



**An Exploration of Self-as-Context and Group Interventions for Individuals with  
a Diagnosis of Functional Neurological Disorder**

being a thesis submitted in partial fulfilment of the  
requirements for the degree of  
Doctor of Clinical Psychology  
in the University of Hull

by

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May 2024

## Acknowledgements

Firstly, to my participants, thank you for taking part. I feel truly honoured and grateful that you have shared your experiences of Functional Neurological Disorder with me.

Dr Pete Fleming and Dr Richard Coates, thank you for your support, guidance and encouragement throughout the research. Thank you, Dr Jo Beckett for joining the project as it was in full swing and for your guidance during the analysis, writing, and editing process. Thank you, Dr Beate Riedel for the support, encouragement, and hope you gave me along my journey.

To my fellow trainees Alyx, Lucy, Philly. We did it. Thank you for your kindness through this wild journey. I'm so excited to see what the future holds for all of us. Emma, thank you for your words of encouragement over the years and our sushi trips to provide a well needed rest from the thesis. I am fortunate to have a friends like you.

A massive thank you must go to Tia. Who would have thought our undergraduate dissertation would have led to the journey we have been on? I could not have asked for a better housemate. Your kindness, patience and strength has been inspiring. I shall always cherish the joy and laughter we shared.

Finally, to my family, thank you for being my anchor in the many stormy seas throughout my journey. Truly, I could not have done this without you. Thank you. Mum and Dad, thank you for your words of encouragement. Jonathan, thank you for providing me with a sense of normalcy in such a long journey. To my wider family, thank you. You have all shaped who I am, and I am eternally grateful for the support and love you all have given me over the years.

## **Overview**

This thesis portfolio is comprised of three parts: a systematic literature review, an empirical paper, and appendices.

### **Part One: Systematic Literature Review**

The systematic literature review explored group psychological interventions for individuals with a diagnosis of Functional Neurological Disorder (FND). A narrative synthesis approach was used to review the 17 studies that were identified as meeting the inclusion criteria following a systematic search of the literature. The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of the included studies. The findings suggest that group psychological therapy can be beneficial in improving: FND symptoms, the understanding of FND, mental and physical health, and quality of life. Participants also described personal benefits of attending the group. The clinical implications and recommendations for future research are discussed.

### **Part Two: Empirical Paper**

The empirical paper explored experiences of Functional Neurological Disorder (FND) through the lens of ‘self-as-context’ from Acceptance and Commitment Therapy (ACT). A qualitative Interpretative Phenomenological Analysis (IPA) methodology was used. From the ten participants that completed a semi-structured interview, three themes emerged. These were: the loss of self in FND, acceptance of FND, and the positioning of self in the FND journey. The findings suggested that individuals with FND may struggle with an incongruence between their self-identity and ability to engage in activities. Self-as-context may play an important role in managing the incongruence. The clinical implications and recommendations for future research are discussed.

### **Part Three comprises the Appendices**

The appendices contained additional information to support the systematic literature review and empirical paper. The appendices included the epistemological position of the researcher and the reflective statement.

Total word count (excluding appendices): 21,615



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## **Part One**

### **Group Interventions for Functional Neurological Disorders: A Systematic Review**

This paper is written in the format ready for submission to the Journal Psychology and  
Psychotherapy: Theory, Research and Practice.

Please see Appendix A for the Guideline for Authors.

Word Count (excluding abstract, tables, figures and references): 5,999/6,000

## **Abstract**

### *Purpose*

Individuals with Functional Neurological Disorder (FND) experience the physical symptoms associated with neurological conditions in the absence of an observable or measurable neurological basis characterising a given condition. Diagnoses of FND have been increasing in recent years. This poses clinical and financial implications for how best to support individuals with FND. One such possibility is group psychological intervention. Therefore, the review explored the outcomes for individuals with FND following group psychological intervention and identified commonalities between the group interventions to help shape clinical practice to help shape clinical practice.

### *Methods*

The following databases were searched: Academic Search Ultimate, APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE. The Mixed Methods Appraisal Tool was used to assess the methodological quality of the 17 quantitative and mixed methods papers that met the inclusion criteria for the review. A narrative synthesis was undertaken to explore the outcomes of the interventions.

### *Results*

Improvements in FND symptoms and the understanding of FND, alongside statistically significant improvements in mental health, physical health and quality of life were identified. Participants reported positive experiences of attending therapeutic groups for FND. The majority

of the participants experienced functional seizures, with other FND subtypes under-researched. The methodological approaches and overall quality differed across the studies.

### *Conclusions*

There is emerging evidence that group psychological therapy can be beneficial for individuals with FND. However, there is a clear need for better quality research before firm conclusions can be drawn regarding the outcomes of group therapy within this population.

### **Keywords**

Functional Neurological Disorder, group therapy, systematic review, narrative synthesis.

### **Practitioner Points**

1. There is emerging evidence to suggest that group therapy for Functional Neurological Disorder (FND) may be beneficial in reducing symptoms of FND and improving mental health.
2. Providing psychoeducation on FND and a space for participants to share experiences of FND with other members of the group is beneficial.

## **Introduction**

Functional Neurological Disorder (FND) is a broad term for neurological symptoms in the absence of observable or measurable neurological basis for a given condition (Espay et al., 2018). Individuals suspected of having a FND are advised to seek a neurological assessment (National Institute of Health and Clinical Excellence [NICE], 2021). FND is the most prevalent diagnosis in outpatient neurology (Herbert et al., 2021), however, once diagnosed in neurology, symptom management care should take place within non-neurology services (NICE, 2021). Therefore, knowing what support is effective is essential for service commissioners when considering how best to support individuals with FND. This is particularly important within the constraints of commissioners' budgets, as many trusts within the National Health Service (NHS) do not have FND-specific services (O'Keeffe et al., 2021).

Approximately 8,000 individuals in the UK are diagnosed with FND annually, with community cases between 50,000 and 100,000 (Bennett et al., 2021). There is emerging evidence to suggest that cases of FND are increasing with contextual stressors (such as the Covid-19 pandemic) influencing the trend (Hull et al., 2021). Additional physical and mental health challenges are common with FND such as anxiety, depression, pain, and fatigue (Ducroizet et al., 2023; Butler et al., 2021). Individuals with FND often experience challenges in accessing support and stigma in health services (O'Keeffe et al., 2021; Foley et al., 2023; Staton et al., 2023).

Complete symptom remission in FND is low, with many individuals developing additional symptoms overtime (Velazquez-Rodriquez & Fehily, 2023). A hospital in the UK



estimated that the average cost of healthcare for an individual with FND was £3327.82 ( $\pm 5445.25$ ) with employment and informal care costs estimated as £6594.40 ( $\pm 8503.74$ ) and £9255.29 ( $\pm 10242.27$ ) respectively (Nelson-Sice et al., 2019). Globally direct and indirect costs of FND annually per person ranged from \$4,964 to \$86,722 in US dollars (O'Mahony et al., 2023). Considering the additional symptoms (Foley et al., 2023), and the associated costs in people with FND, and the fact that those with health problems when given the right support can learn to adjust and live well with their conditions (Helgeson & Zajdel, 2017), it is essential to better understand what works best for those with a FND diagnosis.

A review by Gutkin et al. (2021) suggested that individual psychotherapy is beneficial for individuals with FND in improving their mental and physical health, wellbeing and functioning. FND interventions are estimated to cost thousands of pounds per person annually (Goldstein et al., 2021; Nielsen et al., 2017; Reuber et al., 2007), it is important that cost-effective and psychologically effective therapies are identified. Group therapy is a possible alternative to individual sessions; however, no review of group interventions has taken place with Gutkin and colleagues actively excluding group interventions. Additionally, group interventions have the benefit of reducing stigma for clients (Tong et al., 2020). Group interventions for other health conditions such as chronic pain and diabetes are beneficial for individuals struggling with their mental health (Ryan et al., 2020; Ma et al., 2023).

The review therefore sought to answer: what were the outcomes for individuals with FND following group psychological intervention? It aimed to identify what outcomes

researchers are exploring for the interventions and to identify any common group psychological interventions being used for individuals with FND.

## Method

The Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines were followed (Page et al., 2021). The review was pre-registered on PROSPERO (registration number: CRD42024509833).

### Search Strategy and Terms

The literature search took place in February 2024 across five databases: Academic Search Ultimate, APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE. To limit location bias, multiple databases were searched within discipline specific and multidisciplinary databases, ensuring a wide search of literature. References of included studies were also screened to locate papers not originally captured.

Initial search terms were identified using the PICO framework (Eriksen & Frandsen, 2018) and developed through an iterative scoping process. The search terms relating to interventions were limited to title due to the volume of irrelevant papers being returned. The remaining search terms were applied to the whole document. Limiters were applied to those written in English and studies from 2000 onwards (see Table 1 for rationale). The search terms were as follows:

((functional) N3 (disorder\* or seizure\* or attack\* or symptom\* or weakness\* or dizziness or dystonia or limb\* or sensory\* or movement\* or cognitive\* or speech\* or swallowing\* or drop\* or fac\* or tic\*)) or "FND" or "NEAD" or "PNES" or "conversion disorder\*" or "non-epilep\* attack\*" or "non-epilep\* seizure\*" or "non epilep\* seizure\*" or "non epilep\* attack\*" or

"pseudo\* seizure\*" or "pseudo\* attack\*" or psychogenic or conversion disorder or dissociative neurolog\*

AND Group\*

AND Therap\* OR psychotherap\* OR intervention\*

### Selection Criteria

The selection criteria is located within Table 1.

### **Table 1**

#### *Inclusion and Exclusion Criteria and Rationale*

<b>Criteria</b>	<b>Rationale</b>
<u>Inclusion</u>	
Group psychological intervention (defined as an intervention aiming to produce a change in an individual to better help them in a given situation which has two or more members and run by a clinician; Ricou et al., 2019; Horvath et al., 2011; Ezhumalai et al., 2018)	The research explored the outcomes following group psychological intervention for FND. A range of group sizes and intervention lengths could be included to better reflected current practice within the constraints of some services.

Participants experiencing FND, symptoms of, or diagnosed with FND. The review sought to explore FND; therefore, conditions that did not fall under the FND category were not included.

Individuals who are 18 years old or older. There are differences between young people and adults with FND in prognosis (Perjoc et al., 2023).

Peer reviewed articles, feasibility/pilot studies or grey literature. A range of quality research was included to explore the emerging evidence for the effectiveness of group interventions for FND in practice.

Published after 2000. There have been significant changes in the views and understanding of FND over the last few decades (Popkirov et al., 2019). Including recent understanding was therefore important.

### Exclusion

The research not written in English. As the small research budget could not accommodate translation services, papers had to be in English for the researcher to read.

Literature reviews, meta-analyses, non-primary research.      Reviews were screened for articles; however, the review was interested in primary research, so any reviews or non-primary research were not included.

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### Screening and Data Extraction

Titles and abstracts were screened; those that were irrelevant were removed. In cases that met the criteria or where it was unclear, the whole paper was screened. Those that fulfilled the criteria were then included within the review and data was extracted. A bespoke data extraction framework was developed which included information about FND symptoms, participant demographic details, and information surrounding the group intervention (see Appendix D).

### Data Synthesis

A narrative synthesis approach was utilised to synthesise research findings due to the varied study designs and aims. For this reason, a meta-analysis was deemed inappropriate. The aim of a narrative synthesis is to bring together the evidence to explore links between research, policy, and practice (Snilstveit et al., 2012). It is developed using four steps (Popay et al., 2006): theory development (developing a model for how the interventions worked), preliminary synthesis of each study (organising the results into patterns), relationship exploration between studies (exploring the factors that might explain differences between the studies), and assessing the synthesis robustness (assessing the strength of the evidence drawing the conclusions and generalising the results to different contexts).

### Quality Assessment

The Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018) was used to assess the studies quality. It seeks to critically appraise the methodological quality across multiple study designs and has been used previously in reviews with multiple study designs (Vo & Allen, 2022; Evlat et al., 2021).

To ensure inter-rater reliability, five papers were randomly selected (using computer software) to be rated by an independent peer reviewer. There was an agreement rate of 73.33% (33/45). Where there were differences in ratings the researcher and peer reviewer discussed the reasoning which led to the researcher changing two answers and the peer reviewer changing ten of their answers.

### Researcher Position

The first author identifies as a white-British cis-woman. Employed within the NHS as a trainee Clinical Psychologist, the researcher's ideas influenced the interpretation of the data. Supervision and using a reflective journaling helped the researcher to maintain an awareness of their assumptions.

## **Results**

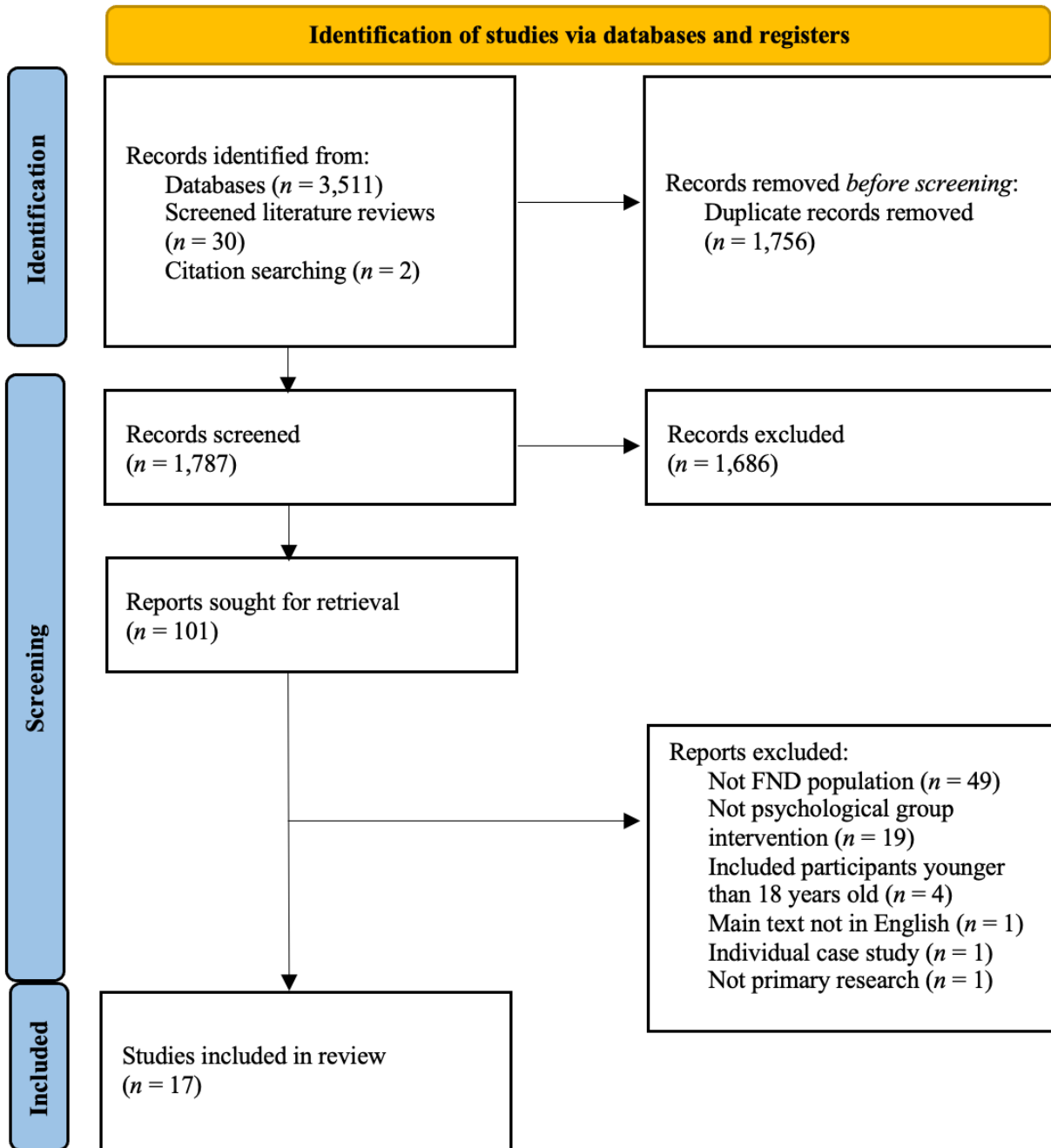
### Search Results

Figure 1 displays the selection process. Once duplicates were removed, 1,787 title and abstracts were screened. Those that did not meet the criteria were excluded. The remaining 101 full text papers were then screened. Of those, 84 were excluded for not meeting the inclusion criteria, leaving 17 studies for the synthesis.



Figure 1

PRISMA – Flow Diagram (Page et al., 2021)



## Characteristics of the Studies

A summary of the characteristics of the included literature can be found in Table 2 and 3. See Appendix E for range of outcome measures used. At least 538 participants were enrolled in group interventions across all studies (with two papers where the number of participants was unclear; Guy et al., 2023; Metternich et al., 2008). A control group was used in five studies (Chen et al., 2014; De Barros et al., 2018; Limburg et al., 2021; Metternich et al., 2008; Senf-Beckenbach et al., 2022), made up of at least 157 participants. Metternich et al. (2008) did not report the number of control participants.

Additionally, seven studies reported that some or all of their participants were undertaking individual therapy or counselling (Barry et al., 2008; Bullock et al., 2015; Chen et al., 2014; Guy et al., 2023; Labudda et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004). Individual therapy was available but the exception for Libbon et al. (2019), and participants for Boico et al. (2023) had individual sessions prior to the group. Conversely Cope et al. (2017) and Conwill et al. (2014) reported no other interventions alongside the group and de Barros et al. (2018), Libbon et al. (2023), Limburg et al. (2021), Metternich et al. (2008) and Sarudiansky et al. (2020) did not report either way.

**Table 2***Characteristics of the Included Studies*

<b>Characteristics</b>	<b>Papers</b>
<u>Population</u>	
Argentina	Sarudiansky et al. (2020)
Brazil	de Barros et al. (2018)
Germany	Labudda et al. (2020); Limburg et al. (2021); Metternich et al. (2008); Senf-Beckenbach et al. (2022)
UK	Boico et al. (2023); Conwill et al. (2014); Cope et al. (2017); Guy et al. (2023)
USA	Barry et al. (2008); Bullock et al. (2015); Chen et al. (2014); Libbon et al. (2019); Libbon et al. (2023); Prigatano et al. (2002); Zaroff et al. (2004)
<u>FND Symptoms</u>	
Functional Memory Disorder	Metternich et al. (2008)
Functional Seizures	Barry et al. (2008); Bullock et al. (2015); Chen et al. (2014); Cope et al. (2017); de Barros et al. (2018); Labudda et al. (2020); Libbon et al. (2019); Libbon et al.

(2023); Prigatano et al. (2002); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022); Zaroff et al. (2004)

Functional Seizures or Functional Neurological Symptoms Conwill et al. (2014)

Functional Vertigo/Dizziness Limburg et al. (2021)

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Comorbid Physical and Mental Health Challenges

Anxiety Conwill et al. (2014); de Barros et al. (2018); Libbon et al. (2019); Limburg et al. (2021); Zaroff et al. (2004)

Bipolar Disorder Barry et al. (2008); Zaroff et al. (2004)

Depersonalisation Disorder Barry et al. (2008)

Depression Barry et al. (2008); Conwill et al. (2014); de Barros et al. (2018); Limburg et al. (2021); Guy et al. (2023); Prigatano et al. (2002)

Dissociative Disorder Barry et al. (2008); Zaroff et al. (2004)

Epilepsy Barry et al. (2008); Bullock et al. (2015); Cope et al. (2017); de Barros et al. (2018); Labudda et al. (2020); Sarudiansky et al. (2020)

Hepatitis C Barry et al. (2008)

Learning Disability	Prigatano et al. (2002)
Mesial Temporal Sclerosis	de Barros et al. (2018)
Mood Disorders	Libbon et al. (2019)
Nonpsychiatric comorbidity	Conwill et al. (2014)
Obsessive Compulsive Disorder	Barry et al. (2008); Guy et al. (2023)
Panic Disorder with Agorophobia	Barry et al. (2008)
Personality Disorders	Guy et al. (2023); Libbon et al. (2019); Prigatano et al. (2002)
Post-Traumatic Stress Disorder/Trauma	Barry et al. (2008); Chen et al. (2014); de Barros et al. (2018); Libbon et al. (2019);
Related Experiences	Guy et al. (2023); Prigatano et al. (2002); Sarudiansky et al. (2020); Zaroff et al. (2004)
Psychiatric Disorders	de Barros et al. (2018)
Psychosis/Psychotic Disorders	Barry et al. (2008); de Barros et al. (2018); Libbon et al. (2019)
Skin-Picking Disorder	de Barros et al. (2018)
Sleep Disorders	Barry et al. (2008); Libbon et al. (2019)
Social Phobia	Zaroff et al. (2004)
Substance Abuse	Barry et al. (2008); Libbon et al. (2019); Prigatano et al. (2002); Zaroff et al. (2004)

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### Therapeutic Approaches

Body-Focused Group	Senf-Beckenbach et al. (2022)
Cognitive Behavioural Therapy	Boico et al. (2023); Conwill et al. (2014); Cope et al. (2017); de Barros et al. (2018)
Dialectical Behavioural Therapy	Bullock et al. (2015); Labudda et al. (2020)
Family Therapy Based	Libbon et al. (2023)
Group Psychotherapy	Limburg et al. (2021); Metternich et al. (2008); Prigatano et al. (2002); Zaroff et al. (2004)
Psychodynamically Oriented Groups	Barry et al. (2008); Libbon et al. (2019)
Psychoeducational Based Group	Chen et al. (2014); Guy et al. (2023); Sarudiansky et al. (2020)

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### Intervention Location

Community/Out-Patient Setting	Bullock et al. (2015); Chen et al. (2014); Conwill et al. (2014); Cope et al. (2017); de Barros et al. (2018); Guy et al. (2023); Libbon et al. (2019); Libbon et al. (2023); Limburg et al. (2021); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022)
Inpatient Setting	Labudda et al. (2020)
Location Not Clearly Described	Barry et al. (2008); Metternich et al. (2008); Prigatano et al. (2002); Zaroff et al. (2004)

Online Group (in preparation for an  
inpatient stay) Boico et al. (2023)

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Group Content

Acceptance and mindfulness	Libbon et al. (2019)
Conflict resolution	de Barros et al. (201)
Connection between body, symptoms and emotions	Boico et al. (2023)
Dissociation	Senf-Beckenbach et al. (2022)
Distress tolerance	Bullock et al. (2015)
Education on FND symptoms and/or their diagnosis	Boico et al. (2023); Chen et al. (2014); Cope et al. (2017); Labudda et al. (2020); Limburg et al. (2021); Prigatano et al. (2002); Sarudiansky et al. (2020); Senf- Beckenbach et al. (2022); Zaroff et al. (2004)
Emotions and/or Emotional Regulation	Boico et al. (2023); Bullock et al. (2015); Zaroff et al. (2004)
Familiarisation to therapy and/or therapeutic model	Boico et al. (2023); Cope et al. (2017); de Barros et al. (2018)

Link between trauma, depression and anger	Zaroff et al. (2004)
Living with the symptoms	Sarudiansky et al. (2020)
Management of triggers	de Barros et al (2018)
Psychoeducation	Barry et al. (2008); Boico et al. (2023); Bullock et al. (2015); Chen et al. (2014); Conwill et al. (2014); Cope et al. (2017); de Barros et al. (2018); Guy et al. (2023); Labudda et al. (2020); Libbon et al. (2019); Limburg et al. (2021); Prigatano et al. (2002); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022); Zaroff et al. (2004)
Psychoeducation of interpersonal effectiveness/relationships	Bullock et al. (2015); de Barros et al. (2018)
Safety measures and the universality of FND symptoms	Chen et al. (2014)
Triggers and what might be maintaining FND symptoms	Cope et al. (2017); de Barros et al. (2018); Libbon et al. (2019)
Understanding dysfunctional cognition and avoidance behaviours	Limburg et al. (2021)



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Number of Participants Per Group

2-4	Cope et al. (2017)
3	Guy et al. (2023)
3-10	Chen et al. (2014)
4-8	Conwill et al. (2014)
5-6	Boico et al. (2023)
6-10	Libbon et al. (2019); Limburg et al. (2021)
8	de Barros et al. (2018)
10	Metternich et al. (2008)
Not clearly reported	Barry et al. (2008); Bullock et al. (2015); Labudda et al. (2020); Libbon et al. (2023); Prigatano et al. (2002); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022); Zaroff et al. (2004)

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**Table 3***An Overview of the Included Studies*

<b>Author (Year) and Study Design</b>	<b>Participant Information</b>	<b>Group Therapy Information</b>	<b>Group Aim</b>	<b>Additional Intervention(s)</b>	<b>Outcome of Interest</b>	<b>Intervention Outcome</b>
Barry et al. (2008)  Before- and-after study time series	PNES  USA  12 participants entered the study	Psychodynamic in orientation  32 sessions, 90- minute sessions, weekly	Education about the disorder and decrease SF and increasing the quality of life	5 participants in follow up therapy following the group	Physical Health and Quality of Life  Depressio n	Reduction in in symptoms, improvement in quality-of-life post- treatment

	7 completed at least 75% of the sessions			Support network between sessions	Self-reported SF	Depression decreased post-treatment (p<0.01).
	Mean age = 45.4 years old (SD+- 7.9)					SF reduction (6/7) or cessation (4/7) post-treatment
	All female					
Boico et al. (2023)	FNSD UK	Adapted QGSH for group therapy format	Understanding of FND and establish collaboration between participant and staff	Inpatient MDT programme following group	Qualitative feedback – session materials, homework task and experience	Positive experience of the group Participants made good use of the group
Mixed Methods	16 participants entered the study	12 sessions, 60-90 minutes, weekly, online				

	10 females, 6 males					of group during each session  Intervention Feedback Questionnai re
Bullock et al. (2015)	CD with seizures  USA  21 participants enrolled	DBT-ST  3 modules of 8-10 sessions, 90-minute sessions, weekly	Skills training  in distress  tolerance,  emotion  regular and  interpersonal  effectiveness	Individual  psychotherapy  alongside group	Self-  reported  SF	SF reduction from  baseline to average  end of treatment by  66%

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19 completed at

least one module

Mean age = 44.5

years old

18 females; 1 male

15 Caucasian

17 unemployed

5 single

Mean year in

education = 13.6

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Chen et al. (2014)	PNES  USA	Brief psychoeducation intervention	Improve overall functionality and/or reducing SF/intensity	Some participants in concurrent counselling/ therapy	Functionin g  Self- reported SF  Self- reported Seizure intensity	Intervention group significantly lower for functioning (p=0.013)  SF and intensity not significantly different at follow up between intervention and control group  Intervention group attentat hospital less than control group at follow up  Seizure related
Randomis ed control trial	34 in intervention group  21 completed full intervention and follow-up  Mean age= 50.76 years (SD 12.27)  25 males, 9 females	3 sessions, 90- minute sessions, monthly				

---

7 employed

19 married

Mean years in  
education: 12.91  
(SD 1.68)

hospital

visits/admi

ssions

Self-

reported

new

symptoms

not

medically

explained

Self-

reported

knowledge

and

---

Perception of

seizures changed

over intervention

No difference

between groups of

developing new

symptoms

					perception of seizures	
Conwill et al. (2014)	NEA/ FNSs UK	CBT-based 4-5 sessions, 60- minute sessions, weekly	Improve the quality of life and physical and emotional symptoms	None reported	Physical Health Depressio n and Anxiety	Physical health and depression and anxiety showed a nonsignificant improvement after the intervention
Before- and-after study time series	16 participants Mean age= 37.4 years old 12 females 11 married, 5 single				Improvem ent in Condition	Minimal-to- considerate improvement in condition  SF slightly reduced



	5 full-time work/education				Self- reported SF	
Cope et al. (2017) Mixed methods	FNEA UK 25 enrolled Age ranging from 18 to 46+ years old 21 females; 4 males	CBT-based psychoeducation group 3 sessions, 90- minute sessions, weekly	To help participants to understand their diagnosis and to meet others with FNEA	None reported	Depressio n Anxiety Functionin g Illness Perception Dissociati ve	Cessation or reduction of seizures post-intervention Significant reduction in distress (p=0.028) and illness perception (p<0.001) scores post- intervention Non-significant reduction in

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11 employed/ student; 12 unemployed, 2 retired/home duties	Experienc es  Distress	depression, anxiety and functioning scores post- intervention
14 single, 8 married/partner, 3 separated/divorced	Self- reported SF and seizure intensity  Self- reported attitudes toward FNEA	High level of satisfaction with group  Learning strategies as helpful  Feeling less alone and gained insight into other people with FNEA

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					Self-reported evaluation of group sessions	Valued space to talk and share
de Barros et al. (2018)	PNES Brazil	Psychotherapeutic group intervention - CBT based	Change in anxiety/depression symptoms on level of alexithymia, quality of life and SF	None reported	Physical Health Alexithymia Depression Anxiety	Significant improvements in physical health (p=0.003) Significant decrease in alexithymia scores after intervention (p=0.02)
Non-randomised control trial	47 took part in group intervention Mean age= 35.9 years old	8 sessions, session length not reported, weekly				

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25 females

Ways of Coping  
Self-reported SF

Significant decrease in depression and anxiety scores after intervention (p<0.0001; p=0.02 respectively)

No statistically significant changes in coping strategies after the intervention

Reduction in SF (P = 0.02)

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Guy et al. (2023)	FND  UK	Group psychoeducational sessions	Group: psychoeducati on	Individual CBT  Physiotherapy	Anxiety  Depressio n	Participants who completed MDT programme had significant
Before- and-after study time series	3 participants in psychoeducation group	‘Alumni’ session  ‘Friends and family’ session	‘Alumni’ session: sharing experiences of programme	Physiotherapy workshops  Mindfulness relaxation exercises	Functionin g  Walking  Mobility  Balance	improvements in all outcome measures: anxiety (p<0.001), depression (p<0.001), functioning (p<0.001), walking (p<0.001), mobility (p<0.001), Balance (p=0.005)
	Unclear how many participants took part in the ‘alumni’ and ‘friends and family’ session	Number, duration and occurrence of sessions for group psychoeducation not reported	= education about the program			

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		One ‘alumni’ and ‘friends and family’ session, duration not reported				
Labudda et al. (2020)	PNES  Germany	Psychoeducation group (DBT influenced)	Stress management  Emotional regulation	Concurrent Individual CBT sessions	Physical Health and Quality of Life	Cessation in seizures for 23% of participants at end of intervention
Before- and- after study time series	80 enrolled  53 completed intervention and six-month follow- up  60 females	6 sessions per area (3 areas), 60 minutes, weekly	Psychoeducati on		Depressio n  Anxiety	Significant reduction at end of intervention in: physical health and quality of life (p<0.001), depression

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<p>Mean years in education = 9.55</p>	<p>Dissociati ve Symptoms (p&lt;0.001), anxiety (p&lt;0.01), dissociative symptoms</p>
<p>Mean age= 33.76 years old</p>	<p>Self- reported PNES rating 74.1% reported subjectively experienced an improved PNES situation at follow up  Increase ability to prevent seizures at end of intervention</p>

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Libbon et al. (2019)	USA	Psychoeducation groups: CGMV plus psychodynamic group for those requiring further intervention	CGMV: provide psychoeducati on surrounding NES	Individual therapy available	Clinic utilisation from healthcare reports	Retention rate of 65.4%
Before-and-after study time series	106 enrolled 89 completed intervention	5 sessions of CGMV, 12 sessions of psychodynamic group	Psychodynami c group: explore themes related to NES	Family therapy available	Healthcare treatment utilisation from healthcare reports	Healthcare utilisation decreased during and after treatment
	Mean age = 40 years old 78 females, 28 males	CGMV: 120 minutes  Psychodynamic group: 80 minutes				



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		Weekly				
Libbon et al. (2023)	NES	Multifamily Group Psychotherapy	To be useful for individuals with NES and family	None reported	Family Functioning	Participants report dysfunctional families
Non-comparative study	USA	1 session, half a day			MFG Feedback Questionnaire	Participants and family members found group to be helpful and satisfied with experienced
	29 participants with NES	Attended with family member(s)				
	Mean age= 34.5 years old					
	25 females, 4 males					
	Not Hispanic/Latino = 26,					

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Hispanic/Latino =

3; White or

Caucasian = 26,

Black or African

American = 3

Married/partner =

15, single = 12,

divorced = 1,

unknown = 1

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Limburg et al. (2021)	Functional vertigo/dizziness  Germany	Integrative group psychotherapy  16 sessions, 90- minute sessions, weekly	Gradual exposure to movements  that are usually avoided	None reported	Impact of Vertigo  Vertigo Symptoms	Vertigo-related impairment was reduced in intervention and control group
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Randomised controlled trial	81 participants enrolled 58 completed intervention and 12-month follow up  Mean age = 53.7 years old  49 Females  42 employed, 3 unemployed, 24 retired, 12 other	Somatisation  Anxiety  Depression	Clinically relevant improvements in depression scores in intervention and control group  Significant effect of time for changes to somatisation (p=0.0008)  Attrition rate higher in control group
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33 married

9th grade or less =

20, 10th grade= 25,

High school

graduate = 14,

University graduate

= 16, Missing

information = 11

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Metternich et al. (2008)	Functional Memory Disorder	Group therapy 13 sessions, session length not reported, weekly	Reducing stress levels, everyday memory lapses and memory- related anxiety	None reported	Metamem ory Perceived Stress	Significantly larger improvement in memory-related self- efficacy in intervention group at
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controlled trial	part in the intervention group				Physical Health and Quality of Life	6-month follow-up (Cohen's d = 0.9) No significant differences in physical health and quality of life and the perceived stress between groups  No change in perception of stress
Prigatano et al. (2002)	NES USA	Group Psychotherapy	To determine whether psychological	One offered individual therapy instead	Self-reported SF	66% reported a decline in SF

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		24 sessions, 90-	treatment	of group part-	11% reported an
Before-	15 participants	minutes, weekly	could affect	way through	increased in SF
and-after	enrolled		the frequency	group sessions	
study time			of self-		
series	9 completed at		reported NES		
	least 58% of the				
	treatment sessions				
	Mean age = 36				
	years old				
	All female				
	Employed full				
	time= 7, employed				
	part-time = 1,				

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unemployed/medic

al disability = 5

Married = 8,

engaged = 1,

Divorced/Single =

4

Mean years in

education = 14.07

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Sarudians	PNES	Psychoeducation	Improve	None reported	Interventio	Reduction in SF for
ky et al.		group	understanding		n	5 participants, SF
(2020)	Argentina		of PNES,		Questionn	remained the same
		3 sessions,120	illness		aire	for 2 participants, SF
Mixed	16 Participants	minutes, bi-monthly	perception and			increased for 5
methods	enrolled				Anxiety	participants

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	affective		
12 participants	scores	Depressio	Better understanding
completed all		n	of PNES (91.7%)
sessions			and able to identify
		Illness	triggers (75%)
Mean age= 30.75		Perception	
years old			Statistically
		Dissociati	significant difference
10 female, 2 male		ve	in:
		Symptoms	anxiety (p=.036),
Employed = 2,			depression (p=.019),
Unemployed = 4,		PTSD	global perception of
student = 6		Symptoms	illness (p=.014)
Completed			No statistically
Elementary = 2,			significant difference

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Incomplete High

school = 7, Trade

school = 1,

Incomplete

university = 1

in levels of PTSD or

dissociative

symptoms

Reduction in

concern about

people witnessing

seizure

Learnt strategies to

manage PNES and

continue to use them

Reduction in

hospital visits

relating to symptoms

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						Experience of group as positive
						Sharing experiences, learning new strategies and gaining knowledge about PNES as useful
Senf-Beckenbach et al. (2022)	PNES Germany 27 participants enrolled	Body-focused group therapy program (psychoeducation, emotion-regulation, body perception)	Decrease seizure severity and level of dissociation	3 individuals in control group started individual therapy and	Dissociative Symptoms Seizure Severity	Improvement in dissociative symptoms scores post-intervention

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Randomised controlled trial	13 participants completed intervention and 6-month follow-up	10 Sessions, 90 minutes, weekly	were discounted from results	Depression	Improvement in seizure severity scores post-intervention
	Mean age = 36.6 years old			Somatisation	No significant change in depression scores
	19 females, 3 males				Improvement of somatisation scores greater in control group
	Average years in education = 11.8 years				

Zaroff et al. (2004)	Psychological nonepileptic seizures	Group psychotherapy	Increase in more task-based and less emotion-based coping strategies, improved quality of life, and decreased dissociative and traumatic symptoms	None reported	Coping Strategies	Dissociative symptoms
Before- and-after study series	USA	10 sessions, 60 minutes, weekly			Trauma	treatment (p=0.04)
	10 Participants enrolled				Dissociative Symptoms	Trauma scores reduced post-treatment (p=0.003)
	7 completed pre and post measures				Anger	Avoidance reduced, task increased,
	Mean age = 25.7 years old				Quality of Life	emotional improved post-intervention
	8 females, 4 males					

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Average years in  
education = 13.4

Self-  
reported  
SF

Anger expression  
reduced post-  
treatment

Improvement in  
quality of life  
(p=0.07)

4 no change in SF, 2  
decline in SF, 1  
increase in SF

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*Note:*

CBT= Cognitive Behavioural Therapy; CD = Conversion Disorder; CGMV= Conversational Group Medical Visit; DBT(-ST) = Dialectical Behaviour Therapy (Skills Training); FNEA= Functional Nonepileptic Attacks; FNSD= Functional Neurological Symptom Disorder; FNSs = Functional Neurological Symptoms; MDT= Multi-Disciplinary Team; MFG= Multi-Family Group; NEA/S =

Nonepileptic Attacks/Seizures; PTSD = Post-Traumatic Stress Disorder; QGSH = Queen Squared Guided Self-Help; SF = Seizure

Frequency

### Quality of Included Studies

The overall quality of the papers was poor with multiple methodological issues present. Whilst many of the research aims were clear, no paper clearly reported their research question. Information about the participants such as age, gender, ethnicity, marital status, employment status, educational attainment was not regularly reported making it hard to identify the representativeness of the sample. The majority of the participants were female (Boico et al., 2023; Bullock et al., 2015; Conwill et al., 2014; Cope et al., 2017; Labudda et al., 2020; Libbon et al., 2019; Libbon et al., 2023; Limburg et al., 2021; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004), with at least two samples only having female participants (Barry et al., 2008; Prigatano et al., 2002). This appears to be representative of the population.

Other areas of potential bias were the small sample sizes and high dropout rates. In 12 studies the starting sample was smaller than 50 participants (Barry et al., 2008; Boico et al., 2023; Bullock et al., 2015; Chen et al., 2014; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Libbon et al., 2023; Prigatano et al., 2002; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004) and six of those had samples of 20 or less (Barry et al., 2008; Boico et al., 2023; Conwill et al., 2014; Prigatano et al., 2002; Sarudiansky et al., 2020; Zaroff et al., 2004). In seven studies, the retention rate was unclear or not reported (Barry et al., 2008; Boico et al., 2023; Bullock et al., 2015; Conwill et al., 2014; Guy et al., 2023; Metternich et al., 2008; Priganto et al., 2022). Where attrition was mentioned, all reported that not all participants completed the intervention (Chen et al., 2014; Cope et al., 2017; de Barros et al., 2018; Labudda et al., 2020; Libbon et al., 2019; Libbon et al., 2023; Limburg et al., 2021; Sarudiansky et al.,

2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004). The definition of completing the intervention was inconsistent. Some studies included participants who had not attended all of the group sessions in their results whereas as other studies discounted those who missed sessions.

Of the randomised controlled trials (Chen et al., 2014; Limburg et al., 2021; Metternich et al., 2008; Senf-Beckenbach et al., 2022), only one provided evidence of random allocation to intervention or control groups (Senf-Beckenbach et al., 2022) and half had comparable groups at baseline (Chen et al., 2014; Senf-Beckenbach et al., 2022). Due to the dropout rate of the studies being greater than 20%, all had incomplete data outcomes, and consequently had issues with participant adherence. The outcome assessors being blinded to the intervention being provided was not present from Metternich et al. (2008) and Senf-Beckenbach et al. (2022), with the other two lacking information about this. These are clear areas of potential bias.

Of the non-randomised studies (Barry et al., 2008; Bullock et al., 2015; Conwill et al., 2014; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Prigatano et al., 2002; Zaroff et al., 2004), six studies used appropriate measures regarding the outcome and intervention (Barry et al., 2008; Conwill et al., 2014; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; 2002; Zaroff et al., 2004), two had complete datasets (Bullock et al., 2015; de Barros et al., 2018), two had the intervention administered as intended (Bullock et al., 2015; Conwill et al., 2014) (with six lacking detail to know whether this took place; Barry et al., 2008; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Zaroff et al., 2004). Confounders were not accounted for within six studies (Bullock et al., 2015;



de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Prigatano et al., 2002).

Across the mixed methods studies (Boico et al., 2023; Cope et al., 2017; Sarudiansky et al., 2020) there was a lack of information to understand whether the qualitative approach was appropriate to answer the research question and aims, whether the qualitative approach collection was adequately derived from the data, and whether the interpretation of the results was sufficiently substantiated by the data.

Libbon et al. (2023) used a quantitative descriptive method. The measurements and statistical analysis was appropriate. However, there was a risk of bias for the sampling strategy which may have impacted the representativeness of the sample. There was a high risk of nonresponse bias.

#### Narrative Synthesis of Findings.

A summary of the themes from the 17 studies and the supporting papers can be found in Table 4.

#### **Table 4**

##### *Themes and Subthemes of Group Interventions*

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<b>Theme</b>	<b>Supporting Papers</b>
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Improvement in FND Symptoms	Barry et al. (2008); Bullock et al. (2015); Chen et al. (2014); Conwill et al. (2014); Cope et al. (2017); de Barros et al. (2018); Guy et al. (2023); Labudda et al. (2020); Libbon et al. (2019); Limburg et al. (2021); Metternich et al. (2008); Prigatano et al. (2002); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022); Zaroff et al. (2004)
Improvement in Understanding of FND	Barry et al. (2008); Boico et al. (2023); Chen et al. (2014); Cope et al. (2017); Labudda et al. (2020); Libbon et al. (2023); Sarudiansky et al. (2020)
Statistically Significant Improvement in Mental Health	Barry et al. (2008); de Barros et al. (2018); Guy et al. (2023); Labudda et al. (2020); Sarudiansky et al. (2020); Zaroff et al. (2004)
Improvement in Physical Health and Quality of Life	Barry et al. (2008); Chen et al. (2014); Conwill et al. (2014); de Barros et al. (2018); Libbon et al. (2019); Limburg et al. (2021); Sarudiansky et al. (2020); Senf-Beckenbach et al. (2022); Zaroff et al. (2004)
Participants Experiences of Attending Group	Barry et al. (2008); Boico et al. (2023); Cope et al. (2017); Libbon et al. (2023); Sarudiansky et al. (2020)

### *Improvement in FND Symptoms*

Of those that undertook measures of FND symptoms, all reported overall changes in symptoms (Barry et al., 2008; Bullock et al., 2015; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Limburg et al.,

2021; Metternich et al., 2008; Prigatano et al., 2002; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004). A decrease in SF was reported by nine studies (Barry et al., 2008; Bullock et al., 2015; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Libbon et al., 2019; Prigatano et al., 2002; Sarudiansky et al., 2020; Zaroff et al., 2004), and two of these reported that the decrease was statistically significant (Bullock et al., 2015; de Barros et al., 2018).

SF was measured using seizure logs or diaries completed by participants weekly (Barry et al. 2008; Bullock et al., 2015; de Barros et al., 2018; Libbon et al., 2019; Prigatano et al., 2002), fortnightly (Sarudiansky et al., 2020), monthly (Conwill et al., 2014; Cope et al., 2017) or pre- and post-treatment (Zaroff et al., 2004). Senf-Beckenbach et al. (2022) reported that seizure severity improved in the intervention group (body-focused group therapy). Labudda et al. (2020) reported a subjective improvement of participants seizures (DBT influenced psychoeducation group). However, as these measures were self-reported, they are subjective and potentially less reliable than clinical measures, particularly for the studies where reports were taken monthly as seizure recall may be more difficult. Due to the small sample size in many of these studies statistical analysis to report potential statistically significant difference was not possible. Critically, the randomised controlled trials did not report statistically significant differences (Chen et al., 2014; Limburg et al., 2021; Metternich et al., 2008; Senf-Beckenbach et al., 2022). The two papers that showed significant differences did not have control conditions to establish causality of the group (Bullock et al., 2015; de Barros et al., (2018).

For those with populations without functional seizures measuring FND symptom change all reported improvements (Boico et al., 2023; Conwill et al., 2014; Guy et al., 2023; Limburg et al., 2021; Metternich et al., 2008); only Guy et al. (2023) reported a statistically significant improvement. There is a clear difference in the ability to report symptom change in individuals without functional seizures. The use of measures or adapted measure for organic conditions measuring symptom change for their FND population was reported by Limburg et al. (2021), Metternich et al. (2008), and Senf-Beckenbach et al. (2022). Consequently, these measures are not validated for the population and lack reliability. Conwill et al. (2014) reported the use of symptom measurement for participants with functional seizures, however no measures of symptom change were undertaken for other FND symptoms. Therefore, it is impossible to know what impact the CBT-based group had on their symptoms.

The absence of symptoms following the intervention was reported in some participants in three studies (Barry et al., 2008, Cope et al., 2017; Labudda et al., 2020). Problematically, the studies included participants who reported no FND symptoms at the start of the group; the group's ability to stop symptoms is therefore in question. Cope et al. (2017) included participants who were seizure-free before the CBT-based group (7/18). It is unclear why participants who were not experiencing seizures were included in the group, but it may reflect the interventions over-arching aim to change mood, illness perception, and dissociation experiences as well as reducing SF. Some participants within the studies that reported the absence of seizures with participants who had seizures at the start of therapy also had individual therapy alongside the group (Labudda et al., 2020; de Barros et al., 2018). It is therefore unclear whether it was the

group intervention, individual intervention or a combination of approaches that influenced the cessation of seizures.

Of those that recorded hospital visits relating to seizure activity, all reported a reduction in usage (Chen et al., 2014; Cope et al., 2017; Libbon et al., 2019). Due to the small sample size and unclear reporting on the regularity of requiring medical attention in the participants, the extent to which the group reduced contact with medical services is unknown. With the exception of Libbon et al. (2019) who reported a statistically significant difference before and after intervention.

Critically, of the 14 studies that reported improvements in FND symptoms (Barry et al., 2008; Bullock et al., 2015; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Limburg et al., 2021; Metternich et al., 2008; Prigatano et al., 2002; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004), only eight had follow-up measures. These were at three months (Guy et al., 2023), three and six months (Chen et al., 2014; Libbon et al., 2019; Metternich et al., 2008), six months (Labudda et al., 2020; Senf-Beckenbach et al., 2022), 12 months (Limburg et al., 2021) or “several months” (Barry et al., 2008). Therefore, the long-term impact of the intervention cannot be understood. However, all of those that undertook follow-up measures of FND symptoms reported positive changes in the desired direction.

Significantly, three studies did not report direct measures of FND symptoms as part of the research (Boico et al., 2023; Libbon et al., 2019; Libbon et al., 2021). It is impossible to

know what impact the groups (adapted QGSH, psychoeducation and psychodynamic group, and multifamily group psychotherapy) had on symptom change.

### *Improvement in Understanding of FND*

Boico et al. (2023), Cope et al. (2017) and Sarudiansky et al. (2020) reported that participants had a greater understanding of their FND diagnosis following the group intervention. Similarly, Libbon et al. (2023) reported a greater understanding of different perspectives of family members including how FND can influence relationships in the family.

Change in participants' ability to recognise the triggers or causes of symptoms was reported Barry et al. (2008) and Sarudiansky et al. (2020). Labudda et al. (2020) reported that participants felt significantly more able to prevent seizures over time ( $p < .01$ ) following the DBT influenced group. Chen et al. (2014) reported that participants were significantly more likely to endorse statements such as "I have some control over my attacks" ( $p = .006$ ) following the brief psychoeducational group.

Cope et al. (2017) reported an increase in acceptance of symptoms following the CBT-based intervention and were less likely to disagree with statements such as symptoms are "not scaring me". Similarly, Chen et al. (2014) reported participants were significantly more likely to endorse statements such as "my attacks do not bother me as much anymore" ( $p < .001$ ). However, using a five-point Likert scale to measure levels of agreement as the researchers did, limits what participants are able to report and may bias their answers.

### *Statistically Significant Improvement in Mental Health*

Multiple studies used mental health measures to assess changes pre- and post-intervention (Barry et al., 2008; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Limburg et al., 2021; Metternich et al., 2008; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022; Zaroff et al., 2004). The most common mood measure assessed depressive symptoms (Barry et al., 2008; Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Limburg et al., 2021; Sarudiansky et al., 2020; Senf-Beckenbach et al., 2022) followed by anxiety (Conwill et al., 2014; Cope et al., 2017; de Barros et al., 2018; Guy et al., 2023; Labudda et al., 2020; Limburg et al., 2021; Sarudiansky et al., 2020). Critically, of the 11 studies that reported the use of mental health measures, three did not have group aims to change mental health symptoms (Barry et al., 2008; Cope et al., 2017; Guy et al., 2023). It is possible that they wanted to explore a relationship between FND and mental health symptomology, but this is unclear.

A significant reduction in depressive symptoms was reported by Barry et al. (2008), de Barros et al. (2018), Guy et al. (2023), Labudda et al. (2020), and Sarudiansky et al. (2020). In all these studies, a reduction or cessation of symptoms was reported for many participants. However, Labudda et al. (2020) reported an increase in depressive symptoms by the follow-up period; the reduction in FND symptoms was maintained.

A significant reduction in anxiety symptoms was reported by de Barros et al. (2018), Guy et al. (2023), Labudda et al. (2020), and Sarudiansky et al. (2020). In these studies, a reduction or cessation of symptoms was reported for many of the participants. Sarudiansky et al. (2020)

reported statistically significant improvements between pre- and post- the psychoeducation intervention measures for state-anxiety ( $p=.036$ ). However, a significant improvement was not reported on levels of trait anxiety ( $p=.098$ ). Labudda et al. (2020) reported a significant decrease in anxiety from pre- to post- intervention. This was not sustained at the follow-up period. In two of the studies that displayed significant reductions (Guy et al., 2023; Labudda et al., 2020), additional interventions were running concurrently including CBT and physiotherapy possibly influencing outcomes. The remaining two did not report any additional interventions (de Barros et al., 2018; Sarudiansky et al., 2020).

Whilst not meeting statistical significance, Conwill et al. (2014) and Cope et al. (2017) papers reported improvement in anxiety and depressive symptoms. They also reported a reduction in FND symptoms and had some of the lowest number of sessions (three and four). Additionally, Limburg et al. (2021) reported clinically meaningful changes in depressive symptoms following the integrative group psychotherapy. Clinically significant results for individuals' participants may differ from statistically significant results, meaning that the lack of statistically significant results may not be problematic.

Of the two papers that explored trauma symptoms (Sarudiansky et al., 2020; Zaroff et al., 2004), only Zaroff et al. (2004) reported a significant decrease in symptoms following group psychotherapy ( $p=.003$ ). Both studies reported a reduction in SF in less than half of their participants. The two papers had a similar number of participants; however, Zaroff et al. (2004) had ten sessions compared to three which may account for the degree in significance. Critically,



Zaroff et al. (2004) reported the decline in SF in two participants (out of seven who completed measures).

### *Improvement in Physical Health and Quality of Life*

The use of physical health measures to assess changes pre- and post- intervention was reported by Barry et al. (2008), Conwill et al. (2014), Cope et al. (2017), Guy et al. (2023), Limburg et al. (2021), Sarudiansky et al. (2020), and Senf-Beckenbach et al. (2022).

Barry et al. (2008) reported meaningful changes in physical health symptoms for some participants (such as no longer needing walking aids) in addition to the reduction of SF. Limburg et al. (2021) reported a significant reduction in somatisation ( $p=.008$ ) alongside improvements to functional vertigo or dizziness symptoms. Senf-Benckenbach et al. (2022) reported improvements in somatoform symptoms alongside improvements in seizure severity. Both Limburg et al. (2021) and Senf-Benckenbach et al. (2022) used randomised controlled designs so the causal nature of the group cannot be established whereas Barry et al. (2008) lacked this ability due to the before and after design.

Of the studies that had measures of quality of life (Barry et al., 2008, Conwill et al., 2014; de Barros et al., 2018; Limburg et al., 2021; Zaroff et al., 2004), all reported improvements alongside improvements in FND symptoms, although only one reported statistically significant improvements in quality of life (de Barros et al., 2018). This study also reported significant reductions in SF unlike the four other studies measuring quality of life. Critically, only Barry et al. (2008) and Limburg et al. (2021) undertook follow-up measures. These improvements were

sustained over a 12-month period. Additionally, Sarudiansky et al. (2020) used a post-measure questionnaire to investigate participants' views on groups and found that the majority of participants felt that group participation would have a positive impact on their quality of life moving forward. However, this is not a direct measure of whether quality of life had improved.

### *Participants Experiences of Attending Group*

Benefits participants disclosed regarding their experiences of group interventions were reported by Barry et al. (2008), Boico et al. (2023), Cope et al. (2017), Libbon et al. (2023), and Sarudiansky et al. (2020). Barry et al.'s. (2008) psychodynamically orientated group reported interpersonal changes such as better-defined interpersonal boundaries following the intervention alongside a reduction in SF.

Boico et al. (2023) explored the qualitative participant feedback from the QGSH group therapy and identified themes such as the instillation of hope, sharing of experience and information, and interpersonal learning.

*“I found other patients inspirational” “I enjoyed sharing experience of the impact of FND”* (Boico et al., 2023, p. 6)

Critically, it appears that Boico et al. (2023) found quotes and made them fit pre-existing themes for groups (Yalom, 1995's group therapeutic factors) rather than following an established method for analysing qualitative data, thus calling into question the quality of analysis and robustness of the data.

Sarudiansky et al. (2020) reported that learning new functional seizure coping strategies was useful for participants in a psychoeducational group. Libbon et al. (2023) reported that participants and their family members found the multifamily psychotherapy group helpful and were satisfied with their experience.

Cope et al. (2017) explained that participants in the CBT-based psychoeducational group felt less alone in their condition and that it was insightful for them to see a range of people with the condition. This is in line with one of the aims of the intervention: to meet others with functional seizures. Additionally, participants reported the value of having a safe space to talk and share experiences. Sarudiansky et al. (2020) reported finding sharing of functional seizure related experiences as one of the most useful aspects of the psychoeducational group. The sharing of experiences was explicitly facilitated within eleven studies (Barry et al., 2008; Boico et al., 2023; Chen et al., 2014; Cope et al., 2017; Guy et al., 2023; Labudda et al., 2020; Libbon et al., 2019; Libbon et al., 2023; Prigatano et al., 2002; Sarudiansky et al., 2020; Zaroff et al., 2004).

Libbon et al. (2023) reported participants found sharing their experience within the multifamily psychotherapy group decreased a sense of isolation. Equally, having an opportunity to express their thoughts and feelings was beneficial. Unique to their intervention, Libbon et al. (2023) reported that participants found the group helped with family communication and that it would be useful to reduce future conflict in the family. The researchers felt this may have unconsciously influenced the expression of functional seizures in participants.

Critically, all of the studies that reported participant experiences (Barry et al., 2008; Boico et al., 2023; Cope et al., 2017; Libbon et al., 2019; Sarudiansky et al., 2020) did not clearly describe their analysis process that produced the themes. Boico et al. (2023) was the only study to provide direct quotes from participants. Many of these studies also used Likert scale type questions for feedback of the group which may have limited what participants were able to share about the benefits they felt they received from the group.

## **Discussion**

This review explored the outcomes of group psychological therapy for individuals with FND in 17 papers. The results suggest that group interventions reduce FND symptoms and improve the mental and physical health of participants. However, few studies showed the symptoms stopped altogether following the intervention. This is in keeping with research from Velazquez-Rodriguez & Fehily (2023) who found that total symptom recovery for FND is uncommon. Unlike individual interventions, group approaches allow individuals with FND to share experiences with each other and to feel less disconnected and ostracised.

Many of the groups reported the influence of well-established therapeutic approaches for therapy groups such as CBT (Schwartz et al., 2019) and DBT (Feigenbaum et al., 2012). Commonalities between the groups included psychoeducation and the sharing of experiences. Psychoeducation has been found to foster understanding of conditions (Galvez-Sánchez & Montoro., 2023) and normalise responses (Lukens & McFarlane, 2004). Additionally, many people following a diagnosis of FND report feeling confused about the diagnosis (Thompson et al., 2009). It is therefore not surprising that many studies report participants feeling they better understand their condition. Sharing experiences can create a sense of connection with others (Sugarman et al., 2022). This can be particularly important for individuals with FND, as individuals report feeling isolated and alone (Canna & Seligman, 2020).

Many researchers reported a decrease in FND symptomology and a greater understanding of their diagnosis and ability to recognise triggers and able to prevent symptoms. Researchers also commented on the change to acceptance of symptoms. Acceptance of health conditions and

symptoms has been linked to greater quality of life and life satisfaction, wellbeing, and mental health (Aaby et al., 2020). This is similar to individual therapies that have increased acceptance in individuals with FND (Barrett-Naylor et al., 2018; Graham et al., 2017; Graham et al., 2018). Group therapy has increased acceptance in individuals with anxiety and depression, diabetes and chronic pain (Coto-Lesmes et al., 2020; Ryan et al., 2020; Ma et al., 2023). Similarly, many researchers in the review reported improvements in their mental health. This is particularly important as 43% of individuals with FND self-report experiences of depression and 51% report anxiety (Butler et al., 2021). It is helpful that groups appear to reduce these mental health symptoms.

### **Limitation and Future Research**

To the best of the author's knowledge, this is the first systematic review into group therapy for individuals with FND. The studies reflect the emerging and current practice in healthcare settings. An overarching limitation is that the quality of the included papers was poor. The small sample size and unclear methodology makes firm conclusions hard to make and generalise for quantitative research. Therefore, further quantitative studies could include larger sample sizes to achieve a statistical power to find an effect if there is one to find. Conversely the mixed methods approaches that included the use of qualitative feedback lack the richness and depth that interviews or more detailed written communication that could be transferable to other group intervention settings. Future research could use qualitative approaches to better understand group therapy such as identify how helpful participants found the group.

Many participants had individual therapy, in conjunction with, or after, the group intervention. This may reflect clinical practice, with those in need of additional support able to access individual sessions. Further research could include comparison between individual, group and combined approaches to waitlist controls with follow-up periods to identify the most effective support for individuals with FND. This is particularly important for commissioners when identifying effective support that may decrease the associated healthcare costs for people with a diagnosis of FND by ensuring people are able to receive the right intervention and support. It may also help to understand who may benefit from additional support through individual sessions and for whom group sessions would be sufficient. Qualitative methodology to further understanding of experiences of groups would be beneficial to shape group developments.

Research with subtypes of FND other than functional seizures is needed. Following recent changes to see FND as a diagnosis of positive symptoms rather than excluding other conditions (Aybek & Perez, 2022), it is hoped that it will become easier to research other FND subtypes. Traditionally, functional seizures have been easier to diagnose as epileptic seizures have clear changes in brain waves that are not seen in functional seizures through a video-electroencephalograph and have distinct differences in observable presentation (Devinsky et al., 2011). Including samples with multiple FND symptoms would be beneficial also, as it is estimated that over 50% experience more than ten FND symptoms (Butler et al., 2021). This will better reflect the population. Additionally, many studies did not report the ethnicity or other social factors (Burnham & Nolte, 2019) of the participants and took the sample from Western, Educated, Industrialised, Rich and Democratic (WEIRD) populations (Henrich et al., 2010). By

being more transparent about the participant sample and moving towards a more inclusive and diverse population the impact of the group can be better understood within the context of the FND community. Research is starting to explore how individuals from the Global Majority experience FND (Baloch, 2021) and how this may be similar and differ from the experiences captured by WEIRD research. Groups can then therefore help to better support and reflect the needs of individuals with FND. This is particularly important as individuals from the Global Majority (Bansal et al., 2022) and FND (O’Keeffe et al., 2021) can report negative and stigmatising experiences within healthcare settings. It is likely that the intersectionality between the two experiences may influence experiences of support within services (Qureshi et al., 2022).

### **Clinical Implications**

NICE (2021) recommends non-neurology intervention for FND following diagnosis. The review highlights that the use of groups for individuals with FND may be beneficial in reducing FND symptoms and helping individuals to understand and accept their diagnosis alongside improvements in mental and physical health. Clinically, drawing upon a therapeutic approach may help shape the group content; however, the review suggests that an important characteristic of the group is to include space for psychoeducation on FND and the sharing experiences of FND. Many of the studies use the groups in conjunction with individual therapy. Practically, following the examples of the included studies, groups would benefit from being held weekly, in-person, and including no more than ten participants per group. Sessions should last no longer than two hours and include participants with similar FND symptoms/characteristics.



## **Conclusion**

This review explored group psychological interventions for individuals with FND with a focus on commonalities between interventions and the outcomes of the group. Most researchers included elements of psychoeducation and providing the space to share their experiences of their condition. Broadly the outcomes of interest related to positive changes to FND symptoms and positive changes in mental and physical health. Whilst the papers were low in quality, group interventions appear to potentially offer some benefit for individuals with the condition in reducing the symptoms of FND and improving mental and physical health. Better quality studies are required to help shape service provision for individuals with FND.

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## **Part Two**

### **An Exploration of Self-as-Context in Individuals with a Diagnosis of Functional Neurological Disorders**

This paper is written in the format ready for submission to the Journal Psychology and  
Psychotherapy: Theory, Research and Practice.

Please see Appendix A for the Guideline for Authors.

Word Count (excluding abstract, tables, figures and references): 7,599/8,000



## **Abstract**

### *Objectives*

Self-as-context from Acceptance and Commitment Therapy (ACT) refers to the ability to observe thoughts, feelings and actions of different parts that make up self-identity. Self-as-context has not been explored in individuals with Functional Neurological Disorder (FND). Individuals with FND experience the physical symptoms associated with neurological conditions in the absence of an observable or measurable neurological basis characterising a given condition. Self-as-context may play a crucial role in the ability to manage a diagnosis of FND. By better understanding this link, it may help therapists to draw on an essential component to psychotherapeutic work within this client group. Therefore, the study aimed to understand experiences of FND through the lens of ‘self-as-context’ defined by the ACT model of therapy.

### *Methods*

A semi-structured interview was undertaken by ten participants exploring their FND journey and sense of self. Each interview was transcribed, anonymised and analysed in accordance with an Interpretative Phenomenological Analysis (IPA) approach.

### *Results*

From the transcripts, three themes were generated ‘*the loss of self in FND*’, ‘*acceptance of FND*’ and ‘*the positioning of self in the FND journey*’.

### *Discussion*

Many individuals with FND described feeling their sense of self (self-as-content) was lost after experiencing FND symptoms. Acceptance and how individuals with FND position themselves in relation to other people appears to play an important role in their ability to take a more reflective stance through self-as-context. Supporting individuals' identity through the use of ACT may be beneficial in the FND population.

### **Keywords**

Functional Neurological Disorder, Acceptance and Commitment Therapy, self-as-context, interpretative phenomenological analysis, qualitative, self-identity.

### **Practitioner Points**

1. Work around self-identity may be beneficial when working with individuals with FND as participants described a sense of losing or hiding parts of themselves after experiencing FND symptoms and receiving a diagnosis of FND.
2. Individuals with FND may struggle with an incongruence between their self-identity narrative (self-as-content) and changes in their ability to engage in activities. Acceptance and adaptation play an important role in managing the difference and supporting a more reflective sense of self (self-as-context).
3. Practitioners can play a role in supporting and advocating with individuals with FND to reduce unhelpful narratives around FND.
4. Acceptance and Commitment Therapy may be a beneficial approach within this community.

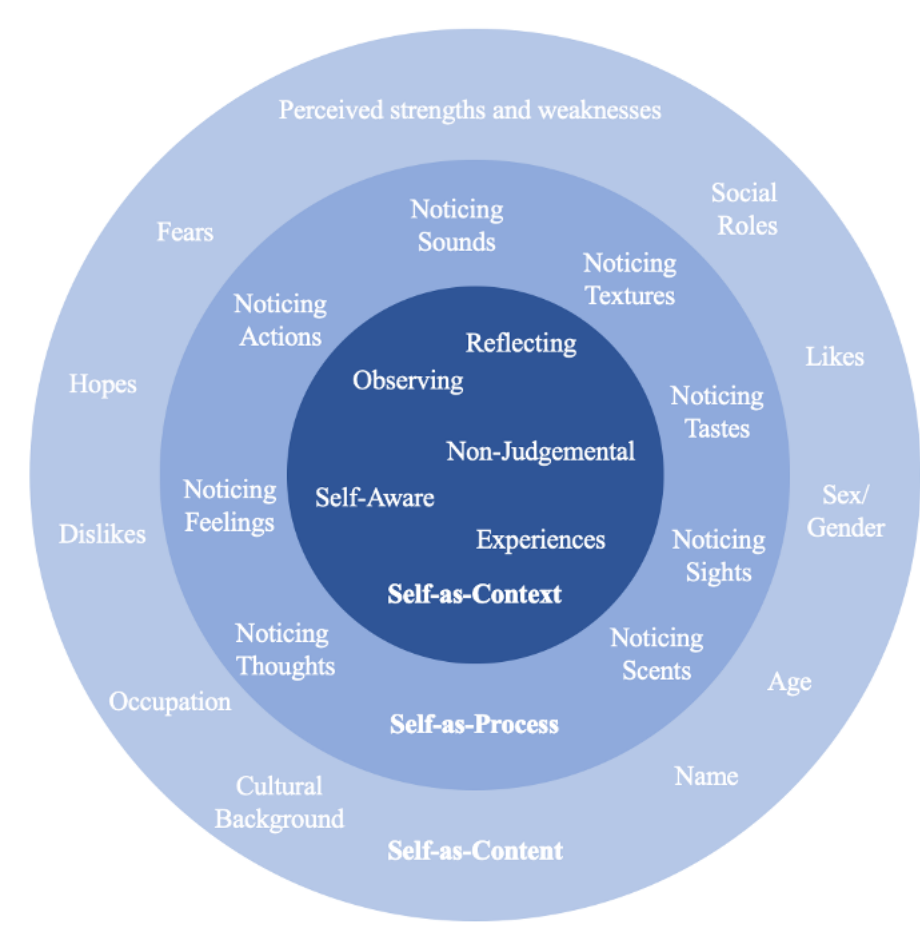
## **Introduction**

Acceptance and Commitment Therapy (ACT) is a cognitive behavioural therapeutic approach (Hayes, 2004). It aims to help individuals accept that experiencing pain is a part of being human and a rich and meaningful life can still be created through acting towards and working with their values (Harris, 2006). It does this through increasing psychological flexibility which is thought to be made up of six elements: present moment connection, values, committed action, self-as-context, cognitive defusion and acceptance (Juncos et al., 2017). Self-as-context is an element of psychological flexibility that has been traditionally under-researched within the ACT literature.

Self-identity within ACT is divided into three elements: self-as-content, self-as-process and self-as-context (Zettle, 2016). Self-as-content is an individual's personal narrative made up of objective and subjective descriptors (Webster, 2011). Self-as-process is formed of ongoing verbal statements of behaviour occurring in the moment (McHugh et al., 2019). This is the part of self that is consciously noticing thoughts, feelings, actions and observations (Harris, 2019). Self-as-context is the part of the self that is able to observe the thoughts, emotions, and behaviours of self-as-content and self-as-process (Zettle, 2016). In essence, it is the part of you that does not change or judge but simply experiences (Moran et al., 2018). Greater psychological flexibility is associated with self-as-context, whereas psychological inflexibility is associated with self-as-content (Rolffs et al., 2018; see Figure 1).

**Figure 1**

*An ACT Model of Self*



ACT has a growing research base and is transdiagnostic, with research suggesting that it is helpful for individuals with mental and physical health challenges including neurological conditions (Wetherell et al., 2011; Orsillio & Batten, 2005; Dewhurst et al., 2015; Parsa & Mohammadifar, 2018). Whilst research suggests self-identity can be impacted when individuals are diagnosed with a neurological condition (Roger et al., 2014), there has been no published research and no theoretical framework to explore how the self is impacted within individuals

with Functional Neurological Disorder (FND). It is unknown whether self-as-context may play a role in the ability to support individuals with FND who experience challenges with the condition.

FND is a broad term for individuals experiencing neurological symptoms in absence of observable or measurable neurological basis for a given condition (Espay et al., 2018).

Approximately 8,000 individuals in the UK are diagnosed with FND annually, with between 50,000 and 100,000 cases in the community (Bennett et al., 2021). Despite this, research and understanding of FND is still in its infancy.

Current National Institute of Clinical Excellence ([NICE], 2021) guidelines recommend care from non-neurology services for individuals with FND including those who experience mental health challenges following diagnosis. This is despite the fact that nearly half of individuals diagnosed with FND experience anxiety and depressive symptoms (Macchi et al., 2021; Walther et al., 2020; Feinstein et al., 2001), and FND accounts for around 16% of neurology referrals (Stone et al., 2010). This in turn adds to the growing pressure on non-neurology services to support additional individuals. It is also estimated that costs associated with medically unexplained symptoms (for which FND was included in this category) costs the NHS as much as £3.1 billion annually (Public Health England, 2016).

Whilst for some an FND diagnosis is experienced alongside co-morbid mental health problems either as a causal factor or as a result of living with the condition, there has been little research into specific therapeutic approaches for individuals with FND. A systematic review explored psychotherapy for adults with FND (Gutkin et al., 2021). Gutkin and colleagues found

cognitive behavioural therapy (CBT) and psychodynamic therapy were generally able to offer some improvements in physical symptoms and functioning as well as improvements to mental health and wellbeing in individuals with FND. To date there have been a small number of studies that have explored the suitability of ACT for individuals with FND. This limited research shows that ACT has been helpful in improving psychological flexibility, symptom inference, mood and quality of life for individuals with FND (Graham et al., 2017; Graham et al., 2018; Barrett-Naylor et al., 2018), but they lack the rich detail that explores each participant's psychological flexibility and particularly their self-as-context, that a qualitative study could capture. By applying the ACT model for self: self-as context, a greater understanding of the impact FND has on self can be explored which may help to better inform interventions to support individuals with FND. Self-as-context may play a crucial role in the ability to manage the psychological challenges associated in some individuals with FND. By better understanding this link, it may help therapists to draw upon a psychological approach essential to psychotherapeutic work within this client group.

This research sought to understand the sense making of experiences of FND through the lens of 'self-as-context' as defined by the ACT model of therapy. Using a qualitative methodology, the aim was to explore participants experiences of FND through the lens of the psychological flexibility model, with a specific focus on the impact their experiences have had on their self-as-context. The research sought to answer the question: how can participant experiences be understood in terms of self-as-context?

## Method

### Ethical Considerations

The study was granted ethical approval by the University's ethics committee. Participation was voluntary with the ability to withdraw from the study at any point until two weeks following the interview. Consent was formally recorded and verbally confirmed prior to the interview (see Appendix F).

### Participants

Inclusion criteria and exclusion criteria for participation can be seen in Table 1.

**Table 1**

*Inclusion and Exclusion Criteria with Rationale*

<b>Criteria</b>	<b>Rationale</b>
<u>Inclusion</u>	
Diagnosis of FND	The research is interested in experiences of FND.
Individuals who are 18 years old and above	The sense of self develops through childhood and adolescence (Branje et al., 2021) therefore by focusing on working-age adults, identity is more formed.

Able to speak English to a sufficient level      The researcher is monolingual. Important nuances could have been missed if translation services were utilised. Additionally, the research budget could not accommodate a translator.

Exclusion

Previous or current attendance of therapies where psychological flexibility and self were a feature      Individuals who are attending or have attended therapies such as ACT will have explored concepts such as psychological flexibility and self; therefore it may not be representative of self of FND as therapy may have changed it. It may be a confounding factor.

Currently attending therapy      Individuals who are currently attending therapy will be excluded as their psychological flexibility and perceptions of their experiences will likely be in the process of change which may make it harder for them to be able to express their sense-making.

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Interest in taking part in the interview was expressed by 13 individuals. Of these, 12 were eligible and willing to take part. However, two individuals failed to respond to communications seeking a time to set up an interview. Thus, ten respondents were interviewed. This is in line with the recommendations for Interpretative Phenomenological Analysis (IPA) studies (Smith et al., 2022). An individual expressed an interest to take part after the end of recruitment window and therefore they were unable to take part.



Demographic information and FND symptom participants experienced are located in Table 2 and 3. Although not explicitly asked, all participants disclosed additional physical and mental health conditions they were currently, or had previously, experienced.

The mean age of the participants was 44.8 years old ( $SD=12.37$ ; range: 24 to 64). Out of the ten participants, nine reported that they had attended therapy or counselling in the past and six of these explicitly stated that it was related to FND. Additionally, three reported being on a wait list for therapeutic support following their FND diagnosis. A participant described being actively discouraged from therapy due to the long waitlist following their FND diagnosis and did not receive a therapeutic intervention.

**Table 2***Summary of Participant Characteristics*

<b>Participants</b>	<b>Gender</b>	<b>FND Symptoms</b>
Toni	Trans Fem	Functional Limb weakness Functional (Dissociative) Seizures Functional Movement Disorders (Dystonia/ Spasms, Jerks and Twitches) Functional Cognitive Symptoms (Memory) Functional Speech Swallowing Symptoms Functional Tics
Helen	Cis-Female	Functional (Dissociative) Seizures Functional Sensory Symptoms Functional Movement Disorders (Gait) Functional Speech Swallowing Symptoms
Edna	Cis-Female	Functional Movement Disorders (Dystonia/ Spasms, Gait) Functional Facial Symptoms

Miranda	Cis-Female	<p>Functional Limb weakness</p> <p>Functional (Dissociative) Seizures</p> <p>Functional Sensory Symptoms</p> <p>Functional Movement Disorders (Gait)</p> <p>Functional Cognitive Symptoms (Thinking, Memory)</p> <p>Functional Speech Swallowing Symptoms</p> <p>Functional Facial Symptoms</p> <p>Bladder Symptoms and FND</p> <p>Visual Symptoms</p>
Violet	Cis-Female	<p>Functional (Dissociative) Seizures</p>
Carrie	Cis-Female	<p>Functional Limb weakness</p> <p>Functional Sensory Symptoms</p> <p>Functional Cognitive Symptoms (Thinking)</p> <p>Functional Facial Symptoms</p>
Jack	Cis-Male	<p>Functional Limb weakness</p> <p>Functional (Dissociative) Seizures</p>

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Evelyn	Cis-Female	Functional Limb weakness Functional Sensory Symptoms Functional Movement Disorders (Dystonia/ Spasms) Functional Cognitive Symptoms (Thinking) Functional Speech Swallowing Symptoms Functional Facial Symptoms Visual Symptoms Functional Tics
Robert	Cis-Male	Functional Sensory Symptoms Functional Movement Disorders (Tremor, Dystonia/Spasms, Gait) Functional Facial Symptoms
Henrietta	Cis-Female	Functional Limb weakness Functional Movement Disorders (Jerks and Twitches) Functional Cognitive Symptoms (Thinking) Functional Dizziness

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## Functional Facial Symptoms

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*Note:* The symptoms participants described were categorised based on the FND Guide symptoms categories (Neurosymptoms.org, 2024).

**Table 3***Summary of Participant Demographics*

<b>Characteristics</b>	<b>Number of Participants</b>
<u>Location</u>	
England	5
Devon	(1)
Leicestershire	(1)
Yorkshire	(3)
Northern Ireland	3
Antrim	(1)
County Down	(1)
County Londonderry	(1)
Canada	2
British Columbia	(2)
<u>Ethnicity (as described by participants)</u>	
White British	4
White European	1
White	2
White Irish	1
White Canadian	1
British	1
<u>Additional Physical and Mental Health Experiences</u>	
Addison's Disease	1
Anxiety	1

Asthma	1
Attention Deficit hyperactivity disorder (ADHD)	1
Autism Spectrum Condition (ASC)	2
Avoidance coping person style personality disorder	1
Cancer	1
Chronic Adjustment Reaction	1
Chronic Pain	2
Depression	4
Dissociative identity disorder (DID)	1
Dysautonomia	1
Fibromyalgia	1
Headaches	3
Health Anxiety	1
Hypothyroidism	1
Long-covid	1
Lower back pain	1
Migraines	5
Muscle Ache	1
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	3
Panic Attacks	1
Pain	1
Painful joints	1
Passing out	1
Post-concussion Syndrome	1
Post-natal Depression	1

Post-traumatic stress disorder (PTSD)	2
Postural tachycardia syndrome (PoTS)	2
Social Anxiety	1
Trauma/Traumatic Experience	5
Trigeminal Neuralgia	1
Vertigo	1

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### Procedure

An advertisement was added to social media sites and sent to FND organisations to advertise the study and asked potential participants to contact the researcher to register an interest (see Appendix G). Interested individuals were emailed a participant information document (see Appendix H) and given at least 48 hours to read and decide whether to participate. Any questions participants expressed were then answered.

Participants took part in one semi-structured interview. At the start of the interview, the researcher described the study allowing time for questions. The right to withdraw was explained and consent was recorded. Demographic details were gathered before the interview commenced. Interview questions were developed by the researcher and supervisors in consultation with an FND charity. The questions (see Appendix I) acted as a guide for discussion. These included participants' understanding of FND, their diagnostic journey and their sense of self. The mean average interview was 67.24 minutes (SD= 17.81), ranging from 42.04 to 111.48 minutes.

On completion of the interview, the participants were verbally debriefed and given sources of support to contact should they need them in the future (see Appendix J). An opportunity to ask questions was given.



An interview took place in person in a private room. The audio was recorded using *Audacity*. The remaining nine interviews were undertaken remotely using *Microsoft Teams* with recordings taken and stored on a secure university server. Each recording was transcribed and anonymised. The recordings were then deleted. The transcripts were then analysed using an IPA approach.

### Data Analysis

The transcripts were analysed in accordance with the seven steps of IPA (Smith et al., 2022). Through reading and re-reading transcripts, the researcher immersed themselves in the original data. Secondly, exploratory noting was undertaken (see Appendix K for an example of data analysis). Then experiential statements were constructed. Connections were then made across the experiential statements. Experiential statements were then clustered to create personal experiential themes (PETs). This was repeated for each transcript then group experiential themes (GETs) were developed from each participants PETs. Please see Appendix L for examples of the development of PETs and the GET.

### Researcher Position

The first author identifies as a white-British cis-woman. Employed within the NHS as a trainee Clinical Psychologist, the researcher's ideas will have influenced the interpretation of the data. The use of supervision and reflective journaling helped the researcher to maintain an awareness of their assumptions.

Traditional positions place the researcher as an 'insider' or an 'outsider' (Breen, 2007). This would place the researcher as an outsider as they do not have personal experiences of FND. However, there is a move to see researcher positioning as shifting and changeable or on a

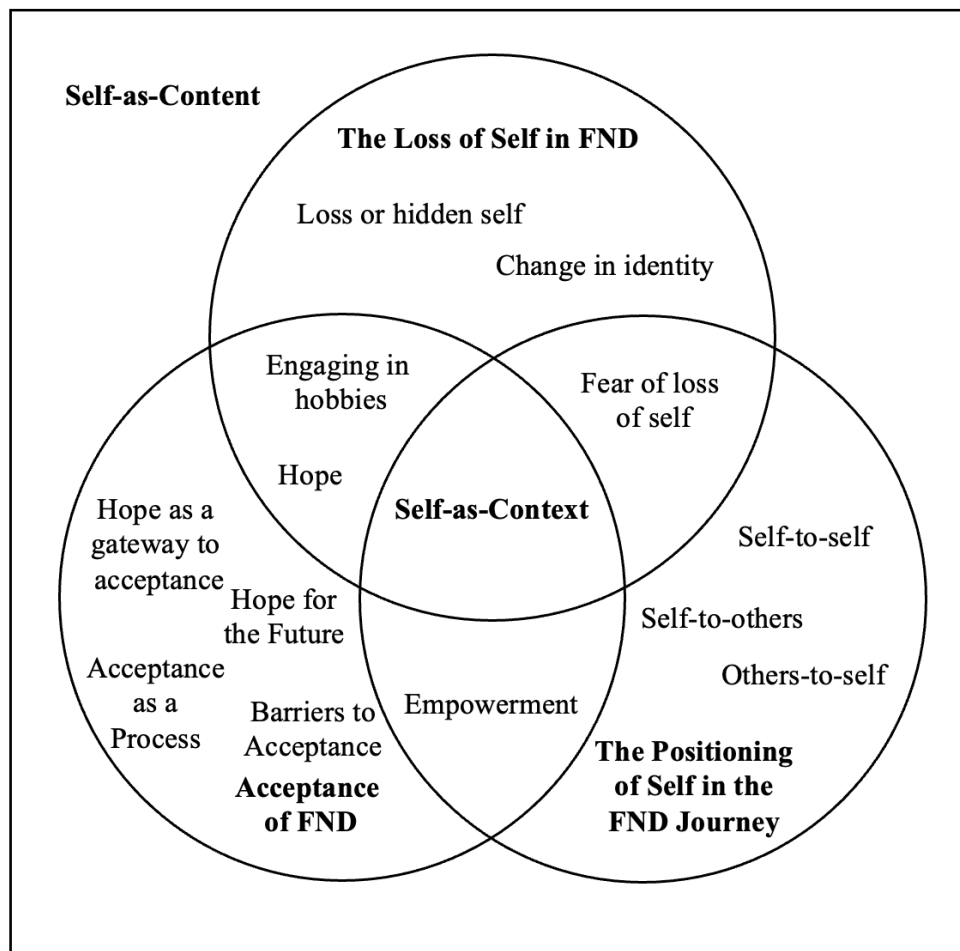
continuum (Breen, 2007). In this way the researcher moves in and out of the outsider position as experiences and understanding of FND is explored within the interviews.

## Results

The researcher generated three GETs themes based upon the interpretation of the sense-making of the participants' experiences: the loss of self in FND, acceptance of FND, and the positioning of self in the FND journey (see Figure 2). All participants stated they have experienced changes and have contemplated the meaning of their sense of self within their FND journey.

**Figure 2**

*Study Themes and Connections Between Themes*



## **The Loss of Self in FND**

The first theme encompasses the sense of loss that participants felt following the development of FND symptoms and is divided into two subthemes: lost or hidden self, and change in identity.

### Lost or Hidden Self

Participants discussed feeling lost or hidden within their FND journey reflecting an unease with the impact FND may be having on their identity. Carrie spoke about meeting a friend who told her

*“I hope you get your sparkle back soon.”*

She went on to explain

*“She [the aforementioned friend] didn’t have a clue who I was...it just gives you an idea of just how much is gone”.*

Carrie appears scared about the ‘lost’ tangible and intangible aspects of her self-identity following her FND symptoms. There is a worry that her “*sparkle*” - the element that makes her feel like herself and unique - will be lost forever. There was a sense of resistance to developing a new self-identity or moving forward from previous aspects of identity. This at times appeared associated with the fear that the new identity will not be good enough or be authentically her as defined by her previous self.

Evelyn reflected that there were times where she recognised “*I’m losing a bit of myself*” within the FND journey. Miranda stated,

*“It’s almost like just reinforcing to make sure I don’t lose the bits of who I am”.*

This highlights the difficulties of feeling lost and a fear of becoming unrecognisable in terms of the self-identity they had developed before FND.

Carrie explained that the fact that because her FND symptoms were not always visible, she felt parts of her had to be hidden.

*“I put a brave face on it about, you know, how I’m feeling”.*

She highlighted the difficulty of feeling able to be yourself and feel they need to hide part of their FND experience with others. This appears to be a protective mechanism she has developed. Violet highlights how keeping parts of the self hidden influenced how she feels able to express her self-identity within relationships

*“Even with my friends, like, I’m not being my true self”.*

Carrie and Violet’s need to hide parts of the self may reflect how they view themselves. Previously seen as caring for others, they struggled to put their own needs first. They may have become worried to be seen as someone who has times where they struggle with managing FND when they view themselves as someone who is capable and resilient.

### Change in Identity

Many participants reflected that they felt different from their sense of self before FND and struggle with the comparison between how they viewed themselves before FND and how they currently view themselves. It reflects a sense of feeling caught between who they were before FND and who they feel themselves to be with FND symptoms.

Jack described feeling unhappy with the change in his identity.

*“[FND] probably made me a stronger person you know. But I’d like my old self back...if I could get my old self back tomorrow, [I] would take it.”*

Similarly, Henrietta described struggling with how she viewed herself before FND

*“Fun, outgoing, like always up for anything”,*

and how she feels she is now

*“I find it very hard to commit because I don’t know how I’ll be, and I find that really hard.”*

Participants described here, a sense of conflict between their self-identity before FND and the difficulty of integrating new parts of their identity into the view of themselves, which may reflect difficulties accepting the diagnosis, resulting in feeling stuck. This conflict may also reflect the constant change and development of aspects of identity throughout life, some of which are welcomed more than others. Henrietta's view of self appears to be through a lens of seeing positives and may reflect an unrealistic or idealistic view of their identity which she now feels unable to live up to. Feeling stuck may reflect the struggles of living with a long-term health condition with an unknown prognosis and learning how to accommodate and adapt to the condition whilst trying to integrate her identity into the management of the condition. Identity may have been less of a priority behind managing the condition.

Toni and Violet reflected a sense of sadness at being unable to recall their sense of self before FND. Toni stated,

*"I really could not tell you what, how we thought of ourselves in childhood for example, or really prior to [FND]."*

Violet said,

*"I can't think of a sense of self before the symptoms it's almost like symptoms defined by sense of like my prior sense of self...That's quite scary."*

The feelings of sadness and fear reflected a change in identity of who they might have been without the condition and how FND has impacted their development of their sense of self. At times this knowledge can feel overwhelming and distressing.

Participants whose sense of loss felt greater appeared to be more fused to their self-identity and struggling with the impact FND brought in changing identity. Conversely, Robert reflected that the change in his sense of self from FND has been positive and was able to reflect on his experience through his self-as-context.

*“...understanding of FND and being able to being able to sort of integrate a little better is that, you know, it’s rather than just observe the, you know, those good things, is really try and experience them.”*

By being more present and participating in life in a way that he had not before, Robert was able to feel more integrated between his mind and body in a new way. He did not describe a sense of loss or a negative change in his identity but instead looked at the changes as a positive or a gain in his identity and outlook on life.

Evelyn described a sense of determination that she was not going to lose her identity in FND.

*“I think it was myself, my sense of self that got me through it, to be honest. If you if you come to this, if you happen upon this condition and you don't have a strong sense of self then I think you're scuppered.”*

This sense of determination was an important value that perhaps provided her with a sense of control and stability when symptoms can be unpredictable and alarming to counteract a sense of loss that FND may bring to her.

## **Acceptance of FND**

The second theme encapsulates experiences of acceptance in the diagnosis and management of FND. It is divided into four subthemes “hope as a gateway to acceptance”, “acceptance as a process”, “barriers to acceptance”, and “hope for the future”.

### Hope as a Gateway to Acceptance

Despite the sense of loss, many participants described a sense of hope. Carrie desired change in how she views FND.

*“I still hope that at some point I’ll something will change, and you know either some something will change inside my brain that makes it not a problem anymore or something”.*

This reflects an unease in how the changes brought about by FND have influenced self-identity. A sense of hope may reflect the first step to acceptance by starting to process and come to terms with having FND and learning to live with it. The theme charts a move away from viewing the self as struggling to one that is learning to adjust and understand FND.

Many participants shared hope in symptom change despite having symptoms for multiple years and following interventions that have not helped. Edna said *“I still have hope”* and stated *“is there room for hope? Yes”*. There is a hope for interventions that reduce symptoms that have remained throughout her experience. Hope appears to play an important role in maintaining Edna’s mental health despite experiencing multiple disappointments with interventions that have not maintained reductions in her FND symptoms.

### Acceptance as a Process

Participants described feeling in different stages of acceptance of their diagnosis, symptoms and the impact this had. Henrietta described feeling

*“I’m probably about a 90 to 95% acceptance now, whereas at the beginning it was probably the other way around”.*

It seems challenging for participants to immediately accept a diagnosis of FND, and instead is an ongoing process of reflection. Acceptance does not appear static but instead dynamic and changing often. This mirrors the changing impact of FND on daily functioning as Helen described

*“I have to sit back and go, OK, but today might not be a good day, but tomorrow might be”.*

There were multiple ways in which the process of acceptance of the FND diagnosis and impact happened for participants. Edna described this as process of acceptance as learning



*“You have to learn to cope with your life”.*

Similarly, Evelyn described the acceptance process as

*“Realigning my expectations in line with what I’m capable of, essentially. And that’s a big adjustment”.*

Acceptance of learning to change and manage the symptoms is a process that helps people feel able to continue to be themselves within the context of FND. Whilst this is similar to the first GET, it differs in it describes how participants feel able to manage the change in addition to noticing the difference in identity. It maps how they are starting to feel comfortable and accepting of the changes FND brings rather than struggling with the challenges.

Engaging with hobbies as part of their self-identity, has also been important as part of the acceptance process. Toni described engaging in *“trying to learn new things”* and Helen spent time engaging in *“crafting”* activities, and Robert *“started taking pictures again”*. This present moment connection appears helpful in aiding acceptance, and it underpins the notion that you can continue to engage in activities that they enjoy whilst also experiencing FND symptoms.

Violet spoke of the desire for understanding as part of their acceptance process.

*“My friends, even at uni were beautiful. Like they got it...They were very non-judgemental. They did what they needed to do to support me. And that was great.”*

This was important for coming to accept FND and recognising that relationships could continue. Understanding and feeling that she was not judged for her symptoms appeared to be important in Violet becoming comfortable and accepting of exhibiting symptoms in public. She recognised that her life could continue and she felt able to participate in her friendship group rather than having to isolate herself from others for fear of judgement.

### Barriers to Acceptance

Participants described other barriers to feeling able to accept their FND diagnosis. Many participants including Henrietta described feeling that their diagnosis was due to excluding other conditions, rather than positive signs.

*“Your MRI is fine, so here’s what’s the matter you’ve got FND. I was a bit like, OK, this is, this is what they’ve told me I’ve got. Let’s ride with it and see how we go. And then my mind started going round and I was like, what if you’ve got it wrong? You know, what if they’re missing something? I’d convinced myself I’ve got a brain tumour.”*

The ability to accept the diagnosis may therefore reflect how the diagnosis of FND is presented to the individual and how confident the clinician appears to be in the diagnosis. A diagnosis of exclusion then can understandably lead to a fear that FND was wrongly diagnosed. Jack was also “*afraid*” of being misdiagnosed. Feeling assured in the diagnosis appears to play an important role in starting to accept the FND diagnosis.

This fear was compounded by a lack of support following diagnosis. Violet said

*“I had this label of NEAD [non-epileptic attack disorder] and I like no idea what it meant for my life”.*

Henrietta said

*“It’s a lonely place to be in the FND world, no care pathway. So you’re just left”.*

Toni described the process as “*rude*” and that there is

*“Very little official help available and unofficial help which is quite frustrating.”*

Feeling isolated and alone through not having clear support appears to hinder the acceptance process as participants described feeling scared and confused on how to manage the condition and what the future might hold. The uncertainty regarding treatment and the impact FND might have on their life appears to influence how able participants process the diagnosis and highlights the need for support to manage symptoms and clear understanding of what FND is to accept the diagnosis.

Helen described struggling with the changes FND had brought.

*“I had thoughts of committing suicide, and because I wasn’t I wasn’t any value to anybody.*

*Nobody needed me anymore.”.*

The ability to care and support other people appears to be important for Helen’s sense of self and she appeared to struggle with the change in how people viewed her ability to give care. This appeared core to the distress many participants felt after experiencing FND symptoms. The distress experienced may reflect the discomfort in feeling their role of caring for others has transitioned into being cared for. The caring role they previously undertook perhaps came at the expense of prioritising their own needs and reflecting a sense of self that may have been unhelpful at times. The acknowledgement of this could also have contributed to low mood when reflecting on life before and after FND symptoms.

Jack similarly experiences thoughts of *“committing suicide”* as the *“seizures were getting me down for oh, ages”* due to the worry of experiencing a seizure in public and not being accepted and understood leading him to isolate himself. This likely in turn influenced his low mood.

Similarly, Miranda described feeling *“heavy”* and struggling with her mental health due to feeling she had to

*“Go through the rails here to see what actually works for me”*

regarding interventions for FND. It highlights the difficulty the impact that not having a clear intervention pathway can have on the ability to accept the diagnosis and management of their symptoms. Coming to terms with the changes that FND brings is difficult and hard to process and accept. It is not a static process and appears to change overtime.

### Hope for the Future

Whilst participants learnt to be accepting in the present moment, participants described looking towards the future. Hope appears to be a motivator for participants in the desire for changes

in the future. The final subtheme reflects coming to terms with their FND experience and the hope that this brings.

Many participants described a hope for systemic change to improve their experiences of FND and FND for other people. Helen said, *“hopefully in ten years’ time, the experience of that we’re all having at the moment will be a better experience”*. The use of “we” is important, suggesting that Helen feels part of a community and not alone. This may have played an important role in her motivation to participate in the interview to help others and herself. This may also reflect how she has adapted her caring role to help other people in a new way.

Similar sentiments were shared by Toni.

*“Hopefully it’s changed in the two years since then [last interaction with healthcare for FND]”*.

Henrietta said

*“Hopefully it’ll come. But these things take forever”*.

The hope for change is impeded by the expectation that change will be slow. This expectation is perhaps influenced by feeling that FND is not prioritised or seen as a legitimate condition within research and healthcare settings unlike other health and neurological conditions in part because of the lack of clarity about where care should fit: neurology or mental health?

### **The Positioning of Self in the FND Journey**

The final theme reflects participants’ relationships with themselves and other people through their FND experience and is divided into three subthemes “self-to-others”, “others-to-self” and “self-to-self”. This theme is connected to the first GET through fear of losing self within the FND experience.

## Self-to-others

Many participants described struggling with the impact their FND had on their loved ones and how their identity is fused with the roles they play. Helen described struggling with the change in relationship with her children following her functional seizures.

*“They don’t want to be around me. And that out of everything really hurt... When I spoke to my eldest son about it, he said, mum I don’t want to see you suffering and I just want my mum back”.*

This is likely to have reflected the complex interaction between Helen’s conceptualisation of FND and recovery and how that influences her son, her son’s own process in awareness and acceptance of FND and the health system and perceived prejudice and stigma of some clinician’s.

Similarly, Carrie described struggling with the impact on her children as

*“hard to manage... that feels so horrible because life is a lot more fun before it happened”.*

The perceived impact of their FND on other people appears to at times negatively impact how they manage FND and view themselves, positioning themselves as different from before FND symptoms and from their loved ones. There is a sense of guilt and shame that their condition has changed homelife. Many participants also described feeling worried about how others may perceive them following FND symptoms. Henrietta said

*“I’ve had to cancel the same person several times. So then I think will they think I’m boring? Will they think I’m not trying? Will I be judged?”.*

Edna described feeling judged and viewed by professionals as

*“Crazy and have FND because of my unhelpful thoughts”.*

These fears of judgements made them see themselves as different and apart from others. For Toni and Edna, this was something they felt predated their FND experience. Toni described feeling they

*“Had trouble with the way people perceived us in the first place because of autism”.*

This was echoed by Edna

*“Being neurodiverse tires you out, you know, like masking your autism day in day out...if I'm in a group of people, I'm always trying to see whether there what I'm talking about is actually interesting”.*

This perception of difference and trying to monitor to see how people perceive them is not unique to their FND experience but is heightened with the interaction of other parts of the self.

### Others-to-self

Many participants described the difficulties they have experienced with how other people have interacted with them and how they position themselves because of those interactions.

Participants described a strong sense of invalidation caused by their FND experience. This centred around a lack of understanding of FND and a sense of powerlessness within healthcare relationships. Miranda said

*“They don't wanna be informed. They know best. They know everything. It's all in my head. That's all they ever say. Nothing wrong with you.”*

There is a sense that not being heard and valued, and being positioned as not knowing the truth influences relationships with other people. Edna described this in the danger of feeling as though she is not positioned as an expert of her own experience.

*“I know it was not their intention to blame me for being sick. But that's what was always implied that it's up to you to get better.... I ended up blaming myself for being sick...what did I do wrong?”.*

Interestingly Robert compared other people's experience of FND diagnosis to his own and reflected that

*“I felt my sort of symptoms were were certainly taken seriously”.*

He wondered whether this may be due to his gender.

*“Most of the people I’m interacting with are women, you know, their experience through the medical profession is is much more antagonistic. It seems like you know, people feel like they’re being gas lit”.*

There is a sense of feeling fortunate for being taken seriously, and guilt in the acknowledgement that being a cis-man within healthcare settings means that his symptoms are investigated and not dismissed. This is heightened through the acknowledgement that “most of the people” with FND are cis-female. It may also reflect a sense of isolation and difference from people without FND and further feelings of difference within the FND community.

Despite this, many participants felt connected, validated, and understood by others within their FND journey. Violet described this when she required medical attention

*“The paramedics were beautiful... They were so chatty and they were just creating a rapport as they have to and they didn’t judge me”.*

Building validating and understanding relationships appeared important for the self. Evelyn described how she found support groups for FND

*“I find it useful going to those things to kind of get and understanding of the condition, know that I’m not alone on it.”*

Jack described the impact of when the self feels connected through relationships with others with FND.

*“We may not all have the same symptoms, but something links us, you know, we’re we’re all able to understand what the other one’s thinking... It’s just nicest feeling part of a group, you know, a club.”*

Being able to identify and connect with other people with similar experiences of FND seems particularly important in how individuals are able to feel valued and validated by other people and in turn how they are able to relate to and make sense of their FND experiences compared to other people with the condition.

## Self-to-self

Participants have also described the impact of FND on their relationship with themselves. Whilst the first theme touched upon the sense of loss and changes to identity from before FND symptoms and after, this subtheme refers to the internalisation of their relationship with themselves in the present moment typically following an element of acceptance within their condition.

Many participants spoke about a sense of shame they hold. When discussing her seizures, Violet said

*“I have to say to people, oh yeah, it’s usually triggered by stress. And then that, again, that just creates shame, I think and just saying, in thinking my body can’t cope”.*

Violet reflected her self-as-context in the interview

*“I don’t actually think I’ve ever thought about myself feeling shameful, so it’s interesting that, that that just came up”.*

Henrietta expressed shame in the way she views her ability to handle stress

*“Why when I get stressed, do I get these symptoms? But then my friends gets stressed and they don’t.”*

The ability to handle stress differently has created a sense of shame for many participants. Many expressed feeling that they should be able to handle stress without exacerbating FND symptoms. This makes the relationship with themselves conflicted with a sense of trying to be good enough, or a “*high performer*” as in Evelyn’s case, and “*perfectionist*” in Toni’s case. This may reflect a lack of societal understanding of FND or stigma around what is perceived regarding mental health, particularly as other stress responses such as headaches or blushing when embarrassed that some people get are not questioned.



Despite these feelings, many participants described feeling empowered to share their experience. Evelyn described this through asserting her own needs for her FND journey.

*“I can recognise if I'm losing a bit of myself and then be an act active and proactive and maintaining relationships, maintaining hobbies and things that are important to me”.*

This reflects a move away from feeling lost or powerless to feeling able to take control of their experience after coming to a place of acceptance.

There was also a sense of strength through the sharing of FND experiences. Edna stated,

*“I've been experiencing these symptoms day in day out and I I have you know arrived at some conclusions what is going on...you just can't ignore completely what we say.”*

The use of “we” from Edna reflects a sense of being united as an FND community who have historically felt overlooked but are now finding power in sharing their stories.

Violet shared a sense of empowerment through feeling more accepting of her diagnosis and experiences. The impact of FND changed from experiencing difficulties to feeling empowered to have a role relating to FND.

*“My sense of self has changed a lot, but FND has defined that on a journey almost from a negative way, if you want to look at it that way, to one that I feel now is more positive and has provided me a career. So like, it's a part of me now that I adore and I'm grateful for because I don't know if I'd be here without it”.*

## **Discussion**

How individuals diagnosed with FND make sense of their experience through a self-as-content lens was explored through ten interviews. Though initially experiencing a sense of loss in their identity, participants' journeys often involved learning to accept the diagnosis and manage the impact of FND. By taking a more reflective stance, individuals are less fused to their self-as-content (self-identity) and are able to take a flexible approach to their identity (self-as-context). The following GETs were generated: the loss of self in FND, acceptance of FND, and the positioning of self in the FND journey.

The loss of self was a prominent theme for many participants. This is consistent with research looking at identity changes following a diagnosis of neurological conditions (Roger et al., 2014). The loss of self may reflect participants feeling fused to their self as content which in turn may alter their psychological flexibility to manage the impact of FND (Rolffs et al., 2018). For example, when descriptors from before FND symptoms dominate such as "I am a runner" it can become unhelpful when circumstances or situations (such as FND symptoms) means that there is an incongruence between self-as-content and what the individual may be able to do. Sitting with the incongruence can be difficult and negatively impact mental health (Moran et al., 2018).

A means by which participants appear to defuse from their fixed concepts of self appears to be through the acceptance of the diagnosis and the impact of FND symptoms. This perhaps reflects a move away from self-as-content to self-as-process, of being able to notice thoughts and emotions. This in turn may then involve moving towards self-as-context, being able to reflect and observe their experience. This transition to acceptance is supported by previous literature exploring responses to changes following a life event. Williams' (1999) transitional cycle described different phases individuals go through prior to acceptance of an event which describes an initial sense of loss before gradually coming to a place of acceptance and transformation. In this way participants

may start to reflect on what made an activity enjoyable (for example enjoying running because they spent time outdoors) and adapting this to meet their current ability (such as yoga outside), transitioning from a sense of loss to a newfound acceptance. This flexibility in self-identity and acceptance has previously been linked to self-as-context and greater psychological flexibility (Rolffs et al., 2018). Improvements in self-as-context has also been associated with improvements in functioning in chronic pain (Yu et al., 2017a). There is also an association between self-as-context and functioning in fibromyalgia (Yu et al., 2017b). This may suggest that self-as-context may also play a role in the functional improvement of FND, as it has previously been beneficial for other long-term health conditions.

Participants described many barriers to acceptance and self-as-context through the way they positioned their self. Self-as-content was seen in relation to how other people appeared to position the participants and how participants positioned themselves. Feeling unable to take a more reflective stance required for self-as-context, may also indicate that the management of FND makes it difficult to be in a reflective space. Developing a sense of empowerment could be seen within the FND context as the first step towards moving out of self-as-content into a self-as-context position as participants feel less distressed by their FND experience. Participants may start to notice, reflect, and become more self-aware and self-assured to seek the changes they want to see in FND care and support.

This is the first study, to the author's knowledge, that explores self-as-context in individuals with FND and shows that self-identity plays an important role in the ability to manage FND which should be included within psychotherapeutic work within this client population. It was a strength that the interviewees provided a richness of detail within which to explore interpretations of experiences of FND.

Another strength was that participants' characteristics were similar across the sample in keeping with the IPA approach. Participants often experiencing multiple FND symptoms and mental and physical health conditions. On average, FND is associated with 9.9 FND symptoms and other physical health symptoms such as fatigue, memory difficulties, and headaches per person (Butler et al., 2021). Whilst the sample could have been limited to those without additional health conditions or only one type of FND symptoms, it would have lacked real life application. These additional symptoms and conditions will likely influence their self-identity in different ways and influence how they view themselves in the context of their FND and other health experiences.

Critically, participants were included from multiple countries. This difference could have impacted upon the homogeneity of the sample, a requirement of the IPA approach (Alase, 2017), particularly as there are differences from European (UK, Ireland) and Canadian cultures (Barron, 2022). However, participants' interpretations of experiences of FND appeared homogenous. European (World Health Organisation, 2019) and American (American Psychiatric Association, 2022) diagnostic criteria are similar for FND, therefore diagnosis between participants will be homogenous despite potential cultural differences.

Additionally, a non-directive and naturalistic approach to self-identity could have meant that the included questions in the semi-structured approach did not amply allow participants to take a self-as-context approach, instead favouring answers around self-as-content. Further research exploring self-as-context with the FND community would be beneficial to aid understanding of self-as-context. This could be done through more probing follow-on questions. IPA research could consider the intersectionality between FND and other characteristics and demographics that make up identity and the impact that may have on how experiences of FND are interpreted. The participants from the current study drew upon the intersectionality between their gender and FND experiences suggesting that different elements of the demographics are important in their FND

journey. Exploring characteristics may be worth investigating in future research. Additionally, research exploring outcomes of therapy such as ACT with a focus on self-as-context could be beneficial to examining how self-identity might be used effectively within the FND population.

### **Clinical Practice**

It is important to recognise that as NICE (2021) suggest interventions in non-neurology services, individuals with FND will be seeking support in different services that Clinical Psychologists will be employed within. This might relate to the FND presentation, or FND may play a role (small or large) in their presentation with physical or mental health settings. Therefore, the implications for clinical practice are not limited to those within FND services, but for all Clinical Psychologists and staff in physical and mental health settings who interact with clients, patients and staff.

Participants described a process of feeling that their self-identity was lost or hidden at times in their FND journey. When participants engage in mental health services the importance of providing a safe, validating, and accepting place will be important. This is particularly important as many participants described feeling invalidated and misunderstood by others in relation to their FND experience. Building a safe therapeutic relationship where clients may feel more able to bring parts of their self may be particularly important in identity work.

Drawing upon the six elements of psychological flexibility, ACT could be used within the FND population to support the management of the health condition. Identifying values and ways to take committed action, alongside establishing skills to develop self-as-context would be particularly important to support the changes brought by FND. Moving away from fixed ideas of the self (self-as-content) towards a more reflective and non-judgemental stance (self-as-context) may be beneficial to explore, including how FND may or may not fit into their identity. Individuals with a

fixed self-as-context may struggle to interact with services particularly if they view themselves as “healthy” or “well”, therefore normalising difficulties with mental health particularly following diagnosis may be of value. Space to help the process of acceptance may also be beneficial alongside aiding participants to feel more empowered in their FND journey. This could be aided by the remaining elements of psychological flexibility: cognitive defusion and contact with the present moment. By developing greater psychological flexibility, individuals with FND may feel more equipped and empowered to manage the challenges that FND brings alongside other life events, which may change the need for contact with services in the future.

Participants described many barriers to acceptance and to ability to access their self-as-context. The main barrier was the lack of access to support following diagnosis. This is echoed in other FND research (McLoughlin et al., 2023; Varley et al., 2023). By creating greater access to support, individuals with FND may feel less alone and able to come to terms with the impact of FND on their lives.

Unhelpful and outdated narratives around symptoms being “all in your head”, “attention seeking”, or a “trauma response”, and stigma continue to be pervasive which mental health professionals and Clinical Psychologists can play a role to reduce these narratives (which may include wider training with multi-disciplinary teams including the use of positive diagnosis rather than a diagnosis of exclusion) and advocating with clients with FND. This is particularly important within neurology services as well as onward care, as NICE (2021) guidelines do not recommend interventions within neurology services. Care for FND falls between physical and mental health support with no discipline seeing themselves as responsible for care. All services need to be trained with an understanding of FND, or areas of specialism developed within every NHS trust to ensure unhelpful narratives cease.

Learning about FND rather than expecting clients to teach FND is also likely to be beneficial so that therapeutic space can be used for the work clients hope for, rather than as an educational space for the therapist. Doctoral training and continuing professional development training should include teaching on FND, particularly as the number of individuals diagnosed with FND is increasing (Hull et al., 2021) and all services will see individuals with FND, not just those specific to FND. Psychoeducation around FND may also be beneficial as many participants in the research described not knowing about FND and having limited opportunity to understand FND when a diagnosis was given.

There is a complex interaction between an individual's FND symptoms and their physical and mental health. It will be important to be mindful that during interventions for one area for the client (for example, mental health), that it may influence change in another area (for example, FND symptoms). The changes might be welcomed or exacerbate the preexisting symptoms. A clear formulation (that is updated and revised) will be helpful for supporting intervention work for individuals with FND. A multi-disciplinary team approach will likely be beneficial to support therapeutic work in light of the physical and mental health symptoms and conditions that are associated with FND.

## **Conclusion**

This study highlighted that self-as-context plays an important role in the ability to manage the impact of FND for the participants. The following themes were identified: the loss of self in FND, acceptance of FND, and the positioning of self in FND journey. Individuals with FND in this research often struggle with the incongruence between their self-identity narrative (self-as-content) and changes in their ability to engage in activities. Acceptance and adaption plays an important role in managing the difference and the ability to take a more reflective stance (self-as-context). ACT may be a beneficial therapeutic approach to aid the management of FND. A focus on self-as-

context, may allow individuals to feel more equipped and empowered to manage the distress and challenges FND can bring.



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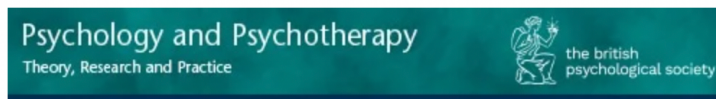
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**Part Three:**

**Appendices**



# Appendix A: Submission Instructions for the Psychology and Psychotherapy: Theory, Research and Practice Journal (Systematic Literature Review and Empirical Paper)



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## **Appendix B: Reflective Statement**

### Topic choice

When exploring topic areas for my thesis research, I found myself being drawn to Acceptance and Commitment Therapy (ACT). As a therapeutic approach I liked the stance behind ACT - that whilst pain is part of the human experience, this does not mean that you are unable to live a rich and meaningful life when living in line with your values (Harris, 2006). For me this approach felt more realistic and in keeping with lived human experience compared to other therapeutic approaches that might seek to reduce or stop all 'negative' thoughts and/or feelings to live a meaningful life. I also enjoyed learning about a new therapeutic approach early on within my training that had not been taught as the research proposals were coming together.

Additionally, I was drawn to ACT within the context of neuropsychology because I was fascinated and intrigued by the complexity and beauty of the human brain. I was interested by how clinical psychology and ACT could be used within the context of a brain injury to support recovery and/or adjusting to changes following discussions with my research supervisors.

As the ideas developed about possible avenues for research on ACT and concepts relating to psychological flexibility within neuropsychology, I attended a workshop as part of clinical training that included teaching on Functional Neurological Disorder (FND). The workshop reminded me of two books I had read during the Covid-19 lockdowns *It's All in your Head (2016)* and *The Sleeping Beauties* by Suzanne O'Sullivan (2021), a neurologist based in London. I found it fascinating to read about the impact our brains can have on our functioning and how changes can happen overnight and for many people without a clear cause. I was shocked and saddened (but not surprised) to hear of the stigma and treatment many individuals with the condition experienced and was left feeling that there is so much to change to ensure the inclusion and acceptance of individuals with FND within healthcare, clinical psychology, and wider society. I noticed feeling

frustration and anger, particularly as a woman, surrounding the misogynistic and sexist ideology that is present in the history of FND and how this may be continuing in different ways in current healthcare settings (McLoughlin et al., 2023). I was left feeling that as a profession clinical psychology could play a part in empowering and sharing the experiences of FND with the hope of playing an active part in changing the narrative of FND.

I had heard about ACT being used within the context of health conditions such as chronic pain (Wetherell et al., 2011) and multiple sclerosis (Parsa & Mohammadifar, 2018) and started to think about how ACT might be used within the FND population.

### Context around the Research

The interviews took place at a time that felt significant for health-related research given the current state of the National Health Service (NHS). Junior doctors, consultants and nurses took part in strikes across the NHS (Lacobucci, 2023; Kmietowicz, 2023; Sanfey, 2024) at a time in which the NHS has been described as being in a “crisis” (Cooksley et al., 2023), “collapsing” (Pickover, 2023), “falling apart” (Otte, 2024) and in need of change (Cooksley et al., 2023). It has taken place in a cost-of-living crisis within the UK (Broadbent et al., 2023) where stress around the ability to eat, work and live has been high. Satisfaction in the NHS and social care services have been at the lowest since records began and people do not feel that the NHS is giving value for money or providing effective services (Jefferies et al., 2024). NHS staff are also reporting discontent and feeling burnout at work (Wilkinson, 2015). I wondered whether this influenced participants’ decision to participate in research and to share their experiences particularly if they had been negative and whether they hoped the interviews might create a space to seek changes in services. I reflected that working within the NHS, I wanted participants’ experiences to have been positive and found myself feeling sad that often this had not been the case.



The research has also taken place in a backdrop of a politically unstable time where the UK has seen three prime ministers since the start of the research development (Ryan, 2024). Within a time of recession, austerity, and rising inflation (Meadows et al., 2024) and fourteen years of a Conservative Government, there has been a restructuring of the NHS (Department of Health and Social Care, 2022). Continual cuts to healthcare budgets have taken place (Hoddinott, 2023) despite the expectation that care will improve (NHS England, 2023). Additionally, the research occurred following the Covid-19 pandemic where many countries were in lockdown with restrictions surrounding contact with other people (Onyeaka et al., 2021). When I think back to conversations with the participants, discussions around the difficulty of the financial impact FND was having occurred. I wonder what impact hearing and experiencing instability may have had on their motivation to participate in the research. Exploring the political landscape within future research I undertake may be beneficial to explore explicitly within interviews.

## Empirical Research

### *Method and Approach*

The sheer paucity of research within FND and psychological interventions, meant that when deciding upon research gaps to explore felt overwhelming at times. There seemed to be different questions and approaches that could have been taken. Considerations included: producing a survey related to FND and ACT, validating a FND related measure, exploring experiences of FND. Thoughts also turned to projects such as research measuring the effectiveness of ACT. It was important to consider what was feasible within the context of the Doctorate research.

They all felt like valid areas of research, and I was unsure what direction to take. Reflecting upon my epistemological position (interpretivist) became important to guide the approach that felt most in line with my values as a researcher. Considering my epistemological position will be important when considering any future research endeavours I undertake.

I started thinking in more detail about FND and psychological flexibility from ACT. As there was a lack of literature on this area, I felt adopting an exploratory and qualitative approach would allow depth of research rich in detail as a way to start to understand this experience. To interview people about the six elements of psychological flexibility (acceptance, defusion, present moment contact, values, committed action, self-as-context; Levin et al., 2012) felt like an over-reach and that perhaps by exploring each one within an interview there would be a lack of richness and detail. But which one to choose instead? I kept being drawn to self-as-context. It felt as though it was an element that is often missed in research, perhaps due to its personal nature making it harder to operationalise in quantitative focused research. Through discussions within research supervision, it kept being the element we were all drawn to and ideas around a research project started to develop.

Interpretative phenomenological analysis (IPA) seemed like the natural fit for the qualitative approach particularly as the research was aiming to explore lived experiences. It also fits with my position as a researcher. Other approaches were considered: thematic analysis and content analysis; ultimately however, I felt that being able to interpret the interviews during analysis would be most helpful for me and a challenge to develop my qualitative analysis skills.

### *Ethics Process and Recruitment*

There was perhaps a sense of nervousness around ethics and the prospect of a potential back and forth between the ethics committee that previous trainees had recounted. There was debate surrounding whether to solely apply for ethical approval via the Faculty of Health Sciences' Research Ethics Committee or whether to apply for NHS Ethical Approval. Ultimately, I felt that due to the lack of FND services particularly within the locality it would not be beneficial to pursue NHS ethical approval. There was also the risk that the research could become a service evaluation if

participants were recruited from the limited services that were commissioned for FND assessments and/or interventions. Luckily, the process of applying and receiving ethical approval from the University was relatively smooth and straightforward. I felt that this in part was due to the thorough planning and editing of the relevant ethics forms between myself and my supervisors.

Early within the recruitment phase, I was surprised by the initial expression of interest in participating in the research. I had previous experience of conducting interviews for research and was anticipating a long recruitment process. However, after each advertisement was uploaded and shared on various social media sites, I received numerous expressions of interest. Additionally, I was surprised when I had interest expressed from potential participants in Canada. I never expected the research to have such a wide-reaching audience. At the time there was debate as to whether to include participants outside of the British Isles. Would their experience be too different? Ultimately, I did not want to restrict where the sample came from, particularly as FND research is still emerging and growing. Additionally, the approach I used for the research (qualitative) is not meant to be generalisable, so I felt having a greater depth in the sample would only be to the benefit of the research.

Reflecting back, it is perhaps not surprising that there was a large amount of interest in the research. Historically, it has been a condition that has been ignored, perhaps due to the uncertainty of where it fits within services. It is therefore hardly surprising that individuals within this population may want to share their experiences in research in the hopes of creating the change they wish to see for themselves and their community.

### *Interviews*

Developing the questions for the interview was an iterative process that involved adapting and changing words, phrases and questions multiple times. I was able to consult with an FND

organisation, *FND Dimensions*, as well as my research supervisors to produce a list that felt relevant to the research question. I was mindful that the questions should provoke some thought but not feel impossible to answer so I tried to answer the questions where relevant myself and reflect on what I might say if I was in a similar situation. This felt beneficial as I was able to reflect on my self-as-context and how that might influence the interviews and interpretation of what was discussed.

My first interview was also the only face-to-face interview I completed. I was feeling nervous about this interview. I was worried how the interview might go. Will it go well? What does a good interview look like? Will I be good enough? What if the recording stops working and I lose the interview? Would my connection to the NHS bring back difficult memories for the participants? Am I assuming they will have negative experiences of their healthcare? Ultimately, having an open and curious stance throughout the interviews and keeping a reflective journal and talking to colleagues and my research supervisors was helpful in reflecting on these thoughts and how I might use my 'outsider' position to benefit the research. I often used the Reflective Cycle developed by Gibbs (1988) to think about what happened, how I felt, what I made of the situation, and thinking about what could have been done differently as a helpful way to reflect on experiences. This would be something that would be helpful to use when conducting research again.

I also felt nervous, not having personal experience of FND and how I might be perceived if I was asked about how I came to research FND. Ultimately, I decided to be honest with how the research developed organically over time and felt that this was valuable when shared with participants. These nerves seemed to reduce after each interview and worries about being good enough slowly went away. I reflected that this feels similar to my clinical training, that as time goes on, I have felt more settled in what I am doing.

During and after the interviews, I recall feeling a sense of renewed enthusiasm and excitement about the research which seemed to grow after each interview. I felt a strong sense of hope that together we could make a positive change; that despite the many negative experience's participants had described, they shared a desire for change so that other people would have a better experience and that they were willing to be a part of the change needed.

I also remember a sense of sadness and disappointment that negative experiences of invalidation did not seem to be unique to each individual. I had a strong sense that as professionals and a society, we need to do better to ensure the inclusion of all individuals. I wondered whether this perhaps reflected a sense of guilt and shame at my part within the clinical profession and working within the NHS.

I feel that throughout the interviews, I have enjoyed being able to learn and hear about different perspectives and feel immensely privileged and honoured to be trusted with what participants have disclosed. I am grateful that people have been willing to take part and be open and vulnerable with me and that we have been able to create a safe space in the hope that change will occur within the future.

### *Data Analysis*

Analysing the interviews has felt like a long and tiring process, plagued with thoughts around "am I doing this right?" I remembered hoping and wishing for a clear answer, but of course there is no answer and reflecting on IPA methodology at these times was helpful. There were so many interesting and important insights from each participant that I felt overwhelmed and concerned that I would not be able to do them justice.

I noted in one research supervision that there seemed to be broadly two groups of people within the analysis and started to think about ACT concepts and how ACT might be a helpful intervention. I was helpfully reminded to think about the research question and to not search for what I wanted to see. Keeping a reflective journal was crucial in this process to think about what was “mine” and what the participants’ experience was.

Producing personal experiential themes then developing group experiential themes across the cases was an enjoyable and challenging part of the research. I found making a dedicated time to focus on the analysis difficult at times with the competing demands of the course but when I was able to make space to analyse being immersed in the data interesting and exciting.

### Systematic Literature Review (SLR)

Identifying and developing a literature review topic has felt at times like the hardest part of the research. Multiple ideas and topics were suggested with many setbacks along the way. Ideas included replicating Gutkin et al’s. (2021) review looking at individual therapy for FND but including small scale research that was excluded. This would enable the exploration of emerging approaches such as ACT and Compassion Focused Therapy. Whilst I was really excited by the thought of such a review it appeared that there was unlikely to be enough studies to warrant a review.

I thought about conversations that were taking place within the interviews. I noticed that a few of the participants were talking about hope. I wondered about the role of hope, particularly within the context of ACT. I was grateful to be put in contact with Dr Marcia Ward, a Clinical Neuropsychologist, interested in hope and ACT. We were both enthusiastic and excited about the prospect of a review and the role of hope with ACT. Unfortunately, due to the limited research and the worry that the review would be too academic and not clinically relevant this proposal had to be

stopped which was a great shame and disappointment. I am excited about the possible prospect of exploring the role of hope in the future and am excited to see what other research project may come out of this research within my clinical practice.

Finally, I re-read the review by Gutkin and colleagues. It was then that I noticed that they had excluded studies that involved group interventions. It was at this point I felt I had a ‘lightbulb’ moment and realised that no review had taken place that had explored group interventions for FND. It felt like a huge relief to have a topic at a time where it felt like that would never happen. The development of the topic, question and research aims seem to happen quickly.

The review of the papers and risk of bias felt relatively quick to do, perhaps in part because I have had previous experience of undertaking a review. The difficulty was balancing the competing demand of the empirical research with placements and coursework and learning a new method of synthesis.

The first draft of the results felt very descriptive and subsequently involved multiple updates and changes to ensure the results more closely followed the narrative synthesis approach. Ultimately by re-familiarising myself with the narrative synthesis approach, it enabled me to produce a literature review more in-keeping with the aims I had set out. I would recommend that other researchers embarking on similar projects should immerse themselves more within the narrative synthesis literature ahead of producing a literature review to aid their understanding of this approach.

### Journal Choices

When deciding upon a journal for the empirical research and literature review, I thought about who the target audience was for the research. Initially, thoughts surrounding clinical

neuropsychologists being the target audience steered me toward clinical neuropsychological journals. However, upon reflection, thinking about the National Institute of Health and Clinical Excellence (NICE; 2021) guidelines for ‘non-specialist’ care, I thought that it will be increasingly likely that Clinical Psychologists will see individuals within FND in mental or physical health services. Therefore, it felt that the target audience would be clinical psychologists. Additionally, I thought about where in the world would the Clinical Psychologists be that I would like to see the research. Despite both parts of the research having participants not just from the UK, I felt that as my lens was heavily influenced by the context of the NHS and UK political environment, a British journal would be beneficial.

I selected the British Psychological Society Journal *Psychology and Psychotherapy: Theory, Research and Practice* for both the empirical research and literature review. It felt like a good fit for the target audience.

### *Final Reflections*

Over the course of the research, there have been multiple changes, challenges and setbacks. I feel I have learnt a lot about my position as a researcher and have come to value the importance of research within the profession in a new light. I have felt incredibly privileged to have been able to have so many interesting conversations with my participants. I feel proud of the work I have created and hope that over the course of my career I am able to frequently undertake and be involved in research.



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## **Appendix C: Epistemological Statement**

The epistemological statement outlines the position of the researcher in relation to the study on an exploration of self-as-context and group interventions for individuals with a diagnosis of Functional Neurological Disorder (FND). Acknowledging the positioning of the researcher is essential to understand how their assumptions have influenced the development and interpretation of the research (Carter & Little, 2007).

### Ontology

Ontology refers to the beliefs surrounding the nature of reality (Holmes, 2020). It is typically thought of as a scale with two pole positions: realist and relativist (Willig, 2016). The realist position takes the belief that reality is measurable and can be done so objectively with generalisable results and seen as static (Slevitch, 2011). The relativist position, in contrast, states that reality is subjective, dynamic and contextual; there is no one reality (Willig, 2012). Realist positioned research might use quantitative measures to explore reality such as the validation of a measure of acceptance (Francis et al., 2016). Conversely, relativist positioned research may use qualitative measures to explore reality such as the process of acceptance (Bloy et al., 2021).

The researcher took a critical realist ontological stance within the empirical research and the systematic literature review. The critical realist belief falls between the two positions. Critical realism takes a pragmatic approach and acknowledges that reality is inherently complex and may go beyond what can be observed, experienced and measured (Haigh et al., 2019). This can be particularly helpful within clinical psychology and health care settings as it seeks to avoid single disciplinary views instead opting for multiple perspectives (Haigh et al., 2019). This lens means that the researcher saw experiences of FND as subjective and dynamic but could be measured as an objective reality.

## Epistemology

Epistemology refers to the view of knowledge and how the individual gains that knowledge (Holmes, 2020). With regards to research, it can consider and explore the relationship between the researcher and the participants (Kapiszewski & Wood, 2022). The researcher undertook an interpretivist epistemological position. This position states that facts are subjective, context-dependent and can be socially constructed (Tuli, 2010). This draws on ideas of knowledge being constructed by individuals. Based on this position, the researcher assumed that there would not be one “truth” or understanding regarding experiences of FND. This fits with the researcher’s understanding of personal experiences being different from other people.

## Empirical Research

The empirical research explored self-as-context from Acceptance and Commitment Therapy (ACT) in individuals with FND. ACT is not aiming to find objective truth (Hayes, 2004). The researcher therefore understands ACT through an interpretivist lens, that ideas around knowledge can be co-constructed by the therapist and client. Within the context of the research, ideas around self-identity and self-as-context are seen through an interpretivist lens. It can be context-dependent and constructed by each individual.

As the researcher took an interpretivist position, a qualitative methodological approach seemed the most appropriate to work in line with the researcher’s values. This in line with the researcher’s view that experiences of FND are inherently individual and therefore are more in keeping with an interpretivist approach.

During the development of the empirical research multiple qualitative methodologies were explored whilst designing the study such as content analysis, thematic analysis and interpretative phenomenological analysis (IPA). Content and thematic analysis were discounted as they seek to

identify themes or categories across participants' experiences (Neuendorf & Kumar, 2015; Clarke & Braun, 2017). IPA was ultimately chosen to explore how each participant made sense of their experiences of FND within the framework of self-as-context from ACT, particularly as research on FND and experiences of FND is limited. The ontological stance (critical realist) and epistemological position (interpretivist) support the IPA methodology which sees knowledge as constructed and reality as an interpretation of their experience.

Given the outsider position that the researcher felt they held at times during the research, another benefit of IPA was identified in the use of double hermeneutics (Pietkiewicz & Smith, 2014); that is that the researcher is attempting to make sense of how the participants interpret their experience (Montague et al., 2020). To do this, the researcher must engage in interpreting what each participant has disclosed. Multiple researchers have described a discourse between 'fore-understanding' and 'cyclical reflexive bracketing' (Tuffour, 2017; Heidegger, 1962). Fore-understanding refers to the researcher's prior understanding (Tuffour, 2017). Cyclical reflexive bracketing, or bracketing, refers to the continuous cyclical nature of reflecting on values on the research (Davidsen, 2013).

Reflexivity, the process of reflecting on one owns assumptions and values and how this might influence research (Jamieson et al., 2023), was also important within the empirical paper. The researcher was continuously exploring how their values and experiences informed their understanding and decision making. The researcher was aware of some of the assumptions underpinning the empirical research. The overarching assumption was that ACT may in some way play a role in supporting individuals with FND based on ACT's understanding of living a meaningful and rich life despite experiencing pain (Borges, 2019) and having first-hand experience of developing skills within ACT to apply within therapeutic practice as the researcher took part in clinical training alongside undertaking the research.

The use of a reflective journal was key in considering the assumptions made of the research and the double hermeneutic process. The use of regular research supervision was also important and valuable in this process.

### Systematic Literature Review

The systematic literature review explored group psychological interventions for individuals with FND. The method of synthesis for the literature review was a narrative synthesis. This approach takes a critical realist approach to ontology (Barnett-Page & Thomas, 2009) and is in keeping with an interpretivist epistemological position.

From the reviewed studies, a narrative synthesis hopes to develop a meaningful account of the results through the construction of a clear story (Popay et al., 2006). In other words, it is socially constructed. Despite conflicting epistemological and methodological stances of the included studies, narrative synthesis has been identified as an appropriate methodology to draw together a meaningful account (Popay et al., 2006). The researcher found the approach particularly helpful as much of the limited research surrounding FND did not agree with the ontological and epistemological position.



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## Appendix E: Measures Used in Included Studies

Author (Year)	Measures
Barry et al. (2008)	Symptom Checklist-90 (Derogatis et al., 1976)  Beck Depression Inventory (Beck et al., 1961)  Self-reported SF
Boico et al. (2023)	Qualitative feedback – session materials, homework task and experience of group during each session  Patient-Reported Outcome Measure- Reduced (Humblestone et al., 2022)
Bullock et al. (2015)	Self-reported SF
Chen et al. (2014)	Work and Social Adjustment Scale (Mundt et al., 2002)  Self-reported SF  Self-reported Seizure intensity  Self-reported Seizure related hospital visits/admissions  Self-reported new symptoms not medically explained

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Self-reported knowledge and perception of seizures

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Conwill et al. (2014)

Short form health survey 36-item (Ware & Sherbourne, 1992)

Hospital Anxiety And Depression Scale (Zigmond & Snaith, 1983)

Clinical Global Impressions (-Improvement) (Guy, 1976)

Self-reported SF

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Cope et al. (2017)

Patient Health Questionnaire-9 (Kroenke et al., 1999)

Generalised Anxiety Disorder Scale- 7 (Spitzer et al., 2006)

Work and Social Adjustment Scale (Mundt et al., 2002)

Brief Illness Perception Questionnaire (Broadbent et al., 2006)

Dissociative Experiences Scale II (Carlson & Putnam, 1993)

Revised Emotional Thermometer Scale (Rampling et al., 2012)

Self-reported SF and seizure intensity

Self-reported attitudes toward FNEA

Self-reported evaluation of group sessions

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de Barros et al. (2018)	Short Form Health Survey 36-item (Ware & Sherbourne, 1992)  Toronto Alexithymia Scale (Leising et al., 2009)  Hamilton Depression Rating Scale (Hamilton, 1960)  Hamilton Anxiety Scale (Hamilton, 1959)  Ways of Coping Checklist (Vitaliano et al., 1985)  Self-reported SF
Guy et al. (2023)	Beck Anxiety Inventory (Beck et al., 1988)  Beck Depression Inventory II (Beck et al., 1996)  Work and Social Adjustment Scale (Mundt et al., 2002)  10-Meter Walk Test (Wade et al., 1987)  Timed Up and Go (Podsiadlo & Richardson, 1999)  Berg Balanced Scale (Berg et al., 1989)
Labudda et al. (2020)	Symptom Checklist-90-Revised (Franke, 1995)  Beck Depression Inventory II (Beck et al., 1996)



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State-Trait Anxiety Inventory (Spielberger, et al., 1983)

Fragebogen zu Dissoziativen Symptomen (Spitzer et al., 2015)

Self-reported PNES rating

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Libbon et al.      Clinic utilisation from healthcare reports  
(2019)

Healthcare utilisation from healthcare reports

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Libbon et al.      McMaster Family Assessment Device (Epstein et al., 1983)  
(2023)

Multifamily Group feedback questionnaire

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Limburg et al.      Vertigo Handicap Questionnaire (Tschan et al., 2008)  
(2021)

Vertigo Symptom Scale (Yardley et al., 1992)

Patient Health Questionnaire 15 (Kroenke et al., 1998)

Beck Anxiety Inventory (Beck et al., 1988)

Beck Depression Inventory II (Beck et al., 1996)

Short Form Health Survey 12-item (Ware et al., 1996)

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Metternich et al.      Metamemory in Adulthood Questionnaire (Dixon & Hultsch, 1983)  
(2008)

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	Perceived Stress Questionnaire (Levenstein et al., 1993)
	Symptom Checklist-90-Revised (Franke, 1995)
Prigatano et al. (2002)	Self-reported SF
Sarudiansky et al. (2020)	Psychoeducational Intervention Questionnaire
	State-Trait Anxiety Inventory (Spielberger, et al., 1983)
	Beck Depression Inventory II (Beck et al., 1996)
	Brief Illness Perception Questionnaire (Broadbent et al., 2006)
	Dissociative Experiences Scale- M (Montes et al., 2011)
	Posttraumatic Stress Disorder Diagnostic Scale (Foa et al., 2016)
Senf-Beckenbach et al. (2022)	Fragebogen zu Dissoziativen Symptomen (Spitzer et al., 2015)
	Liverpool Seizure Severity Scale (Baker et al., 1998)
	Patient Health Questionnaire-9 (Kroenke et al., 1999)
	Patient Health Questionnaire 15 (Kroenke et al., 1998)
Zaroff et al. (2004)	Coping Inventory for Stressful Situations (Endler & Parker, 1999)

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Davidson Trauma Scale (Davidson et al., 1997)

Curious Experience Survey (Goldberg, 1999)

State-Trait Anger Expression Inventory – 2 (Spielberger, 1999)

Quality of life in Epilepsy Inventory – 31 (Vickrey et al., 1993)

Self-reported SF

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# Appendix F: Consent Form

Version 1

Date: 20/04/2023



## CONSENT FORM

Title of study: An Exploration of Self-As-Context in Individuals with Functional Neurological Disorders

Name of Researcher: Rachel Hinchliffe

Please initial box

- 1. I confirm that I have read the information sheet dated 22/06/2023 version. 2 for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to two weeks after completing the interview. I understand that after two weeks after the interview my data cannot be withdrawn as my data will be anonymised.
- 3. I understand that the research interview will be recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations.
- 4. I understand that the research data, which will be anonymised (not linked to me), will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future.
- 5. I understand that my personal data will be kept securely in accordance with data protection guidelines and will only be available to the immediate research team
- 6. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
<u>Rachel Hinchliffe</u>	_____	_____
Name of Person	Date	Signature
taking consent		

## Do you have a Functional Neurological Disorder (FND)?

Would you like to share  
your experiences?

### What is involved?

You will be asked to  
attend one interview,  
online or in person,  
to share your  
experience of FND  
lasting approximately  
45 minutes.



### Interested in taking part?

For more information  
or to express interest  
please email:  
[r.k.hinchliffe-2021@hull.ac.uk](mailto:r.k.hinchliffe-2021@hull.ac.uk)

 **UNIVERSITY OF Hull**

The research aims to explore the sense of self in individuals  
with FND. Researcher: Rachel Hinchliffe. This research is being  
conducted as part of a Doctorate in Clinical Psychology.

### INFORMATION SHEET FOR PARTICIPANTS

#### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

**Title of study:** An Exploration of Self-As-Context in Individuals with Functional Neurological Disorders

I would like to invite you to participate in a research project which forms part of my doctorate in Clinical Psychology research. The sponsor for this research is the University of Hull – contact [researchgovernance@hull.ac.uk](mailto:researchgovernance@hull.ac.uk) if you have any queries. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the study?**

We currently know very little about Functional Neurological Disorder (FND). However, we do know that for many other neurological conditions and long-term health conditions, a person's self-identity can be impacted. The purpose of the study is to better understand individuals' sense of identity following a diagnosis of FND.

One way to explore sense of self is using a concept called self-as-context from Acceptance and Commitment Therapy (ACT). Self-as-context is understood as a person's self-awareness and can be influenced by individuals' personal narratives and in-the-moment statements.

It is anticipated that furthering our understanding of how individuals with FND view themselves and experience living with their condition will help clinicians to tailor psychotherapeutic interventions.

#### **Why have I been invited to take part?**

You are being invited to participate because the researcher is looking to interview individuals who are 18 years old or above with a diagnosis of FND.

Unfortunately, if you are taking part in Acceptance and Commitment Therapy (ACT) or other forms of talking therapy you will not be able to take part in this research.

#### **What will happen if I take part?**

Participation is voluntary. If you choose to take part in the study, you will be asked to take part in one interview exploring your experiences of FND and sense of self lasting approximately 45 minutes. It will take place online (or in-person if requested for individuals living in Hull or surrounding areas).

You will be asked to provide information about your age, gender identity, ethnicity, and FND experience (e.g., when symptoms started, when you received a diagnosis, symptoms).



The interview will be audio and visually recorded. Following the interview, the recording will be transcribed and analysed. Any identifiable data will be removed to ensure the data is anonymised.

**What are the possible risks of taking part?**

Some people may experience distress when talking about their experiences because it may prompt difficult memories and feelings. If this happens the researcher will offer support and you will have the opportunity to pause or end the interview. Following the interview, there will be a short debriefing period whereby you can discuss your experience of the interview, including the impact on your emotional wellbeing. The researcher will provide all participants with a debrief form which will signpost you to sources of support.

**What are the possible benefits of taking part?**

Some individuals find it useful to have an opportunity to reflect on their experiences. Taking part in the study will not alter your own diagnosis or treatment, however the information gathered should help to further our understanding of FND.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and contact details for the arranging the interview. Following the completion of the research, your contact details will be deleted, unless you request a copy of the completed research. Your name and contact details will not be tied with your interview responses.

Your interview response will be transcribed and anonymised so that no-one can work out that you took part in the study.

Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018.

**What are your choices about how your information is used?**

You are free to withdraw up to two weeks after the interview, without having to give a reason but we will keep information about you that we already have.

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

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

You can find out more about how we use your information:

- By asking one of the research team
- By contacting the University of Hull Data Protection Officer by emailing [dataprotection@hull.ac.uk](mailto:dataprotection@hull.ac.uk) or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
- By reviewing the University of Hull Research Participant privacy notice: <https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/docs/quality/research-participant-privacy-notice.pdf>

**Data Protection Statement**





The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) ([www.ico.org.uk](http://www.ico.org.uk) or 0303 123 1113).

**What will happen to the results of the study?**

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's online repository <https://hydra.hull.ac.uk>. Feedback will be provided to all participants who have requested it. Feedback will involve a summary of the main findings alongside some anonymised, verbatim quotes. The research may also be published in academic journals and/or presented at conferences. Participants will not be identifiable in the final study reports or in any conference presentations.

**Who has reviewed this study?**

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee at the University of Hull.

**What should I do next?**

If you are interested in taking part in the research, please send your contact details to the email address below. The researcher will be in touch to arrange the next steps.

**Rachel Hinchliffe**

Clinical Psychology  
Aire Building  
The University of Hull  
Cottingham Road  
Hull  
HU6 7RX  
Email: [r.k.hinchliffe-2021@hull.ac.uk](mailto:r.k.hinchliffe-2021@hull.ac.uk)

**What if I have further questions, or if something goes wrong?**

If you have any questions please contact Rachel Hinchliffe via her email [r.k.hinchliffe@hull.ac.uk](mailto:r.k.hinchliffe@hull.ac.uk). The researcher aims to answer any questions as soon as possible within their typical working hours (09:00am to 17:00pm).

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

**Dr Pete Fleming**

Clinical Psychology  
Aire Building  
The University of Hull  
Cottingham Road



UNIVERSITY  
OF HULL

Version 2 22/06/2023

Hull  
HU6 7RX  
Email: [p.fleming@hull.ac.uk](mailto:p.fleming@hull.ac.uk)

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

# Appendix I: Interview Schedule

Version: 2  
Date: 23/04/2023



## INTERVIEW SCHEDULE

### ***Introduction***

The researcher will introduce themselves and their role, before providing a brief overview of the study and purpose of the interview. This information will reiterate the key considerations from the information sheet. The researcher will check understanding before explaining consent, confidentiality and limitations to confidentiality (in the case of disclosure of potential harm to self-and/or others). The researcher will discuss the format of the interview (length of time, debriefing period, audio-recording) before offering an opportunity to ask further questions. The researcher will request consent to take part and start the audio-recording.

### ***Demographic Questions***

1. I am going to be asking you about what it's like having a diagnosis of FND, I wondered if to begin you could just confirm a few details about you.
  - a. Can you tell me your:
    - i. Age
    - ii. Gender
    - iii. Ethnicity
  - b. Can you tell me about your FND symptoms?
    - i. Symptoms (e.g., location, severity)
    - ii. Occurrence of symptoms (e.g., recurrent, consistent)
    - iii. Duration/Onset

### ***Interview Questions (with Potential Prompts)***

2. Can you tell me a little bit about how you came to have a diagnosis of FND?
  - a. How did things change for you?
  - b. How did you feel about it?
  - c. How do you feel about it now?
3. How do you define FND?
  - a. How would you describe FND to other people?



- b. What does FND mean to you?
4. Has FND influenced how you perceive yourself?
  - a. If so how/why do you think this is the case?
  - b. Can you tell me about how you viewed yourself prior to your diagnosis of FND?
  - c. How do you see yourself now?
  - d. Has this changed? Are you surprised?
5. What was important to you in your life (e.g., prior to FND symptoms)?
  - a. For example:
    - i. Work?
    - ii. Relationships?
    - iii. Attitudes to health?
    - iv. Attitudes to hobbies and interests?
  - b. Has this changed?
    - i. If so, why?
6. Since receiving your diagnosis, has the way you viewed yourself changed?
  - a. If so, how?
  - b. If not, why?
7. What do you find helpful to stay in touch with who you are?
  - a. In what situations do you feel most like you?
  - b. What makes it harder?
8. Is there anything else you would like to say about your sense of self that you have not already discussed?
9. How are you feeling after what you have discussed today?
  - a. How do you feel the interview went?
  - b. Has anything surprised you?

### **Conclusion**

The researcher will facilitate a short debrief and check-in period. This will involve the researcher thanking the participant for their time, offering an opportunity to ask questions and exploring the participants experience of the interview and emotional wellbeing. The researcher will be

Version: 2  
Date: 23/04/2023



compassionate, offer comfort to participants and provide a debrief form to all containing sources of support (GPs, organisational support, third-sector agencies). The debrief form will also include the researcher's contact details for follow-up questions and information about opportunities to withdraw their data. The researcher will then end the interview.

## Appendix J: Debrief Form

Version: 1  
Date: 20/04/2023



### DEBRIEF FORM

Title of study: An Exploration of Self-As-Context in Individuals with Functional Neurological Disorders

Name of Researcher: Rachel Hinchliffe

Thank you for taking part in the present study. Your time is greatly appreciated, and we are hopeful that your contributions to the research will help us to develop the knowledge base.

As a reminder, your data will remain anonymous in the write up of the research, you will be given a pseudonym and any direct quotes that are used will not be linked back to you.

Please note that you are still able to withdraw your data from the research without giving a reason if you wish to do so. However, you can only withdraw your data up to the point of data transcription (in two weeks' time) as your data will have been anonymised and committed to the research.

### Sources of Support

Some people may have found the content of discussions within the interview distressing. If you feel you were affected by the discussions today and would like further support or advice, please contact any of the potential sources of support:

#### ***Mind***

Mind is a charity that provides advice and support for individuals experiencing a mental health problem.

0300 123 3393

<https://www.mind.org.uk/>

[info@mind.org.uk](mailto:info@mind.org.uk)

#### ***Samaritans***

Samaritans is a charity that offers a free telephone service open 24 hours a day all year round for individuals who would like to talk to someone.

116 123

<https://www.samaritans.org/>

[jo@samaritans.org](mailto:jo@samaritans.org)

#### ***Your GP***

You can also seek support from your GP.

#### ***FND Action***

FND Action is a charity offering information about FND and providing online support groups of individuals with functional neurological symptoms and their families and caregivers.

<https://www.fndaction.org.uk/>

[contact@fndaction.org.uk](mailto:contact@fndaction.org.uk)

#### ***FND Dimensions***

FND Dimensions is a charity offering information about FND and providing online support groups of individuals with functional neurological symptoms and their families and caregivers.

<https://fnddimensions.org/>

[enquiries@fnddimensions.org](mailto:enquiries@fnddimensions.org)

#### ***FND Hope***

FND Hope is a charity offering information about FND and providing online support groups of individuals with functional neurological symptoms and their families and caregivers.

<https://fndhope.org/about-fnd-hope/fnd-hope-uk/>

Version: 1  
Date: 20/04/2023



### **Researcher Details**

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

**Rachel Hinchliffe**  
Clinical Psychology  
Aire Building  
The University of Hull  
Cottingham Road  
Hull  
HU6 7RX  
Email [r.k.hinchliffe-2021@hull.ac.uk](mailto:r.k.hinchliffe-2021@hull.ac.uk)

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

**Dr Pete Fleming**  
Clinical Psychology  
Aire Building  
The University of Hull  
Cottingham Road  
Hull  
HU6 7RX  
Email address: [p.fleming@hull.ac.uk](mailto:p.fleming@hull.ac.uk)

## Appendix K: Example of Data Analysis

Participant 008

- 200 **only thing that changes is the pace at which I do it.** So active to me before was, you know, going out and  
*↪ need to pace self, calmer, slower* *↪ active ideas changing following PNB*
- 201 cycling and long walks with the family and, you know, family activities were very much active activities,  
*learning to be present and participating in life*
- 202 you know. And going to the gym and stuff like that, but **active for me now is participating in life,** you  
*↪ present moment*  
*↪ and now is participating in life*
- 203 know, been able to actually, you know, go for a short walk standing in the street to watch the children play  
*↪ being with loved ones as a value*
- 204 instead of being in bed or on the sofa, you know. And it's just realigning what my view is in line, no.  
*↪ important to do things* *↪ realign as difficult*
- 205 **Realigning my expectations in line with what I'm capable of,** essentially. And that's a big adjustment. And  
*↪ taking time, process*  
*↪ change in expectations of capability - challenging at times* *↪ challenging, hard to accept*
- 206 I know that not everyone is capable of, you know, getting to that headspace. I think that that's where self-  
*↪ grateful they can learn to accept* *↪ difficult headspace to enter*  
*↪ self-awareness, self-reflection, important value* *↪ self-compassion is important*
- 207 awareness is quite important. It's just kind of and without doing it without beating yourself up. Do you  
*↪ self-awareness, self-reflection, important value* *↪ self-compassion is important*
- 208 know what I mean? Or, you know, without feeling sorry for yourself. Like a lot of people to stand up and  
*↪ self-pity as something they avoid*
- 209 that space where they just really feel sorry for themselves because and you can't blame them because it's a  
*↪ trying to be compassionate and kind towards self - divide pity*  
*↪ frustration that people don't learn to adjust*
- 210 horrible condition to have to come to terms with. But you do, you just have to come to terms with it. So  
*↪ acceptance as important in journey*

## Appendix L: Examples of Theme Development

Participant 005: First Attempt at Theme Development

Theme	Statements
THEME 1: The Passage of Time	1. Sense of self before FND as undefined
	2. FND symptoms from a young age
	3. FND symptoms previously negatively impacting their sense of self
	4. Transition of symptom management on sense of self as they grow older
	5. Perception of youth negatively influencing experiences in healthcare
	6. Now feel older, wiser and better able to stay in touch with self
THEME 2: Post-Diagnosis	1. Lack of support following diagnosis
	2. Personal responsibility for finding out about FND
THEME 3: Invalidation in Healthcare	1. Invalidation though lack of knowledge and understanding about FND
	2. Invalidation leading to difficult emotions
	3. Invalidation through healthcare system
	4. Invalidation through advice/action from healthcare system

	5. Validation through diagnosis and connection with others
	6. Hope for validation in the future
THEME 4: Self-identity	1. Decision to adopt FND as part of sense of self
	2. Self as helpful
	3. Values making up sense of self
	4. Self as an introvert
	5. Engaging in activities helps maintain sense of self
	6. Difficult to stay in touch with sense of self
	7. Importance of mind body connection
	8. Elements needed for self-expression
THEME 5: Influence of Other people	1. Sharing FND experiences as important
	2. Concerned about the impact of FND symptoms on others
	3. Untrue narratives of FND influencing others behaviours towards self
	4. Negative experiences with healthcare professionals
	5. Others as having power over them
	6. Fear of judgement from others

	7. Isolated from others
	8. Relationships with others as important
	9. Shame as part of their FND journey
	10. Helping others
	11. Safety away from others
	12. Comparison to others
	13. Worried about being a burden to others
	14. Lack of knowledge of FND
	15. Compassion towards others
	16. Other people impacting sense of self
	17. Part of out-group
THEME 6: FND Symptoms	1. FND symptoms as unpredictable
	2. FND symptoms as progressive
	3. Additional health conditions
	4. Psychological factors influencing symptoms
THEME 7: Shame	1. Shame that body copes differently to stress



2. Anger at lack of support
-----------------------------

Participant 005: Theme Development (Second Attempt)

New Theme	Previous Theme	Statements
NEW THEME 1: Helping others & relationship importance	THEME 4: Self-identity	2. Self as helpful
	THEME 5: Influence of Other people	10. Helping others
		8. Relationships with others as important
	15. Compassion towards others	
	THEME 3: Invalidation in Healthcare	5. Validation through diagnosis and connection with others
NEW THEME 2: Empowerment through decisions	THEME 8: Remaining statements	3. Becoming empowered
	THEME 4: Self-identity	1. Decision to adopt FND as part of sense of self
		5. Engaging in activities helps maintain sense of self
	THEME 1: The Passage of Time	6. Now feel older, wiser and better able to stay in touch with self

NEW THEME 3: Power other people hold over them	THEME 5: Influence of Other people	5. Others as having power over them
	THEME 8: Remaining statements	2. Feeling powerless
	THEME 5: Influence of Other people	7. Isolated from others
		6. Fear of judgement from others
17. Part of out-group		
NEW THEME 4: FND Symptoms over time	THEME 6: FND Symptoms	4. Negative experiences with healthcare professionals
		1. FND symptoms as unpredictable
	THEME 1: The Passage of Time	2. FND symptoms as progressive
		2. FND symptoms from a young age
NEW THEME 5: Invalidation through lack of knowledge	THEME 5: Influence of Other people	4. Transition of symptom management on sense of self as they grow older
		3. Untrue narratives of FND influencing others behaviours towards self
	THEME 3: Invalidation in Healthcare	14. Lack of knowledge of FND
		1. Invalidation though lack of knowledge and understanding about FND

and understanding about FND		
NEW THEME 6: Shame	THEME 7: Shame	1. Shame that body copes differently to stress
	THEME 5: Influence of Other people	9. Shame as part of their FND journey
NEW THEME 7: Lack of support following diagnosis	THEME 3: Invalidation in Healthcare	4. Invalidation through advice/action from healthcare system
	THEME 2: Post-Diagnosis	1. Lack of support following diagnosis
	THEME 7: Shame	2. Anger at lack of support

Participant 005: Further Theme Development (Third Attempt)

Theme	Subtheme	Previous Theme	Statements
THEME ONE: Invalidation	Subtheme: Invalidation through lack of knowledge	THEME 5: Influence of Other people	3. Untrue narratives of FND influencing others behaviours towards self
			14. Lack of knowledge of FND

as part of their FND journey	and understanding about FND	THEME 3: Invalidation in Healthcare	1. Invalidation through lack of knowledge and understanding about FND
	Subtheme: Invalidation through lack of support	THEME 3: Invalidation in Healthcare	4. Invalidation through advice/action from healthcare system
		THEME 2: Post-Diagnosis	1. Lack of support following diagnosis
		THEME 7: Shame	2. Anger at lack of support
	Subtheme: Invalidation from actions	THEME 3: Invalidation in Healthcare	3. Invalidation through healthcare system
		THEME 1: The Passage of Time	5. Perception of youth negatively influencing experiences in healthcare
	Subtheme : Power other people hold over them	THEME 8: Remaining statements	2. Feeling powerless
		THEME 5: Influence of Other people	5. Others as having power over them
			7. Isolated from others
			6. Fear of judgement from others

			17. Part of out-group
			4. Negative experiences with healthcare professionals
THEME 2: Empowerment as a part of their FND journey	Subtheme: Empowerment through decisions	THEME 8: Remaining statements	3. Becoming empowered
		THEME 4: Self-identity	1. Decision to adopt FND as part of sense of self
			5. Engaging in activities helps maintain sense of self
		THEME 1: The Passage of Time	6. Now feel older, wiser and better able to stay in touch with self
		THEME 5: Influence of Other people	1. Sharing FND experiences as important
	Subtheme: Empowerment through connection with others	THEME 4: Self-identity	2. Self as helpful
		THEME 5: Influence of Other people	10. Helping others
			8. Relationships with others as important
			15. Compassion towards others
		THEME 3: Invalidation in Healthcare	5. Validation through diagnosis and connection with others

	Subtheme: Empowerment through sense of self	THEME 4: Self-identity	8. Elements needed for self-expression
			3. Values making up sense of self
			7. Importance of mind body connection
	THEME 8: Remaining statements	1. Acceptance of symptoms and diagnosis	

THEME 3: FND Symptoms	Subtheme: FND progressive and unpredictable over time	THEME 6: FND Symptoms	1. FND symptoms as unpredictable
			2. FND symptoms as progressive
	Subtheme: FND symptoms influencing identity	THEME 1: The Passage of Time	2. FND symptoms from a young age
			4. Transition of symptom management on sense of self as they grow older
	Subtheme: Sense of shame about the symptoms	THEME 7: Shame	1. Shame that body copes differently to stress
		THEME 5: Influence of Other people	9. Shame as part of their FND journey
		THEME 4: Self-identity	4. Self as an introvert

THEME 4: Impact of FND	Subtheme: Away from other people	THEME 5: Influence of Other people	11. Safety away from others
	Subtheme: Self as negatively impacting other people	THEME 5: Influence of Other people	12. Comparison to others
			13. Worried about being a burden to others
			2. Concerned about the impact of FND symptoms on others

Theme Development: Group Experiential Statements

<b>Attempts</b>	<b>Changes</b>
Theme 1: Hope on a continuum <ul style="list-style-type: none"> <li>• Self as future</li> <li>• Self as helping others/advocate</li> <li>• Not wanting others to go through similar bad experience</li> </ul>	Theme 1: Loss of self in FND <ul style="list-style-type: none"> <li>• Feeling lost/hidden</li> <li>• Past self, current self, future self</li> </ul>
Theme 2: Acceptance on a continuum <ul style="list-style-type: none"> <li>• Self as struggling</li> <li>• Self as won't change</li> <li>• Self as learning to adjust</li> </ul>	Theme 2: Coming to acceptance <ul style="list-style-type: none"> <li>• Acceptance as a process</li> <li>• Acceptance as a gateway to hope</li> <li>• Acceptance as a barrier (to hope?)</li> </ul>

<ul style="list-style-type: none"> <li>• Self as adjusting</li> </ul>	
<p>Self to Self-positioning</p> <ul style="list-style-type: none"> <li>• Self to self</li> <li>• Stigma - self in relation to others</li> <li>• Time - past self, present self, future self</li> </ul>	<p>Theme 3: Positioning of self</p> <ul style="list-style-type: none"> <li>• Self in relation to others (different, invalidating)</li> <li>• Desire for connection</li> </ul>