to feeling dismissed because of their previous interpersonal experiences?”*

After reflecting on this dynamic in supervision, I decided it may be helpful to address this indirectly at the start of each interview. For example, I explained to participants: *"Sometimes we might find the conversation is going off onto tangents, this is completely natural, but because of the time-limit of our meeting I might have to redirect us back onto topic. This is to ensure I give you enough time to share your experiences without you feeling rushed".* I noticed after introducing this statement at the start of interviews that I felt more able to redirect participants onto more relevant strands of discussion.

The emotional impact of the interviews became evident quickly and I often felt drained and fatigued afterwards. I reflected in supervision on the emotive content of the interviews (e.g., participants sharing experiences of being stigmatised by professionals) and how these evoked personal feelings of sadness and anger:

> *"I'm finding it really sad hearing about participants painful experiences of healthcare professionals. The way people have been treated by professionals goes against all professional values which leaves me feeling angry and frustrated. I suppose it also sits uncomfortably with my own professional identity and makes me question whether I have ever inadvertently enacted stigma within my own clinical practice".*

I found it helpful to reflect on my emotional responses to the data during the interview phase, as this allowed me to not get 'caught up' on this during analysis. Despite the emotional impact, I reflected on my own position of privilege and the importance of representing participants experiences within the research. Furthermore, participants reported that they had found sharing their experiences a 'cathartic' process and that it had been positive to be 'given opportunity to voice this'. Some participants also expressed feeling empowered by their contribution to the research and shared their hopes that future research on the topic would lead to social and clinical change.

4.4.5 Analysis process

As I moved into the analysis phase of the research, I noted feeling overwhelmed with the amount of data. I reflected on this during supervision and considered how compared to data collection, analysis felt ‘unstructured’ and ‘uncontained’. Akin to my reflections of choosing a qualitative methodology, I re-experienced worries about ‘getting my analysis right’. To account for this, I found it helpful to apply Braun & Clarke’s (2006, 2019) principles to guide my analysis, as this provided a sense of structure. After familiarising myself with the data and completing the initial inductive coding I became preoccupied with thoughts about ‘capturing all of the data’. This intensified after I had applied the deductive coding framework and began developing themes as I felt I was discarding other important data. I reflected on this experience in my reflexive diary at the time:

> *“I feel a responsibility to represent all of the data as participants took the time to contribute and share their experiences with me – because of this, I’m finding it difficult to not include data as it feels like I’m disregarding other important themes. I wonder whether a part of this is a worry that some of participant’s perspectives won’t be included in the final report?”.*

During this time I reflected on my personal values and professional membership and how this influenced my interpretation of the data and thus ‘what felt important about the story I was telling with the data’. This led to considerations about whether this narrative would be meaningful and important to the participants. However, after discussing this in research supervision I reflected that although I may never be able to fully convey participants’ experiences, reflexive thematic analysis views researcher subjectivity as an essential component of analysis (Braun & Clarke, 2021). As such, I noted a shift between ‘fighting against’ my own subjectivity, to reflecting on how this influenced my interpretation of the data. As I started to define and name the themes, I became mindful of how participants would perceive my interpretation:

> *"One of the most salient aspects of my interpretation of the data is the impact of internalised stigma. I'm mindful of whether this may be perceived by participants as judgemental or placing the blame on them! This is certainly not my intention, as I believe internalised stigma is the product of previous experiences of enacted stigma. I wonder whether my awareness of participants' perceptions of being blamed by professionals is influencing my worries?"*

To address these concerns and ensure that I was not inadvertently re-enacting unhelpful patterns, I discussed this with my research supervisors.

4.4.6 Closing reflections

I found that engaging in the reflective process supported me to consider my role as the researcher at each stage of the research. This allowed me to learn more about my personal and professional values, as well as my philosophical position. Finally, the findings of this research have provided an opportunity to reflect on my own clinical practice. As such, I have noticed an increased awareness of how psychological formulations may be perceived by clients who are anticipating a physical explanation of their difficulties. Furthermore, I explicitly consider how experiences of stigma impact relational dynamics within the therapeutic encounter.

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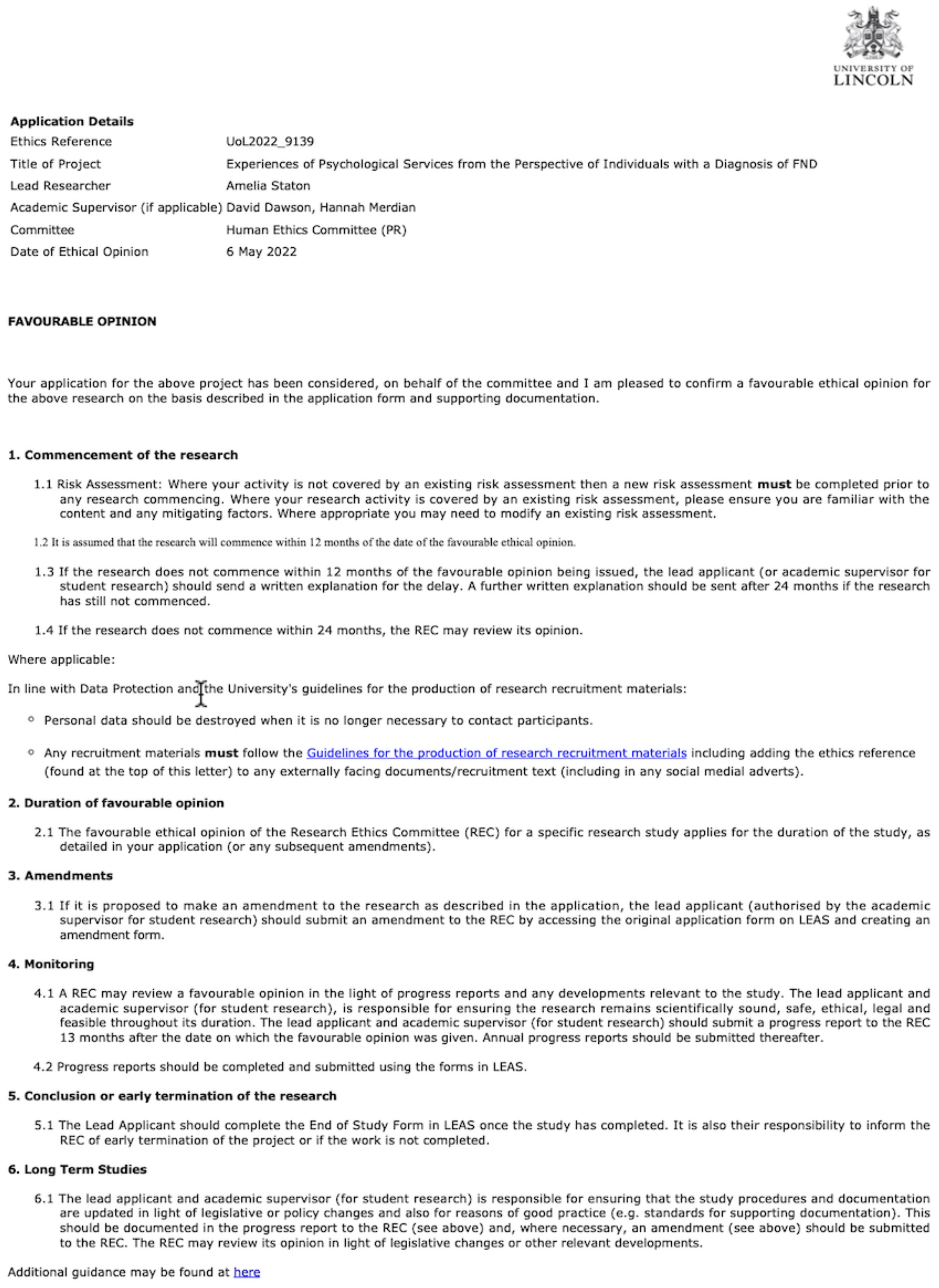
Appendices

Appendix C *Ethical Approval Letter*



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Application Details

Ethics Reference	UoL2022_9139
Title of Project	Experiences of Psychological Services from the Perspective of Individuals with a Diagnosis of FND
Lead Researcher	Amelia Staton
Academic Supervisor (if applicable)	David Dawson, Hannah Merdian
Committee	Human Ethics Committee (PR)
Date of Ethical Opinion	6 May 2022

FAVOURABLE OPINION

Your application for the above project has been considered, on behalf of the committee and I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation.

1. Commencement of the research

1.1 Risk Assessment: Where your activity is not covered by an existing risk assessment then a new risk assessment **must** be completed prior to any research commencing. Where your research activity is covered by an existing risk assessment, please ensure you are familiar with the content and any mitigating factors. Where appropriate you may need to modify an existing risk assessment.

1.2 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

1.3 If the research does not commence within 12 months of the favourable opinion being issued, the lead applicant (or academic supervisor for student research) should send a written explanation for the delay. A further written explanation should be sent after 24 months if the research has still not commenced.

1.4 If the research does not commence within 24 months, the REC may review its opinion.

Where applicable:

In line with Data Protection and the University's guidelines for the production of research recruitment materials:

- Personal data should be destroyed when it is no longer necessary to contact participants.
- Any recruitment materials **must** follow the Guidelines for the production of research recruitment materials including adding the ethics reference (found at the top of this letter) to any externally facing documents/recruitment text (including in any social medial adverts).

2. Duration of favourable opinion

2.1 The favourable ethical opinion of the Research Ethics Committee (REC) for a specific research study applies for the duration of the study, as detailed in your application (or any subsequent amendments).

3. Amendments

3.1 If it is proposed to make an amendment to the research as described in the application, the lead applicant (authorised by the academic supervisor for student research) should submit an amendment to the REC by accessing the original application form on LEAS and creating an amendment form.

4. Monitoring

4.1 A REC may review a favourable opinion in the light of progress reports and any developments relevant to the study. The lead applicant and academic supervisor (for student research), is responsible for ensuring the research remains scientifically sound, safe, ethical, legal and feasible throughout its duration. The lead applicant and academic supervisor (for student research) should submit a progress report to the REC 13 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be completed and submitted using the forms in LEAS.

5. Conclusion or early termination of the research

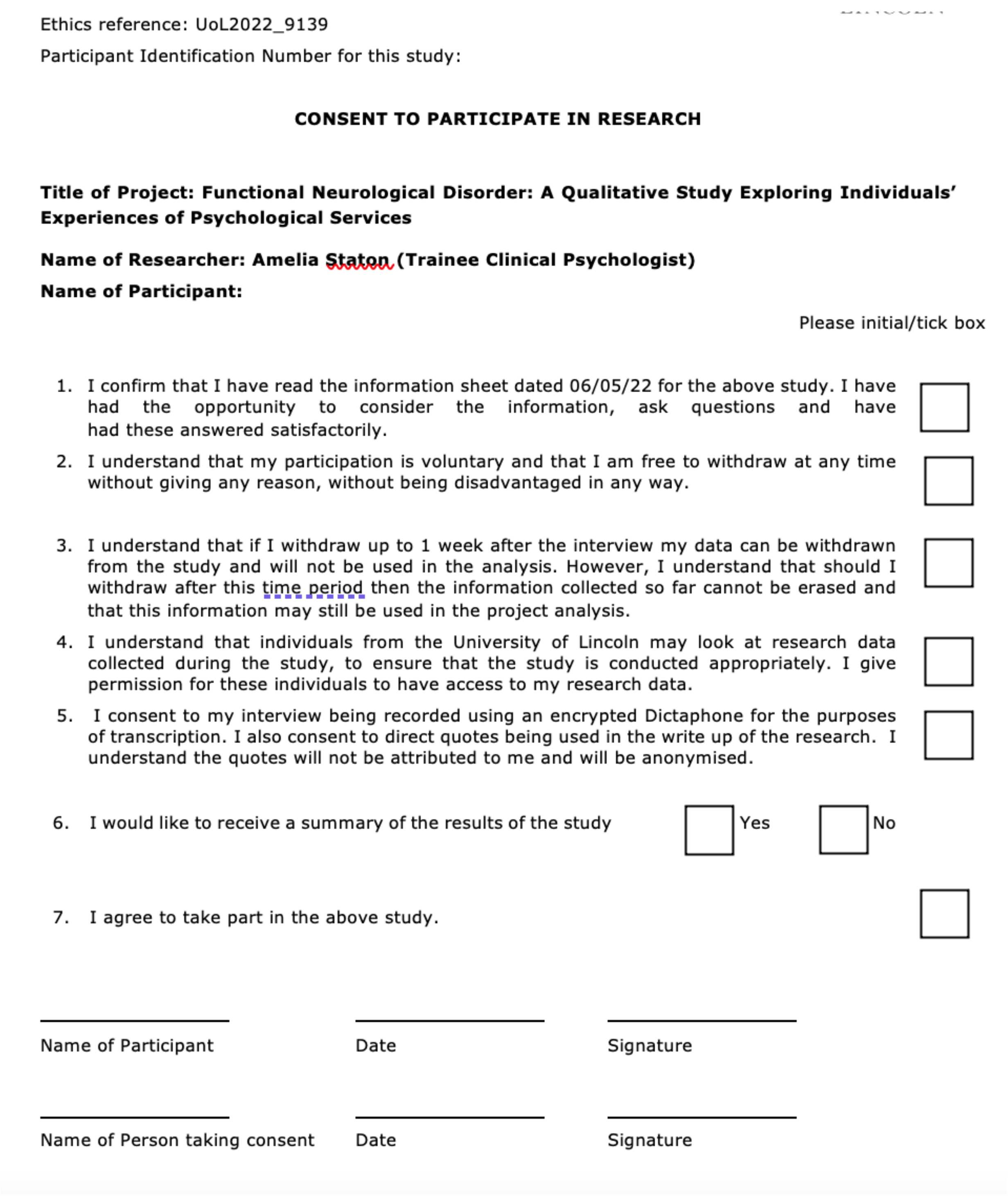
5.1 The Lead Applicant should complete the End of Study Form in LEAS once the study has completed. It is also their responsibility to inform the REC of early termination of the project or if the work is not completed.

6. Long Term Studies

6.1 The lead applicant and academic supervisor (for student research) is responsible for ensuring that the study procedures and documentation are updated in light of legislative or policy changes and also for reasons of good practice (e.g. standards for supporting documentation). This should be documented in the progress report to the REC (see above) and, where necessary, an amendment (see above) should be submitted to the REC. The REC may review its opinion in light of legislative changes or other relevant developments.

Additional guidance may be found at here

Appendix D *Study Consent Form*



Ethics reference: UoL2022_9139
Participant Identification Number for this study:

CONSENT TO PARTICIPATE IN RESEARCH

Title of Project: Functional Neurological Disorder: A Qualitative Study Exploring Individuals' Experiences of Psychological Services

Name of Researcher: Amelia Staton (Trainee Clinical Psychologist)
Name of Participant:

Please initial/tick box

1. I confirm that I have read the information sheet dated 06/05/22 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without being disadvantaged in any way. ☐
3. I understand that if I withdraw up to 1 week after the interview my data can be withdrawn from the study and will not be used in the analysis. However, I understand that should I withdraw after this time period then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
4. I understand that individuals from the University of Lincoln may look at research data collected during the study, to ensure that the study is conducted appropriately. I give permission for these individuals to have access to my research data. ☐
5. I consent to my interview being recorded using an encrypted Dictaphone for the purposes of transcription. I also consent to direct quotes being used in the write up of the research. I understand the quotes will not be attributed to me and will be anonymised. ☐
6. I would like to receive a summary of the results of the study ☐ Yes ☐ No
7. I agree to take part in the above study. ☐

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

Appendix E *Participant Information Sheet*

Participant Information Sheet/Information about the research
(Version 2.1 – 06/05/22)

Title of Study: Functional Neurological Disorder: A Qualitative Study Exploring Individuals' Experiences of Psychological Services

I am a trainee Clinical Psychologist based at the University of Lincoln. I am completing this research as part of my professional doctorate in Clinical Psychology. We are inviting you to take part in a research study. Before you decide, it is important that you know why we are doing the study and what is involved. Please read the following information carefully.

What is the purpose of the study?

This research study would like to explore the experiences of UK psychological services, from the perspective of individuals with a diagnosis of Functional Neurological Disorder (FND). Individuals who have received a diagnosis of FND are often referred to psychological services, however findings from the research literature suggest that treatment outcomes are generally mixed. This study aims to explore this client groups experiences of the support offered by UK psychological services. It is hoped that this information will provide insight that can guide clinicians in their practice and improve client experiences of this healthcare provision.

Am I eligible to take part?

You are being invited to take part because you are aged 18 years or older, have received a diagnosis of Functional Neurological Disorder and have accessed UK psychological services as a result of this condition.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway.

What will I be asked to do?

If you are interested in taking part in this research after reading this participation information sheet, please contact the lead researcher Amelia Staton (contact details can be found at the end of this information sheet). The researcher will contact you via telephone within 7 working days. If you have any questions about the research, the researcher will be available to meet to discuss this with you. You may provide eConsent or print, sign and scan your consent form if you prefer. Following this, you will be asked to attend a 60–90-minute interview which will take place over telephone or video call. During this interview, you will be asked questions about your experiences of accessing UK psychological services related for difficulties related to FND. The interviews will be audio recorded using an encrypted Dictaphone and transcribed using the University of Nottingham's automated transcription service. No-one outside the research team will have access to them and the recording will be deleted after it has been transcribed. Personal data (such as your name and contact details) will be collected for the purposes of your participation in this research and will not be shared with anyone outside of the research team. Your personal data will be deleted from study records within twelve months. All information about you will be handled in confidence.

Will I be paid expenses for taking part?

You will be paid an inconvenience allowance to participate in the study (£20 high-street voucher). The interviews will take place remotely via telephone or video call and therefore no travel is expected as part of involvement in this research.

What are the possible benefits / risks of taking part?

There may not be any direct benefits to you, although some people find it helpful to talk about their experiences. It is hoped that the results of this study will increase our understanding of client experiences which will be used to guide clinicians in their practice.

The possible disadvantages and risks of participating in this research are expected to be minimal. I anticipate that the main disadvantage will be the inconvenience of taking time out of your day. To account for this, you will be able to choose a date and time that is most convenient for you and you will also receive a £20 high-street voucher as a reimbursement for your time. You could find it difficult to discuss your experiences of accessing psychological services. In the event of this, you will be provided an opportunity to take a break or to end the interview. At the end of the interview, I will ensure space and time to de-brief. Contact details for support organisations can be found at the end of this document and on the study de-brief sheet.

Will anyone know I have taken part?

The University of Lincoln (UoL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The research team will keep your name and contact details confidential and secure. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UoL may look at your research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The interview will be confidential unless you reveal that you or someone you know is at serious risk of harm. We will talk about it with you so that we can work out together how best to handle this.

Where will my data be stored?

The data obtained from the study will be stored securely on the university OneDrive in password protected files. Only the researchers will have access to it. The data from this study *may* be put in an Open Access repository for other researchers to use in future research. If so, responses will be anonymised and any personal data (e.g. contact details) will be removed.

Your contact information will be kept by the University of Lincoln after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. Your personal data will be deleted within twelve months. All other data (research data) will be kept securely for 5 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

What will happen if I don't want to carry on with the study?

You are free to withdraw at any point from this study, without having to give a reason, by contacting the researcher using the contact details at the end of this information sheet.

If you withdraw up to one week after the interview, then your data can be withdrawn from the study and will not be used in the analysis. Should you withdraw after this time period then the information collected so far cannot be erased and may still be used in the project analysis. The reason for this is because after one week the interviews will be sent for transcription (typed up word for word). If you withdraw after this period, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of this study will be reported in the researcher's doctoral thesis. The research will also be prepared for publication in a peer-reviewed journal and may be presented at relevant conferences. Whilst direct quotes from interviews may be included in the final report, all information will be anonymised, and the confidentiality of all participants will be protected.

Who is organising and funding the research?

This research is being conducted as part of the researcher's Doctorate in Clinical Psychology and is funded by the University of Lincoln.

Who has reviewed the study?

All research conducted by the University of Lincoln is looked at by an independent group of people, called a Research Ethics Committee, to protect your rights, dignity and wellbeing. This study has been reviewed and given favourable opinion by a University of Lincoln Research Ethics Committee [Ref UoL2022_9139].

What if there is a problem?

It is very unlikely that this study would cause you any harm. If you have a concern or a complaint about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

If you remain unhappy and wish to complain formally, you can make a formal complaint through the University complaints procedure or by contacting ethics@lincoln.ac.uk.

Further information and contact details

If you have any questions about this study, please do not hesitate to contact us on the details below.

Amelia Staton (Researcher/Trainee Clinical Psychologist)
13397295@students.lincoln.ac.uk

Dr Dave Dawson (Research Supervisor)
ddawson@lincoln.ac.uk

Dr Hannah Merdian (Research Supervisor)
hmerdian@lincoln.ac.uk

Information compliance

The University of Lincoln is the lead organisation for this study and will be the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The university's Research Participant Privacy Notice (https://ethics.lincoln.ac.uk/research-privacy-notice/) explains how we will be using information from you in order to undertake this study.

If you feel that we have let you down in relation to your information rights then please contact the Information Compliance Team by email on compliance@lincoln.ac.uk or by post at Information Compliance, Secretariat, University of Lincoln, Brayford Pool, Lincoln, LN6 7TS.

You can also make complaints directly to the Information Commissioner's Office (ICO). The ICO is the independent authority upholding information rights for the UK. Their website is ico.org.uk and their telephone helpline number is 0303 123 1113.

Further help and support

If you have been affected by any of the issues raised by taking part in this study the following organisations may be able to provide help and advice:

NHS non-urgent helpline: 111

NHS Urgent Mental Health Helpline (Location Specific): https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline

Samaritans: 116 123 (24-hour helpline)

Mind Mental Health Charity: www.mind.org.uk / 0300 123 3393

Appendix F *Participant Debrief Sheet*

Participant Debrief Sheet

(Version 2.1 – 06/05/22)

Title of Study: Functional Neurological Disorder: A Qualitative Study Exploring Individuals' Experiences of Psychological Services

This study has been reviewed and given favourable opinion by a University of Lincoln Research Ethics Committee [Ref UoL2022_9139].

Name of Researcher: Amelia Staton
Contact Details of the Researcher(s) are given at the end.

We'd like to thank you for taking part in our research study. This research will provide crucial information and broaden our understanding of the experiences of individuals with a diagnosis of Functional Neurological Disorder who access UK psychological services.

What was the aim of the study?

This research study aimed to explore the experiences of UK psychological services, from the perspective of individuals with a diagnosis of Functional Neurological Disorder (FND). It is hoped that this information will provide insight that can guide clinicians in their practice and improve client experiences of this healthcare provision.

Questions and withdrawing

If you have any further questions about the study or would like to receive a copy of the final write up of this research, please feel free to ask the researcher before you finish or alternatively contact the researcher or their supervisor at any time on 13397295@students.lincoln.ac.uk

Participation is completely voluntary and you can withdraw at any time. If you withdraw up to one week after the interview, then your data can be withdrawn from the study and will not be used in the analysis. Should you withdraw after this time period then the information collected so far cannot be erased and may still be used in the project analysis. The reason for this is because after one week the interviews will be sent for transcription (typed up word for word). If you withdraw after this period, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

Further help and support

If you have any ethical concerns regarding the current research, your treatment as a participant or your involvement in the study please feel free to contact ethics@lincoln.ac.uk.

If you have been affected by any of the issues raised by taking part in this study the following organisations may be able to provide help and advice:

NHS non-urgent helpline: 111

NHS Urgent Mental Health Helpline (Location Specific): https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline

Samaritans: 116 123 (24-hour helpline)

Mind Mental Health Charity: www.mind.org.uk / 0300 123 3393

Functional Neurological Disorder Charity: https://fndhope.org/about-fnd-hope/fnd-hope-uk/

Contact Details of Researcher(s)

If you have any questions about this study, please do not hesitate to contact us on the details below.

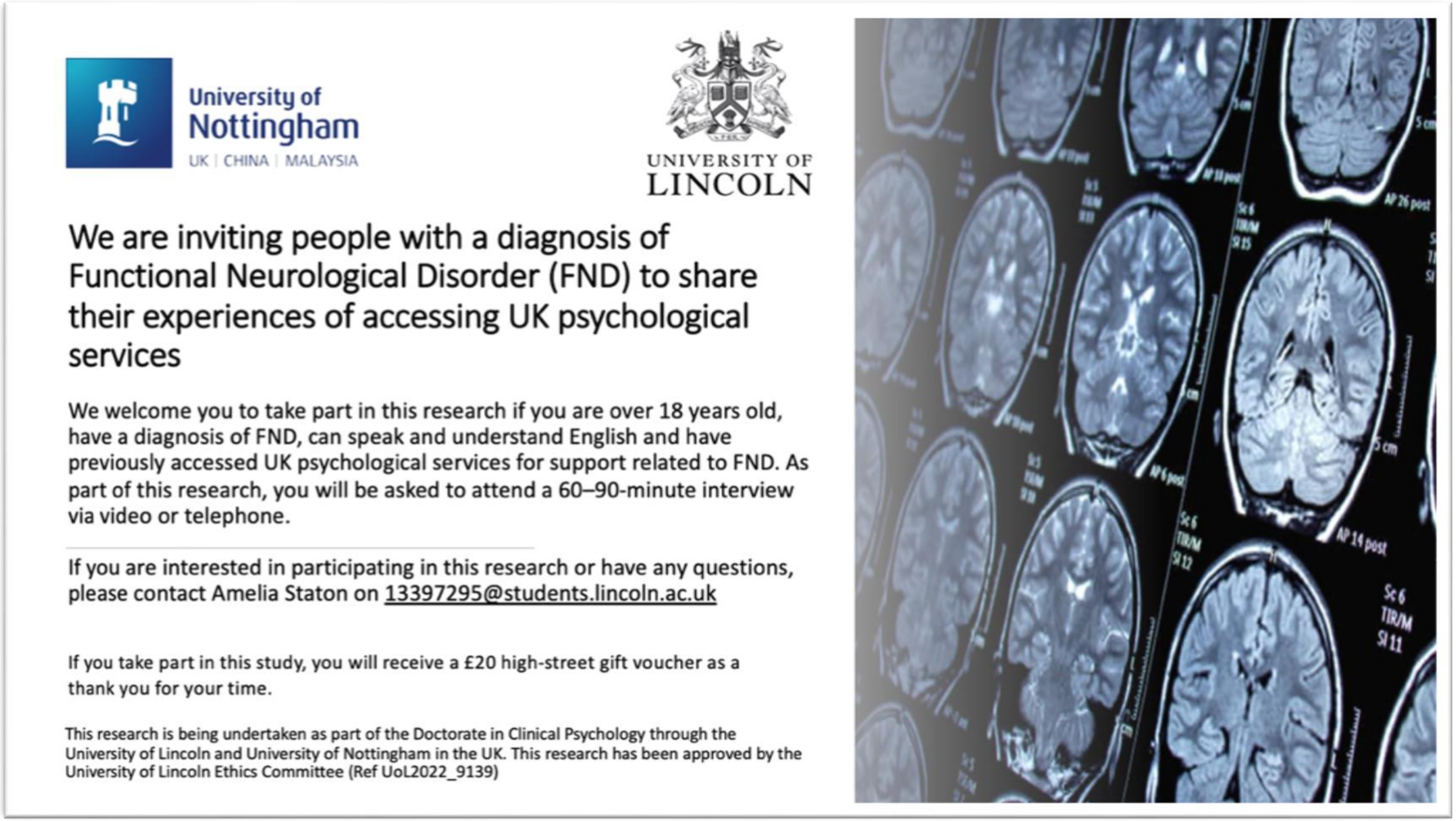
Amelia Staton (Researcher/Trainee Clinical Psychologist)
13397295@students.lincoln.ac.uk

Dr Dave Dawson (Research Supervisor)

ddawson@lincoln.ac.uk

Dr Hannah Merdian (Research Supervisor)
hmerdian@lincoln.ac.uk

Appendix G *Social Media Advert*



University of Nottingham
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UNIVERSITY OF LINCOLN

We are inviting people with a diagnosis of Functional Neurological Disorder (FND) to share their experiences of accessing UK psychological services

We welcome you to take part in this research if you are over 18 years old, have a diagnosis of FND, can speak and understand English and have previously accessed UK psychological services for support related to FND. As part of this research, you will be asked to attend a 60–90-minute interview via video or telephone.

If you are interested in participating in this research or have any questions, please contact Amelia Staton on 13397295@students.lincoln.ac.uk

If you take part in this study, you will receive a £20 high-street gift voucher as a thank you for your time.

This research is being undertaken as part of the Doctorate in Clinical Psychology through the University of Lincoln and University of Nottingham in the UK. This research has been approved by the University of Lincoln Ethics Committee (Ref UoL2022_9139)

Appendix H *Semi-Structured Interview Schedule*

Functional Neurological Disorder: A Qualitative Study Exploring Individuals' Experiences of Psychological Services

Interview Schedule (questions and prompts to guide discussion)

<u>Demographic Information</u>

Age ("How old are you?")
Gender ("What gender do you identify as?")
Ethnicity ("What best describes your ethnicity?")
What is your current employment status?
How long did you access support from psychological services?
(Follow up: how many sessions? Did you attend all sessions offered?)

<u>Diagnosis of Functional Neurological Disorder</u>

Tell me about your experience of receiving your diagnosis?
(Prompts: which service did this take place? How long between symptoms starting to receiving the diagnosis? How did the clinician explain this diagnosis to you?)
How did the psychologist/mental health professional explain the diagnosis to you?
(Prompts: was this different to how it was explained when you received your diagnosis e.g., by the Neurologist?)

<u>Referral to Psychological Services</u>

Who made the referral to psychological services?
(Follow up: how long was this after receiving the diagnosis? How was this referral explained to you?)
How did you feel about this referral being made?

(Follow up: If any, did you have any concerns about this referral being made? If any, what were your expectations about what support could be offered by these services?)

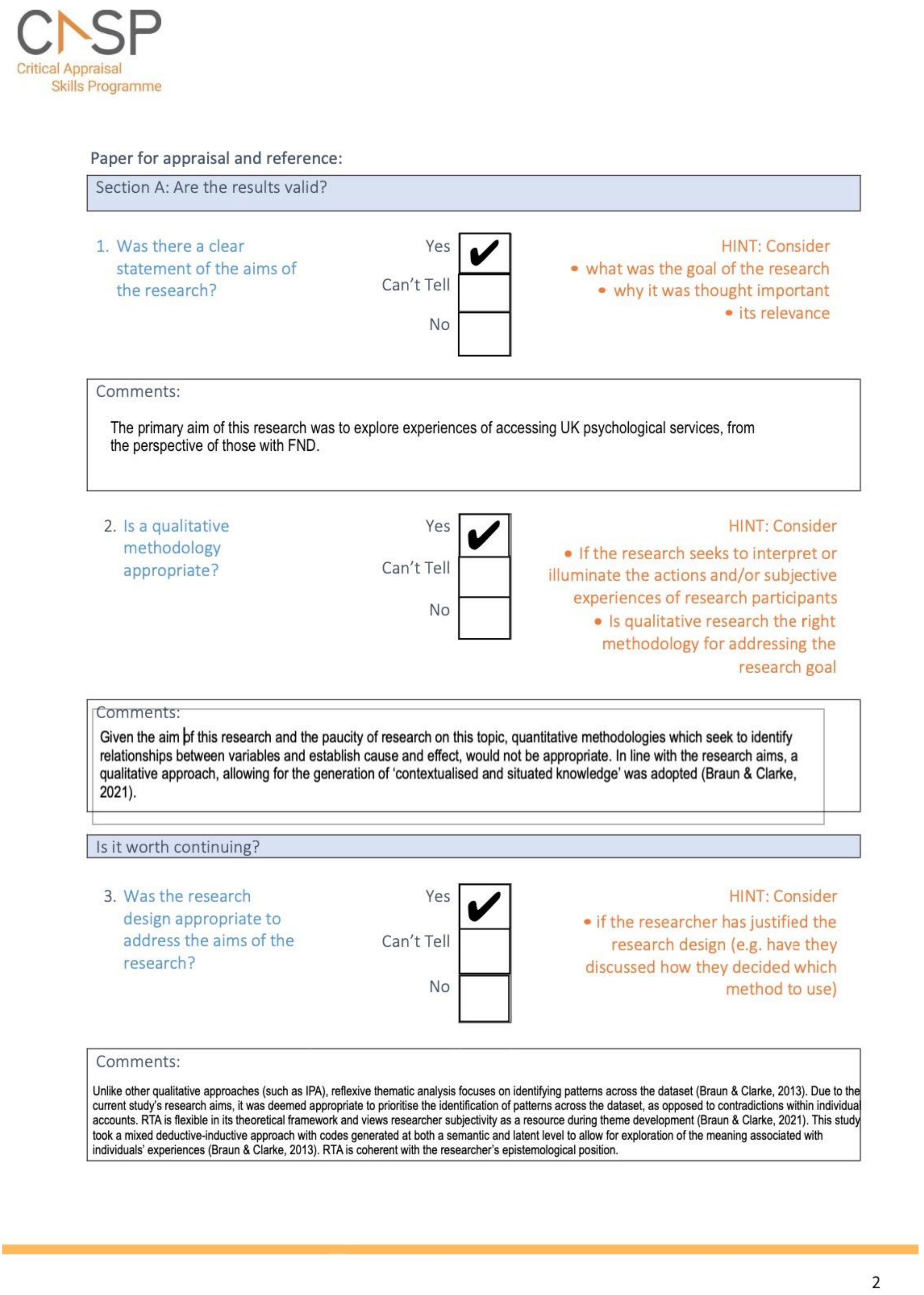
Experiences of Psychological Services

What were your experiences of trying to access psychological services?
Prompts: Did anything hold you back/stop you from seeking professional support before you did? If so, what? What did you think about yourself about seeking professional help? What did you think others might think of you? If so, what? Was there anything that helped you seek professional support?
What were your experiences of using psychological services?

Follow up questions: What type of professional did you work with? What was your relationship with the professional you worked with like? Was there anything within or outside of the therapy that impacted your experience of the support?

What was the focus of the sessions/support?
(Prompts: type of therapy e.g., trauma focused, CBT, CAT, CFT, ACT, ISTDP)
If any, what goals did you set in therapy?
(Follow up: do you feel that these goals were met?)
What are your views on the support offered by the professional?
Are there any aspects of the support that could have been improved?

Appendix I *CASP Quality Checklist*



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

The primary aim of this research was to explore experiences of accessing UK psychological services, from the perspective of those with FND.

2. Is a qualitative methodology appropriate?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Given the aim of this research and the paucity of research on this topic, quantitative methodologies which seek to identify relationships between variables and establish cause and effect, would not be appropriate. In line with the research aims, a qualitative approach, allowing for the generation of 'contextualised and situated knowledge' was adopted (Braun & Clarke, 2021).

Is it worth continuing?

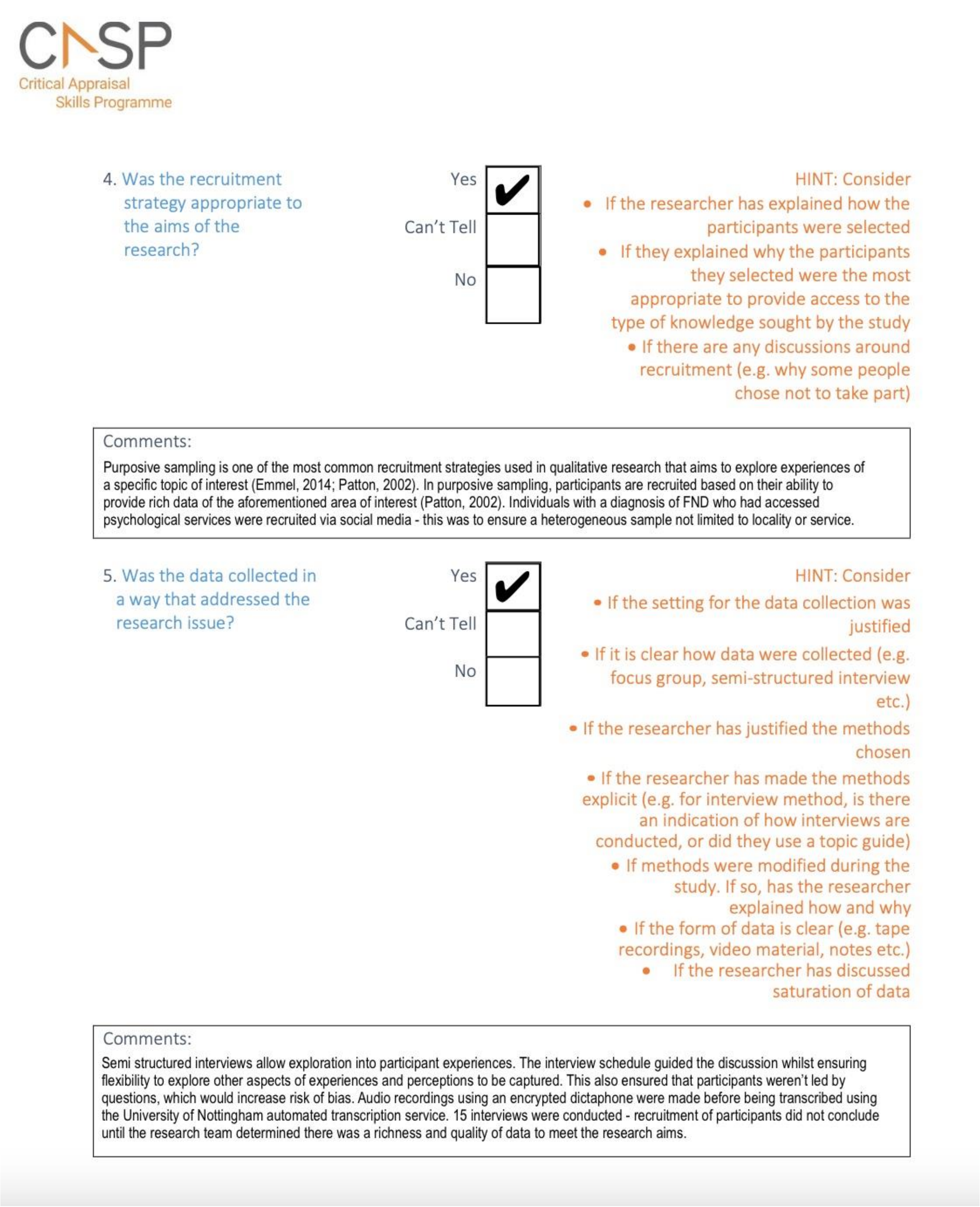
3. Was the research design appropriate to address the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

Unlike other qualitative approaches (such as IPA), reflexive thematic analysis focuses on identifying patterns across the dataset (Braun & Clarke, 2013). Due to the current study's research aims, it was deemed appropriate to prioritise the identification of patterns across the dataset, as opposed to contradictions within individual accounts. RTA is flexible in its theoretical framework and views researcher subjectivity as a resource during theme development (Braun & Clarke, 2021). This study took a mixed deductive-inductive approach with codes generated at both a semantic and latent level to allow for exploration of the meaning associated with individuals' experiences (Braun & Clarke, 2013). RTA is coherent with the researcher's epistemological position.



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

Purposive sampling is one of the most common recruitment strategies used in qualitative research that aims to explore experiences of a specific topic of interest (Emmel, 2014; Patton, 2002). In purposive sampling, participants are recruited based on their ability to provide rich data of the aforementioned area of interest (Patton, 2002). Individuals with a diagnosis of FND who had accessed psychological services were recruited via social media - this was to ensure a heterogeneous sample not limited to locality or service.

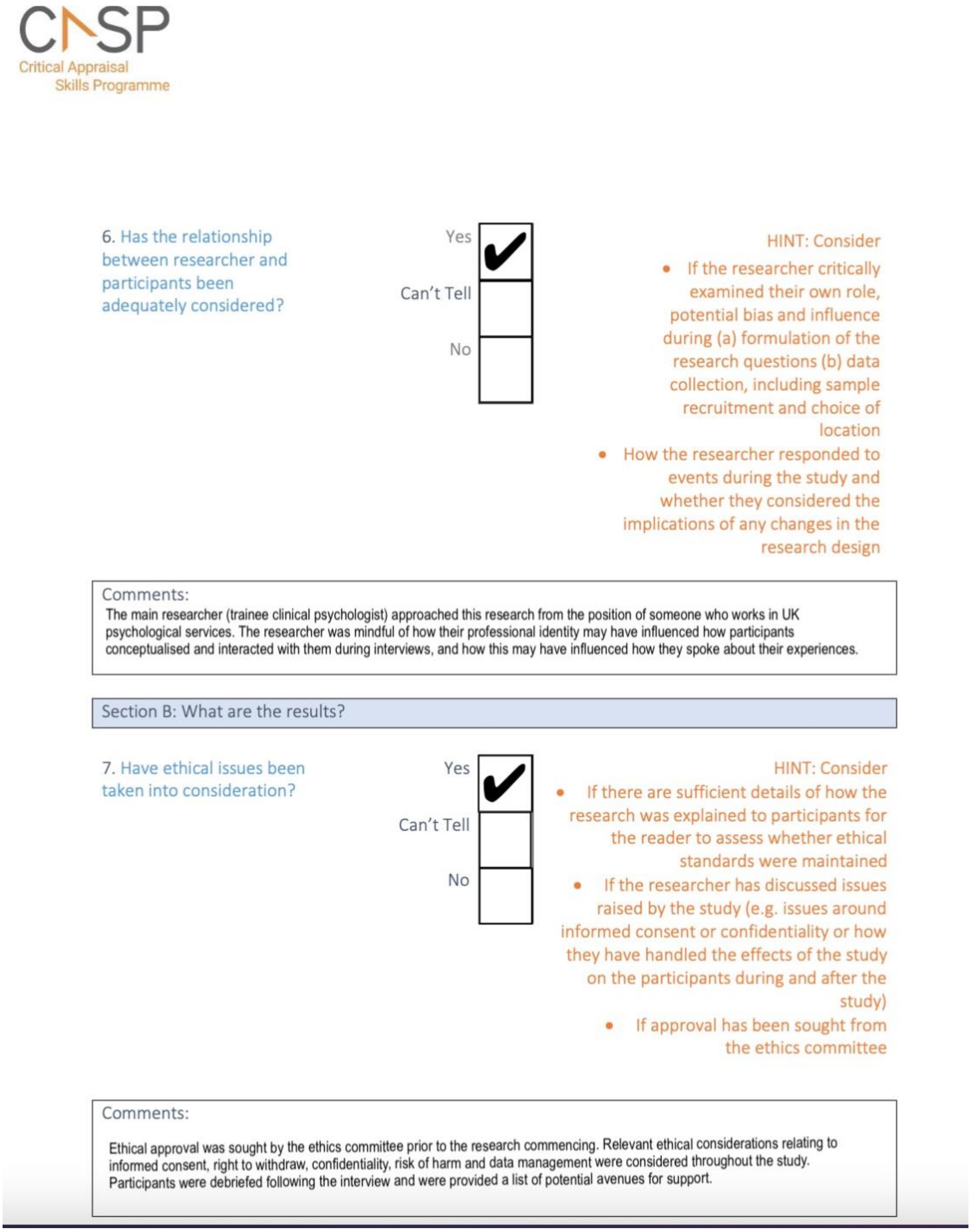
5. Was the data collected in a way that addressed the research issue?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

Semi structured interviews allow exploration into participant experiences. The interview schedule guided the discussion whilst ensuring flexibility to explore other aspects of experiences and perceptions to be captured. This also ensured that participants weren't led by questions, which would increase risk of bias. Audio recordings using an encrypted dictaphone were made before being transcribed using the University of Nottingham automated transcription service. 15 interviews were conducted - recruitment of participants did not conclude until the research team determined there was a richness and quality of data to meet the research aims.



CASP
Critical Appraisal
Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:
The main researcher (trainee clinical psychologist) approached this research from the position of someone who works in UK psychological services. The researcher was mindful of how their professional identity may have influenced how participants conceptualised and interacted with them during interviews, and how this may have influenced how they spoke about their experiences.

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:
Ethical approval was sought by the ethics committee prior to the research commencing. Relevant ethical considerations relating to informed consent, right to withdraw, confidentiality, risk of harm and data management were considered throughout the study. Participants were debriefed following the interview and were provided a list of potential avenues for support.

8. Was the data analysis sufficiently rigorous?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:
All criteria met.

9. Is there a clear statement of findings?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

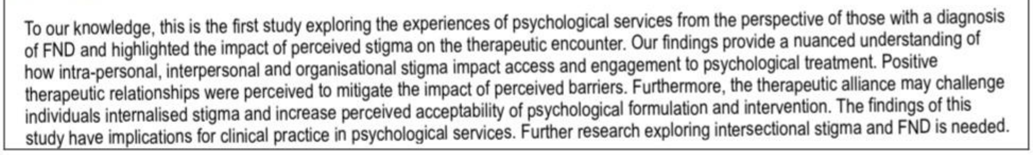
Comments:
All criteria met.

Section C: Will the results help locally?

10. How valuable is the research?

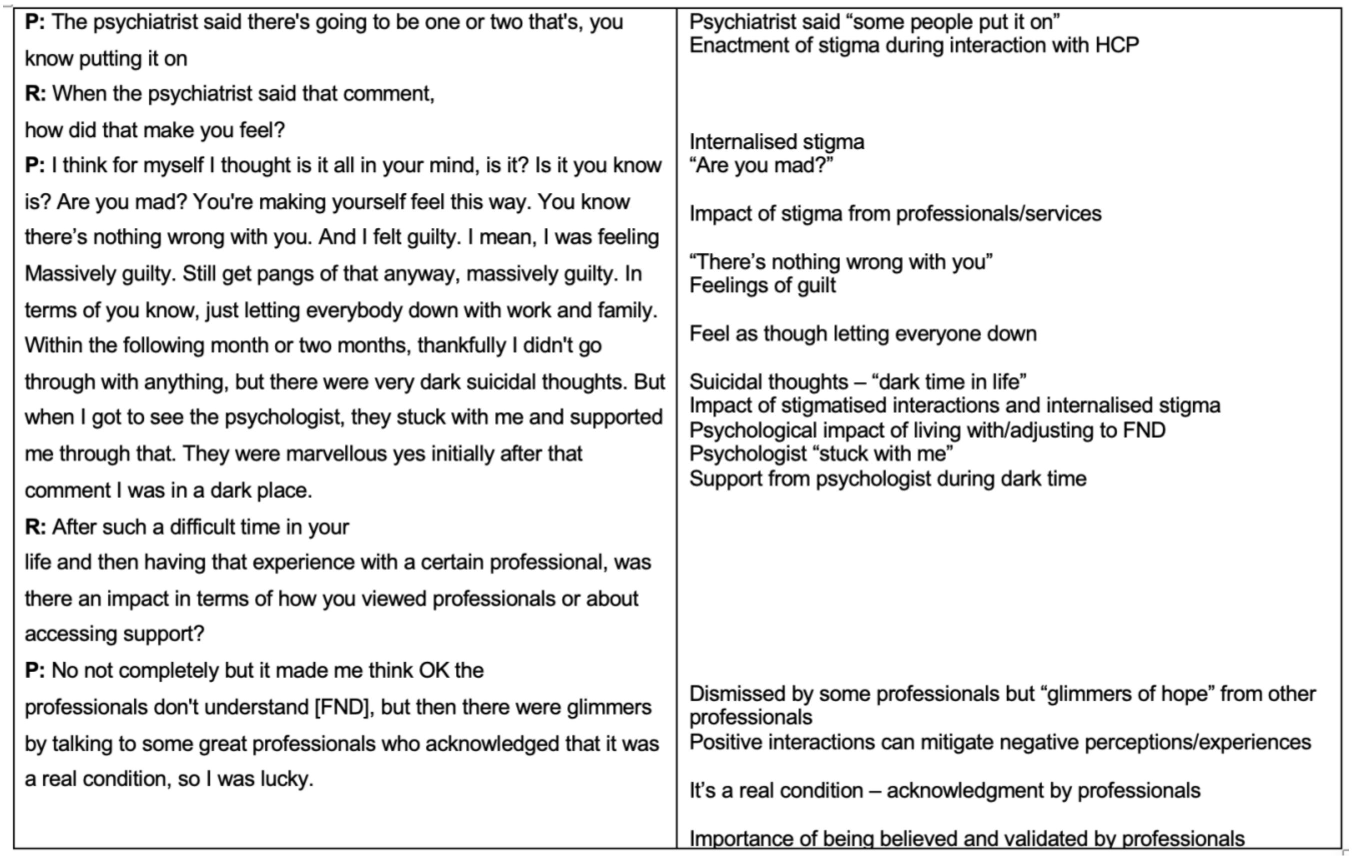
HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

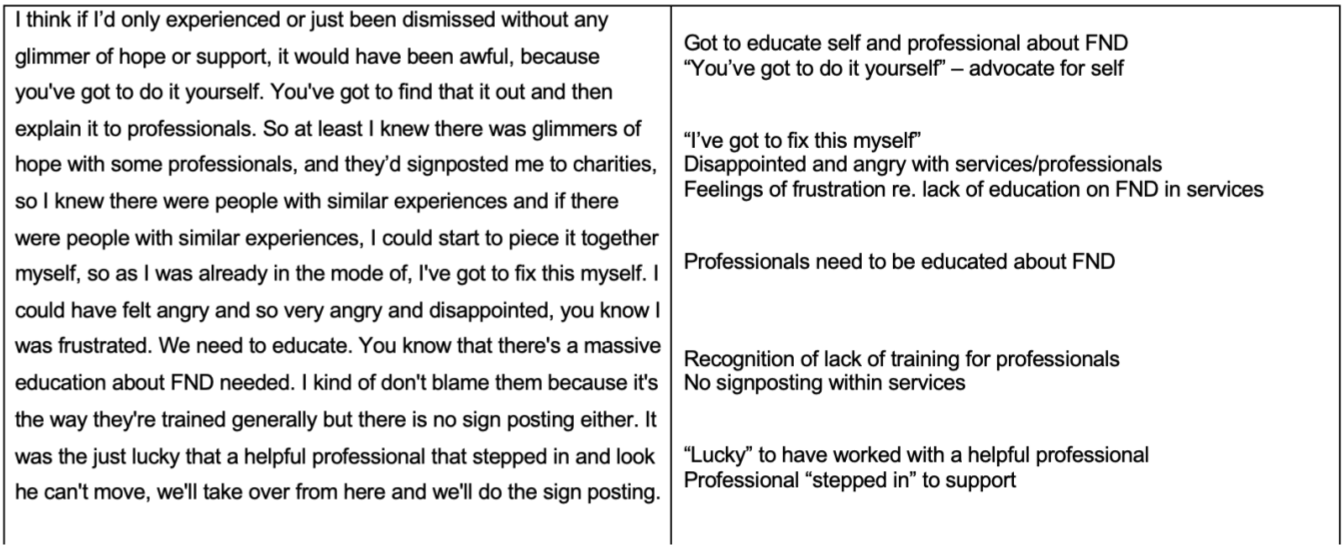


To our knowledge, this is the first study exploring the experiences of psychological services from the perspective of those with a diagnosis of FND and highlighted the impact of perceived stigma on the therapeutic encounter. Our findings provide a nuanced understanding of how intra-personal, interpersonal and organisational stigma impact access and engagement to psychological treatment. Positive therapeutic relationships were perceived to mitigate the impact of perceived barriers. Furthermore, the therapeutic alliance may challenge individuals internalised stigma and increase perceived acceptability of psychological formulation and intervention. The findings of this study have implications for clinical practice in psychological services. Further research exploring intersectional stigma and FND is needed.

Appendix J *Qualitative Interview Initial Coding Excerpt*



P: The psychiatrist said there's going to be one or two that's, you know putting it on **R:** When the psychiatrist said that comment, how did that make you feel? **P:** I think for myself I thought is it all in your mind, is it? Is it you know is? Are you mad? You're making yourself feel this way. You know there's nothing wrong with you. And I felt guilty. I mean, I was feeling Massively guilty. Still get pangs of that anyway, massively guilty. In terms of you know, just letting everybody down with work and family. Within the following month or two months, thankfully I didn't go through with anything, but there were very dark suicidal thoughts. But when I got to see the psychologist, they stuck with me and supported me through that. They were marvellous yes initially after that comment I was in a dark place. **R:** After such a difficult time in your life and then having that experience with a certain professional, was there an impact in terms of how you viewed professionals or about accessing support? **P:** No not completely but it made me think OK the professionals don't understand [FND], but then there were glimmers by talking to some great professionals who acknowledged that it was a real condition, so I was lucky.	Psychiatrist said "some people put it on" Enactment of stigma during interaction with HCP Internalised stigma "Are you mad?" Impact of stigma from professionals/services "There's nothing wrong with you" Feelings of guilt Feel as though letting everyone down Suicidal thoughts – "dark time in life" Impact of stigmatised interactions and internalised stigma Psychological impact of living with/adjusting to FND Psychologist "stuck with me" Support from psychologist during dark time Dismissed by some professionals but "glimmers of hope" from other professionals Positive interactions can mitigate negative perceptions/experiences It's a real condition – acknowledgment by professionals Importance of being believed and validated by professionals



I think if I'd only experienced or just been dismissed without any glimmer of hope or support, it would have been awful, because you've got to do it yourself. You've got to find that it out and then explain it to professionals. So at least I knew there was glimmers of hope with some professionals, and they'd signposted me to charities, so I knew there were people with similar experiences and if there were people with similar experiences, I could start to piece it together myself, so as I was already in the mode of, I've got to fix this myself. I could have felt angry and so very angry and disappointed, you know I was frustrated. We need to educate. You know that there's a massive education about FND needed. I kind of don't blame them because it's the way they're trained generally but there is no sign posting either. It was the just lucky that a helpful professional that stepped in and look he can't move, we'll take over from here and we'll do the sign posting.	Got to educate self and professional about FND "You've got to do it yourself" – advocate for self "I've got to fix this myself" Disappointed and angry with services/professionals Feelings of frustration re. lack of education on FND in services Professionals need to be educated about FND Recognition of lack of training for professionals No signposting within services "Lucky" to have worked with a helpful professional Professional "stepped in" to support

Appendix K *Qualitative Interview Deductive Coding Excerpts*

Relevant Transcript Excerpt	Initial Code	Deductive Code
It's like in your head and you kind of start doubting yourself. So a lot of the time you're like it's actually in my head. I'm thinking is it? You kind of start questioning yourself a lot. Am I actually? Is it my fault that I'm having these seizures?	All in my head Questioning and doubting self Is it my fault?	A
You know, I know I'm not faking my symptoms but there's always that little voice of doubt in my head that says what if you are? What if you are?	Not faking symptoms Voice of doubt in head	A
I feel like I was gonna be in that situation again where I couldn't really say what I wanted to because it's almost feeling like you might be judged in a certain way	Worries around judgement Perceptions based on previous experiences "in that situation again"	B
I've found there's less stigma in mental health services [compared to medical settings] and more absolute terror on the faces of people who didn't know what to do with me. In hindsight, I think some of it was just complete uncertainty about what to do with this [FND]. Just complete lack of awareness of the condition or what to do with someone with it	"Absolute terror" on professionals faces Perception that professionals are uncertain, lacking experience of FND Lack of awareness in services	B, C
	Feeling invalidated	B

You don't feel believed, you don't feel supported, you don't feel validated	Not believed by professionals Feel unsupported in services	
They’re uneducated, ignorant, dismissive. They just don't want to hear anything else, they're very closed minded and I think there's too much of a stigma attached to it as in its hysteria or it's all made-up. Even if you Google it, it still makes a reference to it being hysteria. That’s the main thing that give it a negative view. When people look at it, they'll go oh yeah, so really she hasn't got anything actually wrong with her and that can make yourself start thinking like that too	Professionals are close-minded Professionals perceived as uneducated, ignorant Feel dismissed by professionals Historical stigma associated with FND (e.g., hysteria) Internalised stigma from interactions with HCPs	A, B
The literature, particularly the old literature, is very stigmatising. It makes out that you are a scrounger, you want the easy way out, you're putting it on, you’re malingering. There is quite heavy bias towards that and that has a huge impact on how you see yourself	Stigmatising literature Historical stigma (e.g., malingering) Internalised stigma – stigma affects sense of identity	A, B
My experience isn't a great one, but there is way worse, but also because most people that get this like the ones I've talked to and what I've seen, people are really, really, ashamed. That doesn't matter if it's a	Feelings of shame Not acknowledged as a real condition	A, B

conclusion of how you got it, but because it's not really acknowledged even now as a real condition		
I think my experience of having FND as a whole has just been stigma and a disregard for the effect it has on your life, and a disregard to the scariness of it and being made to feel that you're just being stupid, which makes it very difficult to keep seeking help and to keep advocating for yourself	FND experiences impacted by stigma Lack of consideration of psychological impact Difficult to seek help Impact on ability to advocate for self	B

NB: This table contains excerpts from multiple participant transcripts and is for illustration purposes to demonstrate how the deductive coding framework was applied.

POSTER

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Functional Neurological Disorder: A Qualitative Study Exploring Individuals Experiences of Psychological Services

Amelia Staton, Dr David Dawson, Dr Hannah Merdian, Dr Anna Tickle, Dr Tammy Walker
Trent Doctorate in Clinical Psychology

UNIVERSITY OF LINCOLN

INTRODUCTION

Functional Neurological Disorder (FND) is classified as an “acute presentation of neurological dysfunction involving the motor and sensory nervous system”[1]

Individuals with FND report stigmatised interactions with medical professionals[2, 3]

Despite individuals with FND regularly accessing psychological services, there is no published research on individuals’ experiences in these settings[4]

The perspectives of those accessing services are essential in understanding and improving the quality of healthcare provision[5]

RESEARCH AIM

To explore experiences of accessing UK psychological services, from the perspective of those with a diagnosis of FND.

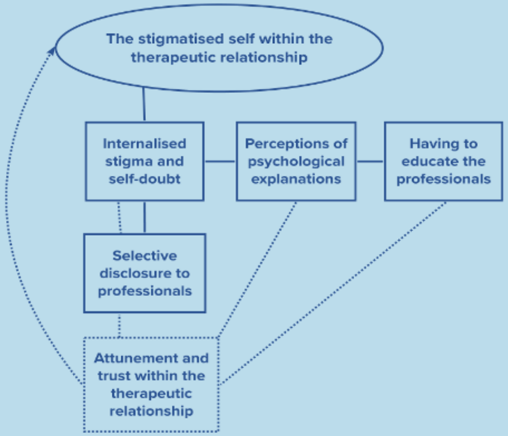
METHODS

Qualitative design

Participants
Purposive sampling. 15 participants who had a diagnosis of FND and had accessed psychological services were recruited.
Procedure
Participants were recruited via social media. Interviews were completed via telephone or videoconference.
Analysis
Audio recorded interview data was transcribed and analysed using inductive-deductive reflexive thematic analysis[6]

RESULTS

One superordinate theme and five interrelated main themes were identified:



- ‘What the client brings’ and the perception of how this was responded to by services and professionals was a central tenet throughout the related themes.

- These were considered in the context of reciprocal roles; the roles adopted by individuals in response to the perceived role that has been adopted by the professionals/services.

DISCUSSION

- Stigma functioned across three levels: intra-personally, interpersonally and structurally[7]

- The perceptions of participants were consistent with previous research that highlighted professionals lacked knowledge about FND and may avoid patients with FND due to feelings of anxiety[8, 9]

- Practitioners should explicitly address perceptions of blame and consider how experiences of stigma may influence perceptions of psychological models.

- This study does not consider how individuals experiences may compare to other stakeholder perspectives. Future research is needed to explore how psychological practitioners experience working with this client group.

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SMALL SCALE RESEARCH PROJECT

Specificity and Sensitivity of the SCQ Lifetime Screening Tool for Autism Spectrum Disorder in a UK CAMHS Service

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Abstract

Introduction: The Social Communication Questionnaire is used to identify children and young people (CYP) who may require formal ASD assessment. However, there is a paucity of research on its utility in Children and Adolescent Mental Health Services. This evaluation aimed to determine the sensitivity and specificity of the SCQ in a UK, Midlands CAMHS service.

Method: Forty young people (mean age 13.75 years) were screened using the caregiver reported SCQ before completing ‘gold standard’ assessment.

Results: The SCQ had a sensitivity of 80% and a specificity of 25.7%. ROC curve analysis indicated low diagnostic accuracy. Differences in predictive accuracy of SCQ and diagnostic standard were statistically significant (p<0.0001).

Conclusion: This evaluation builds on previous research suggesting that the SCQ may not be an efficient screening tool in CAMHS settings.

Keywords: Autism, Social Communication Questionnaire, Screening, CAMHS

Introduction

Whilst an estimated 1.76% of school age children in the UK meet the diagnostic threshold for ASD (Roman-Urrestarazu et al., 2021), autism presentations appear to be significantly higher in looked after children and children who have experienced attachment trauma (Rutter et al., 1999). These findings are consistently replicated in several cross-cultural studies (Green et al., 2016; Hoksbergen et al., 2005; Meltzer et al., 2003; Sadiq et al., 2012), providing support within the wider literature around overlapping autism and attachment symptomologies (McKenzie & Dallos, 2017; Minis et al., 2020). Clinical observation has highlighted several similarities in these presentations such as inflexibility, atypical play, emotional dysregulation, sensory needs and communication difficulties (Moran, 2010). In addition to overlapping symptom profiles, the literature suggests that autistic children may be more likely to develop insecure attachments (Rutgers et al., 2004; Naber et al., 2007). This may be exacerbated by systemic factors such as parental mental health (Berry & Drake,

2010) and parent's own attachment experiences (McKenzie & Dallos, 2017). This is likely to impact on psychological well-being, with recent meta-analysis indicating that mental health difficulties are significantly higher in autism populations (Lai et al., 2019), and thus may be overrepresented in mental health settings.

Whilst there appears to be a complex relationship between these presentations, their differentiation is crucial in minimising the risk of misdiagnosis. Screening tools are used to identify children and young people (CYP) who may require further investigation for a possible diagnosis of ASD. The Social Communication Questionnaire (SCQ; Rutter, Bailey & Lord, 2003) is one such tool commonly used in clinical practice for children aged 4 years and older. Developed from the Autism Diagnostic Interview – Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003; Lord, Rutter, & Le Couteur, 1994), the SCQ is a 40-item caregiver-reported questionnaire that explores language development and social communication throughout the child's developmental history (SCQ Lifetime) and behaviours observed in the past 3 months (SCQ Current). When evaluating the accuracy of screening tools and diagnostic tests, it is essential to consider whether the test can correctly identify individuals with a condition (sensitivity) and correctly classify those who do not (specificity). This is of particular importance in clinical settings where standardised screening and assessment tools are used to provide diagnoses and determine appropriate intervention. When assessing the diagnostic validity in clinical samples, the SCQ was found to have a sensitivity (*Se*) of 0.96, specificity (*Sp*) of 0.80 and an area under the curve (AUC) of 0.95 indicating high diagnostic accuracy (Berument et al., 1999). Recent meta-analysis examining the utility of the SCQ found the tool had moderate diagnostic accuracy (pooled AUC of 0.82) and thus could be considered an acceptable screening measure (Chesnut et al., 2017). Though, these findings have not been consistently replicated with several studies highlighting lower diagnostic accuracy when used with younger children (Allen, 2007; Eaves et al., 2006, 2007; Marvin et al., 2017; Norris & Lecavalier, 2010) and children with developmental and intellectual disabilities (Allen, 2007; Corsella, 2007; Snow & Lacavalier, 2008). Divergence in findings between studies is hypothesised to be a result of using different forms of the SCQ (Chesnut et al., 2017; Wei et al., 2015), the age of sample (Barnard-Brak et al., 2015), and varying sample populations (Chesnut et al., 2017). Furthermore, only one SCQ validation study included individuals with co-existing anxiety/mood disorders within the larger sample (Corsella et al., 2007), and two referenced inclusions of CYP with ‘behavioural disorders’ (Allen et al., 2007; Norris & Lecavalier, 2010). Whilst the interrelation between autism, attachment and mental health difficulties have been highlighted in the literature, this appears to be rarely considered when developing and validating screening tools.

The overlap between autism, attachment and co-occurring mental health presentations has considerable implications on assessment and diagnosis. Screening tools that are not effective in distinguishing autism from other presenting difficulties may lead to inappropriate clinical and educational intervention. In addition, tools with poor diagnostic accuracy increase the likelihood of unnecessary assessments and burden on CYP and their families. During a time of increasing demand and rising pressure within specialist CAMH services (Ludlow, Hurn & Lansdell, 2020), efficient assessment pathways and effective use of service resources are essential. Hollocks and colleagues (2019) evaluated the utility of both the SCQ Lifetime and Current forms in this setting. The results suggested low diagnostic accuracy in young people with co-existing mental health needs; SCQ Lifetime (*Se* 0.87, *Sp* 0.12, AUC 0.52), SCQ Current (*Se* 0.72, *Sp* 0.35, AUC 0.56). However, the evaluation compared the SCQ using only the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Hus & Lord, 2014) as the diagnostic standard. Current ‘gold standard’ assessment includes use of both the ADOS-2 and the Autism Diagnostic Interview – Revised (Lord, Rutter, & Le Couteur, 1994) as this has been found to have the most reliable results (Risi et al., 2006).

Therefore, this study aimed to partially replicate Hollocks and colleagues’ (2019) evaluation of the utility of the SCQ in a CAMHS service, using the ‘gold standard’ assessment (ADOS-2 and ADI-R) as the diagnostic standard.

Service context

This evaluation was conducted in a UK Midlands, CAMH service. The service provides assessment and diagnosis of autism for young people (<18yrs) currently receiving input from Community CAMHS provision. The ASD assessment clinic was established in 2009 due to increased wait-list times in ASD specialist services. The clinic is comprised of 3 x Clinical Psychologists (0.6 wte), 1 x

Specialist Practitioner (0.2 wte) and 1 x Independent Non-Medical Prescriber (0.2 wte). The team meet fortnightly and all meetings are multi-disciplinary, involving members from at least two professional backgrounds.

Aims

1) To evaluate the sensitivity and specificity of the SCQ screening tool in this CAMH service.

Method

All referred young people between June 2017 and January 2022 were included if they had a complete assessment at the time of data collection. No other exclusion criteria were applied. Once referred to the ASD assessment clinic, the caregiver completed SCQ and referral information were reviewed by the MDT and a decision was made on whether there was a rationale for further assessment. The assessment process involved the Autism Diagnostic Observation Schedule (ADOS; Hus & Lord, 2014) and the Autism Diagnostic Interview – Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003).

This service evaluation was registered with the Trust Research and Evidence department in line with the Health Research Authority (HRA) guidelines. The data was routinely collected by the service and was anonymised prior to analysis.

Measures

SCQ – Lifetime

The SCQ Lifetime (Rutter, Bailey & Lord, 2003) is a parent/caregiver completed ASD screening tool developed for individuals over the age of four. It includes 40-items exploring language development and social communication. The SCQ Lifetime form asks respondents questions that span the child's developmental history (i.e., *"can you have a to and fro conversation with her/him that involves taking turns or building on what you have said?"*) and a specific period of time (i.e., *“when she/he was aged 4 to 5, did she/he show a normal range of facial expressions?”*). Scores can range from 0-40 with a suggested clinical cut-off of 15 and above indicating the need for ASD assessment.

ADOS-2

The Autism Diagnostic Observation Schedule (ADOS) is a standardised assessment that covers several domains: communication, social interaction, and play (Hus & Lord, 2014). It is designed to be used by clinicians to assess current behaviour and can be used with children of varying ages and developmental stages. In line with best practice, this assessment is recorded and reviewed in a multi-disciplinary context. Recent meta-analysis found sensitivity ranged between 0.89-0.92 and specificity between 0.81-0.85 indicating high diagnostic accuracy (Lebersfeld et al., 2021).

ADI-R

The Autism Diagnostic Interview – Revised (Le Couteur, Lord, & Rutter, 2003) is a structured interview completed with the young person’s parent/caregiver that covers “reciprocal social interaction, communication and language, interests and behaviours”. It is designed to be used in conjunction with the ADOS-2. Findings from meta-analysis have found a pooled sensitivity of 0.75 and specificity of 0.82 indicating high diagnostic accuracy (Lebersfeld et al., 2021).

Statistical Analyses

To assess the predictive accuracy of the SCQ, we planned to use McNemar’s analysis (McNemar, 1947). Given that we included all service referrals with complete assessment data, a post-hoc power analysis was completed. Power calculations were completed using G*Power version 3.1 (Faul et al., 2009). Statistical analysis was performed using SPSS version 27. The sensitivity and specificity were calculated for the SCQ, with the ADOS and ADI-R as the diagnostic standard. McNemar’s test was used to compare the binary response for these matched pairs data, represented as a 2x2 contingency table. This table showed the number of observed outcomes in each category (McNemar, 1947). Positive predictive value (the likelihood that if you score above the SCQ clinical cut-off that you will receive a diagnosis of ASD) and negative predictive value (likelihood that if you score below the SCQ clinical cut-off that you will not receive an ASD diagnosis) were calculated using suggested formulas (Molinaro, 2015). A Receiver Operating Characteristic (ROC) curve analysis was completed to determine the area under the curve (AUC) and to identify optimal cut off for diagnostic performance. We used widely agreed criteria to interpret the area under the curve (AUC); low (<0.7), moderate (0.7-0.9) or high accuracy (>0.9) (Hanley & McNeil, 1982; Swets, 1988). Youden's index was calculated (sensitivity + specificity) – 1) to evaluate discriminative power of the SCQ (Youden, 1950). A Youden's index of 0.6 or above is considered 'acceptable' for diagnostic tests (Chen et al., 2015).

Results

Between June 2017 and January 2022, 121 referrals were screened using the SCQ with 60 (49.5%) of these accepted for assessment. 20 cases were excluded from analysis due to incomplete assessment: did not opt in for assessment (*n* = 1); declined assessment (*n* = 1); assessment postponed on family's request (*n* = 2); ongoing assessment (*n* = 7); discharged due to change in presentation (*n* = 1); aged out of service whilst on waiting list (*n* = 2), and missing data (*n* = 6). 10 cases scored below the SCQ suggested clinical cut off but were recommended for assessment following a multi-disciplinary discussion.

The final sample consisted of 40 young people (62.5% female, 37.5% male), mean age of 13.75 (range = 9-17 years; SD = 2.15; SE = .341). A post hoc analysis was performed to calculate power using obtained sample size, odds ratio and α level (α = .05). Results indicated an achieved power of 98% with a significance criterion of (α = .019).

5 of the 40 cases (12.5%) were assessed (using the ADOS and ADI-R) as meeting diagnostic criteria for ASD. The remaining 35 young people (87.5%) were deemed to have "significant emotional/psychological difficulties" (e.g., anxiety, low mood, developmental trauma, and attachment difficulties) that required further assessment and intervention with their usual care team. Of the 5 who met criteria for diagnosis of ASD, 3 identified as female and 2 identified as male. Due to the

nature of the service and referral pathway, all young people were referred by a CAMHS professional currently involved in their care.

Social Communication Questionnaire (SCQ)

The overall sample had a mean score of 20.38 (range 1-35; *SD* = 7.72). 75% of the sample met the SCQ clinical cut-off (≥15) with a mean score of 23.20 (range 15-35; *SD* = 5.83). 15.3% of those that met the suggested clinical cut-off received a diagnosis of ASD. 25% of the sample scored below the clinical cut-off (<15) with a mean score of 10.22 (range 1-14; *SD* = 3.96). One (11.1%) of the cases scoring below the SCQ cut off met diagnostic criteria for ASD following assessment.

Table 4. SCQ Cut-Off and Diagnostic Outcome

	ASD	No Diagnosis of ASD
SCQ ≥15	4	26
SCQ < 15	1	9

Sensitivity and Specificity of the SCQ in CAMHS population

Using the tools recommended clinical cut-off (≥15), the SCQ had a sensitivity of 80% and a specificity of 25.7%. The negative predictive value was 90% and the positive predictive value was 13.3%. McNemar within-subjects chi-squared χ^2 test (McNemar, 1947) was used to assess whether differences in the predictive accuracy of the SCQ tool and diagnostic standard (ADOS and ADI-R) were statistically significant. The chi-square statistic and odds ratio ($\chi^2 = 21.3$) indicated that the odds of positive classification by the SCQ were 21.3 times greater than the odds of positive classification by the diagnostic standard (ADOS and ADI-R) ($p<0.0001$).

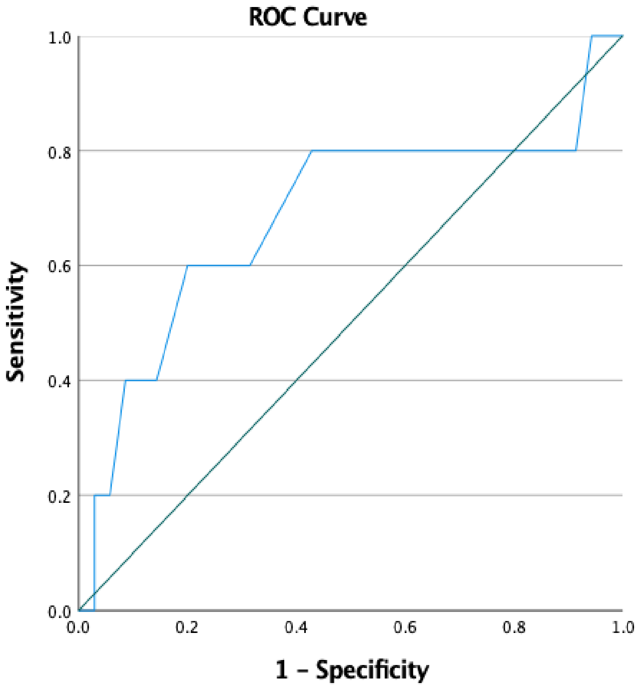
Table 5. Sensitivity and Specificity of SCQ Screening Tool

	n	Sensitivity	Specificity	PPV[1]	NPV[2]	McNemar's test	Odds ratio χ^2	Youden's J
SCQ ≥15	40	80%	25.7%	13.3%	90%	$p<0.0001$	21.3	0.06

[1] *Positive Predictive Value;* [2] *Negative Predictive Value*

For the total SCQ score, the AUC was 0.68 (95% CI 0.38-0.98) with a Youden's index of 0.06 indicating low diagnostic accuracy. The findings suggest that 74.3% of those that score above the SCQ cut-off will be assessed to not meet the diagnostic threshold. In addition, at least 1 in 5 young people with ASD will score below the SCQ cut off. ROC curve and Youden index analysis indicated that the optimal cut off for diagnostic performance in this setting would be ≥ 21, maximising Youden's J at 0.37, retaining sensitivity at 80% and increasing specificity to 57%.

Fig 3. ROC Curve Analysis



Diagonal segments are produced by ties.

Discussion

The aim of this evaluation was to evaluate the sensitivity and specificity of the SCQ screening tool in this setting. This evaluation arose as a result of the growing literature around overlapping attachment and autism symptomologies and the implications of this on screening and assessment, particularly in CAMH services. Consistent with previous evaluation of another service (Hollocks et al., 2019), our findings suggest that the Social Communication Questionnaire (SCQ) may not be an efficient screening tool in this clinical context.

With a low diagnostic accuracy and an estimated sensitivity of 80%, at least 1 in 5 young people who meet the diagnostic criteria for ASD will be screened out prior to assessment. In addition, almost three quarters of those scoring above clinical cut off do not receive a diagnosis of ASD when formally assessed. The differences in the predictive accuracy of the SCQ tool and diagnostic standard (ADOS and ADI-R) were statistically significant. In comparison to other studies (Berument et al., 1999; Chesnut et al., 2017), the sensitivity, specificity, and diagnostic accuracy of the SCQ in this service is considerably lower than expected. The differences in study samples may explain the divergence in findings between this evaluation and previous research. The findings of our evaluation appear consistent with previous evaluation of the SCQ Lifetime form in an East England CAMHS service which found the SCQ to have low diagnostic accuracy and poor specificity (Hollocks et al., 2019). These findings have considerable implications on clinical practice with young people likely to be excluded from appropriate clinical and educational intervention due to inaccurate diagnosis. The low specificity of this tool increases the risk of unnecessary and burdensome assessments on young people and their families. In addition, screening tools with a likelihood of high false positives increase clinician workload and clinic waiting times. At a time of unprecedented waiting times and staff shortages within specialist CAMHS, it is essential that limited resources are used efficiently (Ludlow, Hurn & Lansdell, 2020).

The SCQs limited ability to accurately screen out those that are unlikely to require further ASD assessment may be due to the complexity of cases in CAMHS. Although research on the incidence of attachment presentations in

CAMH services is limited, insecure attachment styles are often correlated with mental health difficulties (Goodwin, 2003) and thus may be overrepresented in these settings. Furthermore, attachment difficulties are correlated with emotional dysregulation, heightened threat response and issues around interpersonal functioning (Mikulincer & Shaver, 2012); characteristics which arguably underpin an array of mental health presentations referred into CAMHS. When considering the utility of ASD screening tools in mental health settings, it could it postulated that the SCQ is inadequate in differentiating between attachment difficulties, autism and co-occurring mental health difficulties. For example, items on the SCQ Lifetime form such as *“does her/his facial expressions seem appropriate to the particular situation, as far as you can tell?”,* could be answered *“no”* for children with autism or attachment difficulties. Research evaluating differences in facial expression have found that individuals with autism (Trevisan, Hoskyn & Birmingham, 2018) and insecure attachment (Altmann et al., 2021) have atypical facial expressions compared to their counterparts. Similarly, other questions on the SCQ such as items pertaining to communication of empathy (e.g., *“when she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt?”*) may also lack differentiation as difficulty communicating empathy may be observed in both autism and attachment presentations (Davidson et al., 2015). Despite this overlay in symptomologies (Lai et al., 2019; McKenzie & Dallos, 2017; Minis et al., 2020), attachment and mental health presentations appear to be rarely considered when developing ASD screening tools.

As the SCQ is not designed to provide formal diagnosis, prioritising sensitivity over specificity in this context is sensible. However, the SCQs extremely limited ability to screen out young people in which autism is not present, indicates that it is not an appropriate screening tool in this service. ROC analysis and Youden’s index suggests an optimal cut-off of ≥ 21 for diagnostic performance in this setting, which would reduce the number of false positive cases and therefore reduce the number of unnecessary assessments. However, this clinical threshold would not increase sensitivity and therefore would not decrease the number of false negative cases. As discussed in Hollocks et al. (2019) evaluation, there are alternative age-appropriate ASD screening tools. For example, the Social and Communication Disorders Checklist (SCDC; Scuse, Mandy & Scourfield, 2005), the Social Responsiveness Scale (SRS; Constantino et al., 2003), and the

Children’s Communication Checklist (CCC; Bishop, 1998). Though, the SCQ has been found to out-perform these screening tools (Charman et al., 2007) and therefore using an alternative tool is unlikely to address concerns regarding screening accuracy in this clinical context. In addition, systematic review of ASD screening tools highlighted that only the SCQ and SRS had been examined in more than two studies (Hirota et al., 2018). Thus, the wider literature does not appear to lend support for an alternative ASD screening tool in this clinical context. The development and validation of a novel measure designed to distinguish between overlapping autism, attachment, and mental health symptom profiles is urgently required.

Recommendations for Clinical Practice

To address these issues, it may be appropriate to include additional screening tools alongside the SCQ to support clinical judgement and decision making. Mental health screening measures such as the Revised Children’s Anxiety and Depression Scale (RCADS; Chorpita, Moffitt & Gray, 2005) and the Strength and Difficulties Questionnaire (SDQ; Muris, Meesters & van den Berg, 2003) are already routinely collected in CAMHS and provide a broader understanding of the child’s presentation. However, it may be useful to consider the results of these measures during ASD clinic MDT discussions to aid formulation of the young person’s presenting difficulties. Collecting information from multiple sources (i.e., teachers, GPs) is also recommended during the screening and assessment process (National Institute for Health and Care Excellence [NICE], 2017).

Unlike broader psychological measures, the evidence base for attachment screening tools and assessments is limited. Whilst there are interviews and measures such as the Child Attachment Interview (CAI; Target, Fonagy, & Shmueli-Goetz, 2003) and the Inventory of Parent and Peer Attachment (IPPA; Gullone & Robinson, 2005), a systematic review concluded that these should be used with caution in clinical practice due to low inter-rater reliability (Jewell et al., 2019). In addition, these tools are unlikely to support differentiation between autism and attachment presentations. The Coventry Grid (Moran, 2010) was developed as a result of clinical observations that identified similarities in autism and attachment symptom profiles. Although the tool aimed to support clinicians to recognise the differences in presentations, it has faced criticism for conflating different attachment styles (McKenzie & Dallos, 2017). However, used judiciously, the Coventry Grid may support clinicians in the ASD assessment clinic during the screening and assessment process.

Limitations

The results of this evaluation must be considered in the context of the methodological limitations. Due to the nature of this service specific evaluation, only a small sample of young people were included. Although the sample was representative of the types of cases seen in this service, the conclusions drawn from this study may not be generalisable. However, given the consistency of our findings with Hollocks and colleagues' study (2019), it could be argued that the limitations of the SCQ may extend to other CAMH services. Whilst the use of post hoc analysis to calculate power indicated an achieved power of 98% with a significance criterion of ($\alpha = .019$), research using Monte Carlo simulation suggests that this type of power analysis may be inaccurate (Zhang et al., 2019). However, due to the nature of this evaluation a priori power analysis to calculate the required sample size was not possible.

The sensitivity of the SCQ in this service has been estimated based on the available data. However, this data is likely to be incomplete as only cases with full assessments were included in analysis. Whilst some cases scoring below the clinical threshold went on to be assessed due to clinical judgement, other cases scoring below this threshold were screened out prior to assessment. It is unclear whether there were false negatives among these screened out on the basis of SCQ scores and thus sensitivity and negative predictive value could indeed be lower. Additional research is needed determine true sensitivity of the SCQ in this setting. To calculate the true negative predictive value, a random sample of referrals would need to be formally assessed irrespective of the SCQ screening score. However, it is acknowledged that NHS CAMH services are overstretched and under resourced which poses significant challenges to completing research in these settings.

Conclusions

This evaluation builds on the findings and subsequent recommendations from Hollocks and colleagues' (2019) study suggesting that the SCQ may not be an efficient screening tool in CAMHS settings. Further research is needed to develop a novel ASD screening measure for use in CAMHS settings, with a particular focus on distinguishing between autism, attachment, and co-occurring mental health presentations. For current clinical practice, it is recommended that screening processes consider multiple sources of information and include judicious use of available measures and tools to support clinical judgement.

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