# Exploring change processes in Functional Neurological Disorder

Jocelyn Rachel Arbuthnott

Submitted in accordance with the requirements for the degree of Doctor of Clinical Psychology (D. Clin. Psychol.) The University of Leeds School of Medicine Division of Psychological and Social Medicine

August 2020

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to others' work.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

The right of Jocelyn Rachel Arbuthnott to be identified as the author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988.

© 2020 The University of Leeds and Jocelyn Rachel Arbuthnott

#### Acknowledgements

A huge heartfelt thank you goes to Ciara Masterson and Charlotte Baker for their time, expertise, and incredible ongoing support throughout this thesis. I would also like to thank Rebecca Yeates for her expertise and support in this thesis's fast-paced changes. Without all your encouragement, thoughtful reflections, time, and patience, this work would not have been possible.

A special thank you goes to all those who agreed to give up their time participating in this research and sharing some of their experiences.

I am grateful for my friends' great companionship from the Leeds Doctorate in Clinical Psychology and for the support from all the staff members on the course.

Thank you for the ongoing love and support from my friends and family in what has turned out to be a much longer than expected journey. In particular, Sue, your friendship has been immeasurable.

Finally, to my husband, there are no words to express how grateful I am for your support during one of the most challenging times. Thank you for being there every step of the way.

#### Abstract

**Introduction:** There is a dearth of literature on third-wave Cognitive Behavioural Therapies (CBT) for Functional Neurological Disorder (FND). These approaches adopt a transdiagnostic approach to support people to change their relationship with their psychological experiences (Hayes, 2004). This thesis examines the existing literature regarding these approaches and explores the impact of a Clinical Health Psychology Service two-phase psychological intervention for FND. This consists of assessment and formulation sessions (Phase 1) and an innovative seven-week Acceptance and Commitment Therapy (ACT) group (Phase 2).

**Aims:** A scoping review explores the extent and nature of the literature on third-wave CBT for FND and determines whether there is good quality evidence available regarding its effectiveness. Preliminary factors for intervention feasibility, acceptability and effectiveness are explored within the review. The empirical study aims to evaluate the impact and experiences of participants receiving the two-phase psychological intervention for FND.

**Methods:** A broad scoping review of third-wave CBT for FND was carried out on the bibliographic databases PsychINFO, EMBASE and MEDLINE, which were searched from the earliest listing up to June 2020. Key information is charted and explores factors related to intervention feasibility, acceptability and effectiveness. For the two-phase psychological intervention, pre and post standardised outcome measures are explored for three participants who attended assessment and formulation and three participants who attended the ACT group and participated in a Single Case Experimental Design (SCED). Seven participants completed a semi-structured Change Interview (Elliott, 1999; Elliott et al., 2001) regarding their experiences of the intervention and perceived changes, explored through thematic analysis (Braun & Clarke, 2006).

**Results:** The scoping review found a small number of low-quality studies have applied third-wave CBT in different formats across several FND presentations. All lacked information on feasibility and acceptability. There was promise for third-wave CBT effectiveness with improvements found for QoL, distress and psychological flexibility measures for some. The study found that changes in standardised outcome measures following each phase of the two-phase psychological intervention were complicated with a mixture of improvement, lack of change and, in some cases, worsening on standardised measures. In contrast, participants' interview accounts described the intervention positively and detailed important therapeutic changes attributable to the intervention.

**Conclusion:** Third-wave CBT is not well established for FND. While some patients benefit from these approaches, it is unclear what factors influence effectiveness. Higher quality intervention studies are required and could be developed through feasibility studies and qualitative research on different patient's perceptions and experiences of psychological intervention. The results from the two-phase psychological intervention for FND highlight the challenges of providing psychological intervention for a complex and heterogeneous clinical population.

## **Table of Contents**

Ack	nowle	dgements	iii			
Abstractiv						
Tabl	Table of Contents					
List	List of Tablesix					
List	List of Figures x					
1	Intro	oduction	. 1			
	1.1	Research overview	. 1			
	1.2	The research process	. 2			
	1.3	Overview of FND	.3			
		1.3.1 The challenges of managing FND	. 4			
	1.4	Making sense of FND	. 5			
		1.4.1 Early models	6			
		1.4.2 Psychodynamic models of FND	6			
		1.4.3 Cognitive behavioural and somatisation models	. 7			
		1.4.4 Integrative conceptual model of FND	10			
		1.4.5 Psychobiological approaches 1	13			
		1.4.6 Summary 1	15			
	1.5	Psychological interventions for FND	17			
		1.5.1 A psychodynamic approach	18			
		1.5.2 A cognitive behavioural approach	19			
		1.5.3 Third-wave CBT	20			
		1.5.4 Acceptance and Commitment Therapy	22			
	1.6	Research aims	24			
2	A sc	oping review of third-wave CBT for FND2	25			
	2.1	Rationale	25			
	2.2	Method	26			
		2.2.1 Identifying the research questions	27			
		2.2.2 Identifying relevant studies	28			
		2.2.3 Study selection	30			
		2.2.4 Data charting and collation	31			

		2.2.5 Critical appraisal	. 32
	2.3	Summarising and reporting findings	. 34
		2.3.1 What third-wave CBT interventions for individuals with FND have been reported?	. 34
		2.3.2 What is the quality of evidence for third-wave CBT for FND?	. 47
		2.3.3 Is there any preliminary evidence of factors related to intervention feasibility, acceptability and efficacy or effectiveness?	. 55
	2.4	Discussion	. 63
		2.4.1 Strengths and limitations	. 66
		2.4.2 Addressing gaps in the literature	
		2.4.3 Future direction and conclusion	
3		valuation of the impact and experiences of a two-phase psychological vention for FND	. 73
	3.1	Introduction	.73
		3.1.1 Research aims and hypotheses	.73
	3.2	Method	.74
		3.2.1 Overview	.74
		3.2.2 Design	.75
		3.2.3 Description of procedure and intervention	.76
		3.2.4 Measurement	. 81
		3.2.5 Recruitment and service context	. 89
		3.2.6 The participants	. 93
		3.2.7 Ethical considerations	. 94
		3.2.8 Inclusion and exclusion criteria	. 95
		3.2.9 Data analysis	. 95
	3.3	Results	100
		3.3.1 Overview	100
		3.3.2 Changes across a two-phase psychological intervention for FND	100
		3.3.3 SCED analysis	106
		3.3.4 Change Interview analysis	119
		3.3.5 Acceptability of the intervention	119
		3.3.6 Experiences of the intervention and change	122
	3.4	Discussion	138

		3.4.1 Phase 1 findings	138	
		3.4.2 Phase 2 findings	140	
		3.4.3 Change Interview findings	152	
	3.5	Summary of findings	155	
		3.5.1 Implications	157	
		3.5.2 Conclusion	168	
References				
List of Abbreviations				
Appendix A Full details of the search strategy, including MESH terms 193				
Appe	ndix	B Extraction tool	195	
Appe	ndix	C Quality ratings and Fleiss's kappa calculation	196	
Appe	ndix	D Measures used in scoping review studies and their references	198	
Appe	ndix	E Ethics approval	199	
Appe	ndix	F Phase 1 participant information sheet	200	
Appe	ndix	G Phase 2 participant information sheet	202	
Appe	ndix	H Change Interview	204	
Appe	ndix	I Preliminary thematic map	205	

### **List of Tables**

Table 1	Key Search terms	30
	Data extraction table detailing key information from the studies included the review	
Table 3	Description of the interventions	41
Table 4	Appraisal tools	48
Table 5	Group session topic, skill, key focus and home practice	79
Table 6	Measures used and rationale	82
Table 7	Daily survey	87
Table 8	The data provided by participants	92
	<i>The number of assessment and formulation sessions attended by</i> <i>rticipants</i>	92
Table 1	0 The number of ACT group sessions attended by participants	93
Table 1	1 Participant demographics	93
Table 12	2 RCI calculations	96
Table 1.	<b>3</b> ACT fidelity measure	98
	<b>4</b> Summary of scores for participants who completed pre and post- casures for the assessment and formulation10	03
	<b>5</b> Summary of scores for participants who completed pre, post- and low-up measures for the ACT group10	05
	<b>6</b> <i>P5 Change Interview, changes rated by expectancy, likelihood without ervention and importance</i>	10
	7 P6 Change Interview, changes rated by expectancy, likelihood without ervention and importance	15
	<b>8</b> <i>P7 Change Interview, changes rated by expectancy, likelihood without ervention and importance</i>	19
Table 19	9 Participant's responses to Change Interview questions	23

## List of Figures

<b>Figure 1</b> Factors involved in the creation and maintenance of medically unexplained symptoms taken from Chalder and Willis (2019)	8
Figure 2 Factors involved in the development of symptom chronicity from the ICM (taken from Brown, 2006)	. 12
Figure 3 Flow diagram of study identification and inclusion	31
Figure 4 The Treatment Assessment Funnel (adapted from Morley, 1996)	81
Figure 5 Types of measure used and timepoints	89
<b>Figure 6</b> Flowchart of patients who attended the Clinical Health Psychology Service between the 1st June 2019 to the 27 <sup>th</sup> February 2020	91
<b>Figure 7</b> Bar chart of participants' pre and post-intervention illness perception domain scores on the B-IPQ for Phase 1	104
<b>Figure 8</b> Visual display of P5's FND symptom severity, distress and interference scores	
<b>Figure 9</b> Visual display of P5's weekly use of ACT processes	09
<b>Figure 10</b> Visual display of P6's FND symptom severity, distress and interference scores	11
<b>Figure 11</b> Visual display of P6's weekly use of ACT processes 1	14
<b>Figure 12</b> Visual display of P7's FND symptom severity, distress and interference scores	16
<b>Figure 13</b> Visual display of P7's weekly use of ACT processes	18
<b>Figure 14</b> Thematic map of changes due to the two-phase psychological intervention	124

#### **1** Introduction

#### 1.1 Research overview

Functional Neurological Disorder (FND), also known as conversion disorder, describes neurological symptoms, such as limb weakness, seizures and visual disturbances, which, while not feigned, are inconsistent with known disease pathologies or structural or pathophysiological changes in the nervous system (American Psychiatric Association, 2013). FND results in chronic and severe symptoms associated with high health and social care costs (Adjei & Coebergh, 2014; Stone et al., 2010). The literature on effective treatments is scarce, with emerging evidence supporting the use of psychological therapies and physical rehabilitation (Baslet et al., 2020; Mayor et al., 2010; Nielsen et al., 2017; Sattel et al., 2012).

This thesis evaluates the impact of third-wave CBT for people with FND. Thirdwave CBT adopts a transdiagnostic approach to support people to change their relationship with their psychological experiences (Hayes, 2004). Special attention will be paid to the impact and experiences of a two-phase psychological intervention FND treatment pathway within the Clinical Health Psychology Service at Mid Yorkshire Hospitals NHS Trust. In Phase 1, patients with FND are offered an assessment and formulation with a Clinical Psychologist, which can last up to six sessions. Suitable patients are then offered a seven-session Acceptance and Commitment Therapy (ACT) group in Phase 2.

A multi-methods design is adopted. First, a scoping review of the extent and nature of third-wave CBT for FND is presented. The quality of evidence available regarding the effectiveness of third-wave CBT for people with FND is explored, alongside preliminary evidence of factors related to intervention feasibility, acceptability and effectiveness. Next, the impact of a two-phase psychological intervention for FND is evaluated, focusing on exploring therapeutic change. This evaluation is achieved through looking at pre and post-standardised outcome measures across each phase and by a Single Case Experimental Design (SCED) for the participants who attend the ACT group. In addition, a Change Interview (Elliott, 1999; Elliott et al., 2001) explores each participant's experiences of the intervention, perceived changes and how they make sense of this change.

#### **1.2** The research process

Initially, this work focused on a SCED exploring the changes that patients with FND experienced across a seven-week ACT group, offered as part of clinical care. The first group ran between September and November 2019, and data for three participants was collected. Unfortunately, due to the exceptional circumstances caused by the pandemic, the second ACT group was abruptly stopped in March 2020, with data collection less than halfway through. The first group participants were enthusiastic and dedicated a significant amount of their time to complete daily surveys and a Change Interview on their experiences of the group. Subsequently, it was considered essential to present this data to the best of the author's ability.

Due to the uncertainty caused by the pandemic, it was necessary to adapt some of the research objectives. It was decided to keep the initial exploration of ACT for FND and to perform an additional systematic review of the literature focused on this topic. Since the literature on ACT interventions for FND was small, this review was expanded to explore all third-wave CBT for FND. In the current thesis, due to the small and diverse nature of the studies covered, this review is presented as a scoping review.

- 2 -

Data collection from the FND pathway was amended to include Change Interviews with the four participants recruited from the suspended ACT group. Rather than focusing on their ACT group experiences, these interviews explored their experiences of assessment and formulation sessions (Phase 1). This approach has provided a broader account of participants' experiences of change across the two-phase psychological intervention and is complimented by pre and post-standardised outcome measures for each phase.

#### **1.3 Overview of FND**

FND covers a diverse range of symptoms. The most common symptoms are sensory (such as numbness or visual impairment), seizures, and motor symptoms (such as limb weakness, tremor, dystonia or gait disorders)(Carson et al., 2012). Motor Functional Neurological Disorders (mFND) covers several presentations, including weakness, gait disorders and tremor (Ricciardi & Edwards, 2014). Several terms are used to describe seizures, such as dissociative seizures/dissociative nonepileptic attack, Non-Epileptic or Psychogenic Seizures (abbreviated to NES or PNES), Functional Non-Epileptic Attacks Disorder (FNEAD) and Non-Epileptic Attack Disorder (NEAD)(Cope et al., 2017). Throughout this work, seizures will be referred to as NEAD. FND symptoms can begin suddenly and progress quickly, disappear with distraction and increase with attention or fatigue (Espay et al., 2018). The frequency and persistence of symptoms range from a single acute episode to a more chronic presentation (Stone et al., 2011).

FND frequently co-exists with somatoform/psychosomatic disorder, also known as Somatoform Symptom Disorder (SSD), which refers to physical bodily symptoms in response to psychological distress (Kozlowska, 2013; Stone et al., 2004). Comorbidity

- 3 -

of above 50% has been reported (Şar et al., 2004). Furthermore, FND is commonly associated with experiences of medically unexplained symptoms (MUS). Dixit et al. (2013) found the comorbidity to be as high as 82%.

The prevalence of FND is currently unknown. Establishing a population prevalence is difficult due to changes in its terminology, diagnostic criteria and the need for neurological examination before diagnosis (Binzer et al., 1997). Black and Andreasen (2014) estimate that 20-25% of patients admitted to neurology wards have FND symptoms, with an 18-month follow-up showing an inaccurate diagnosis in only 0.4 cases (Stone et al., 2009). A large study of neurology outpatients in Scotland estimated that around 5000 cases of FND were diagnosed per year and that functional symptoms were the second most common disorder after a headache (Stone, 2010).

#### 1.3.1 The challenges of managing FND

FND is as disabling and distressing as other neurological disorders, such as multiple sclerosis and epilepsy (Stone, 2010). It is associated with as much or more disability, distress and unemployment as other neurological disorders presented to neurologists. The long-term prognosis for FND, while variable, is often poor (Carson et al., 2012). FND is also associated with frequent hospital admissions, lengths of stay and high costs (Adjei & Coebergh, 2014; Bermingham et al., 2010). Bermingham et al. (2010) estimated the health care costs in the United Kingdom (UK) of patients with FND to be £3 billion in 2008-2009. This cost accounted for 10% of the total NHS expenditure for the working-age population during that time. They also estimated that the cost of sickness absence and decreased quality of life of people experiencing FND amounted to over £14 billion. An audit of nineteen patients diagnosed with FND in a UK hospital between 2009-2012 found that these individuals had on average five ward

admissions, six Accident and Emergency admissions, and twenty-four days of hospital stay (Adjei & Coebergh, 2014).

Qualitative studies on patients' experiences of FND and MUS highlights several difficult experiences associated with the diagnosis (Gerskowitch et al., 2015; Nielsen et al., 2019). Frequent misdiagnosis, stigma, dysfunctional medical encounters and inadequate treatments can lead to patients feeling misunderstood (Canna & Seligman, 2020). These experiences are often associated with conflicts with Health Care Professionals (HCP) and feeling abandoned by the health care system (Ahern et al., 2009; Nielsen et al., 2019). Nettleton et al. (2005) used the term 'medical orphans' to describe patients' experiences of FND. Acceptance of diagnosis is associated with higher chances of recovery. However, acceptance can be dependent on how the illness is viewed. Literature highlights the need for an integrated biopsychosocial explanatory model to help patients make sense of their illness experience and the importance of careful communication of the diagnosis as a first step in the treatment (Espay, 2018).

#### **1.4 Making sense of FND**

The aetiology of FND remains far from being fully understood. One of the earliest accounts dates back to the 19<sup>th</sup> Century when Jean-Martin Charcot proposed that 'functional lesions' to the nervous system gave rise to 'hysteria' (Bogousslavsky, 2011). Researchers have identified various psychological and psychiatric factors common in people with FND, which are purported to support different theories of FND. This section describes the following theories:

- early models;
- psychodynamic models of FND;
- cognitive behavioural and somatisation theories;

- integrative models;
- psychobiological approaches.

#### 1.4.1 Early models

Classical models of FND attributed symptoms to psychological stressors, particularly historical traumas. Janet's (1889) dissociation theory of hysteria posits that symptoms result from exposure to stressful events that cause psychological fragmentation or dissociation. Thus, a person's ability to synthesise mental content breaks down when faced with stress, resulting in disturbances of a person's voluntary control and heightened suggestibility and fragmentation (i.e. dissociation) of psychological systems. Within this framework, somatic flashbacks reflect the activation of triggered memory fragments. The person has limited awareness that they are reliving a previous experience, as memory fragments remain separated from consciousness because of the anxiety associated with recalling them. Associations between FND and increased suggestibility, attentional dysfunction and trauma have been purported to provide evidence for this dissociation theory (Brown, 2016).

#### 1.4.2 Psychodynamic models of FND

In contrast to Janet, Freud surmised that trauma could lead to the forcible repression of feelings and memories into the subconscious, with the person entirely unaware of their existence. Within this framework, psychological trauma can lead to physical excitation, which, without an outlet, can be converted into a physical complaint. Thus, symptoms are seen as a defence that helps a person survive traumatic experiences and cope with overwhelming emotions (Bowman, 2006; Goldstein & Mellers, 2006). Both Freud and Breuer postulated that once the trigger (past traumas) for the symptoms re-entered the realm of conscious recollection, catharsis can be found. The terms dissociation and conversion are still widely used. Links with early trauma and FND have been alleged to support this psychodynamic approach to FND (Ludwig et al., 2018; Myers et al., 2019). However, it is recognised that many people with FND do not report experiencing early trauma or adversity (Reuber, 2018).

FND is associated with more disruptions in emotion processing than controls and alexithymia, which refers to difficulties recognising or acknowledging affect (Novakova et al., 2015; Urbanek et al., 2014). Emotion processing difficulties correlate with more severe FND symptoms, psychological distress and poorer illness understanding. In FND, emotion processing difficulties are characterised by excessive avoidance and suppressing emotions (Novakova et al., 2015; Roberts & Reuber, 2014). Early and accumulating emotional stress can substantially impact emotion processing (Steffen et al., 2015), posited to ensue when emotional disturbances are not absorbed. This process can result in a broad range of signs that include intrusive or obsessive thoughts, irritability, fatigue, and insomnia (Rachman, 1980). These signs of emotional processing disruption are linked to interactions between predisposing, precipitating, and perpetuating factors that lead to the onset and maintenance of FND symptoms (Carson et al., 2012).

#### 1.4.3 Cognitive behavioural and somatisation models

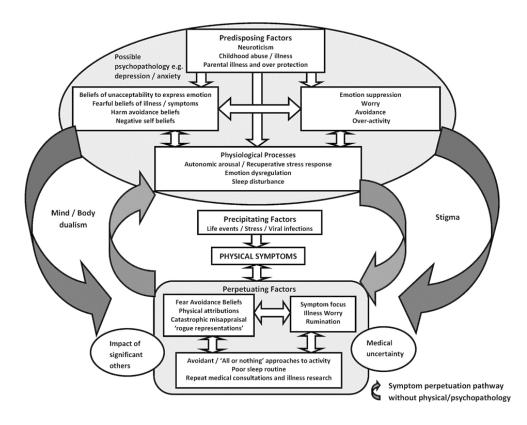
Cognitive-behavioural models of MUS (Deary et al., 2007) propose that distorted illness beliefs (such as thinking something is catastrophically physically wrong) inform unhelpful illness behaviours (such as avoidance), which in turn, maintains symptoms. Similarly, a somatisation model of MUS assumes FND symptoms reflect psychological distress (Lipowski, 1988). This model provides a broader perspective by acknowledging the importance of biological, psychological and social variables, which

- 7 -

are also identified in cognitive behavioural models. Figure 1 illustrates the key factors implicit within cognitive behavioural and somatisation models of MUS and FND.

#### Figure 1

Factors involved in the creation and maintenance of medically unexplained symptoms taken from Chalder and Willis (2019)



There are several predisposing factors for FND, such as temperamental characteristics, genetic factors and early experiences such as trauma (Myers et al., 2019). Early trauma experiences appear associated with increased symptom severity, comorbid mental health difficulties and MUS (Selkirk et al., 2008). A subgroup of FND patients appears to experience insecure and fearful attachments and increased psychological and emotional regulation difficulties (Jalilianhasanpour et al., 2019; Levita et al., 2020). Researchers have found two distinct profiles evident in NEAD patients. The first group is associated with conforming and overly controlled behaviour. The second group is characterised by more significant emotional dysregulation, a

history of using psychiatric services and a significantly poorer prognosis (Brown & Reuber, 2016a).

Several precipitating factors have been associated with FND, including a higher frequency of childhood and adulthood stressors and current or recent illness or injury (Deary et al., 2007; Ludwig et al., 2018; Nicholson et al., 2016). Additionally, higher employment in caregiving positions has been found in mFND patients, where it is hypothesised that observing unwell others can create the modelling of neurological symptoms (O'Connell et al., 2020). Potential perpetuating factors for FND patients include sensitisation processes; attributions, beliefs and responses to illness; and attention, cognitive and emotional processes (Deary et al., 2007).

Until recently, the somatosensory amplification model of functional symptoms (Barsky & Wyshak, 1990) formed the central basis of functional symptoms' cognitivebehavioural models. This model hypothesises that stress-related physical arousal and attention to physical symptoms lead to the misattribution of normal physical sensations to disease. Over time, with increased attention on physical symptoms, tolerance decreases and arousal increases, further exacerbating physical symptoms (Nakao & Barsky, 2007). However, the model does not explain why subjective and measured stress levels can be lower in those with functional symptoms (Tak et al., 2011). This is accounted for by the predictive coding framework of functional symptoms (Van den Bergh et al., 2017). Here symptoms are a set of perceptions guided by experience and based on the brain's interpretation of information from the body. Preconscious cognitive representations of a symptom are activated when specific triggers are present, such as physiological stress (Van den Bergh et al., 2017). Thus, the predictive coding framework of functional symptoms explains symptoms that occur in the absence of subjective stress and highlights the importance of context on the individual's interpretations of symptoms.

The models of FND discussed so far are all limited by the assumption that FND symptoms are a product of psychological distress. This is a premise not well established empirically. Moreover, these models fail to explain how physical symptoms can exist in the absence of visible physiological changes, such as those observed in NEAD. Attempts to account for these shortfalls have been made by integrating various models into a single coherent model explained next.

#### 1.4.4 Integrative conceptual model of FND

At the heart of the Integrative Conceptual Model (ICM) of FND, there is an awareness of the different components of consciousness, such as attention, perception and memory, that guide the preconscious interpretation of the world (Brown, 2006). Dissociation is a disruption in conscious awareness, where there is an unaccounted loss of contact with surroundings (American Psychiatric Association, 2013). There are two types of dissociative phenomena: detachment and compartmentalisation (Brown, 2016). Detachment is an altered state of consciousness characterised by a sense of separation from aspects of everyday experiences. In contrast, compartmentalisation is a shortfall in controlling processes or actions, but in which the disrupted functions continue to operate (Holmes et al., 2005). FND is fundamentally compartmentalisation (Brown, 2016).

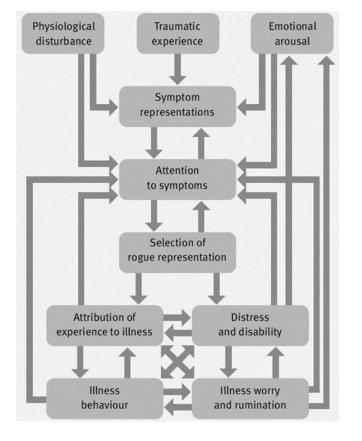
Two mechanisms underlie compartmentalisation in FND (Brown, 2016). The first is a monitoring problem, where symptoms arise due to a person triggering a behaviour or processes they are unaware of. Consequently, the person experiences the symptom as an involuntary experience of control dissociated from their experience. The second mechanism is a loss of executive control over lower-level systems. Low-level processing is automatically triggered by cues in the environment, without direct input from the executive system. Thus, symptoms are experienced as involuntary because they bypass the systems responsible for initiating intentional action.

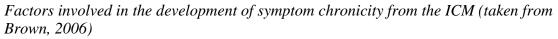
The ICM describes how information in memory shapes the automatic predictions or hypotheses we make about the input of data from our senses, which plays a critical role in our experiences and actions. Sensory information is combined with the most current hypothesis to produce a working representation of the environment, which corresponds to conscious awareness. This process enables the interpretation of events quickly by drawing on prior experiences. Typically, sensation and experiences match preconscious predictions about the world and are accurate. However, if a hypothesis in memory is disproportionately active due to strong expectation or motivation, this 'rogue representation' can be inappropriately selected as the most likely interpretation of sensory input and distort awareness to create FND symptoms. Researchers have found several disruptions to subjective experience in FND patients. These disruptions include implicit attentional biases (Pick et al., 2019), perceptual-cognitive inferences (Edwards et al., 2012), and mnemonic contributions to metacognition (Bègue et al., 2018).

Brown and Reuber (2016b) propose that NEAD results from the automatic activation of a dynamic mental representation termed 'seizure scaffold' that contains cognitive-emotional-behavioural action programs developed through experience (such as observing seizures in others, experiencing trauma, previous loss of consciousness or illness) (See Figure 2).

- 11 -

#### Figure 2





These action programmes interact with behavioural response tendencies (such as hard-wired fear-escape responses), triggered in response to internal or external cues (such as trauma memories, autonomic arousal, conditioned stimuli). This integrative model explains why some factors, such as psychiatric difficulties and early adversity, may be present in some people diagnosed with FND but not others. Edwards et al. (2012) describe a predictive coding account of mFND, which suggests that symptoms arise from disturbances in basic neurocognitive processes of sensory feedback during movement and attention to movement, which a person is unaware of. As with other models, these processes can become represented in high-level cognitive processing, such as illness beliefs and vice-versa. This account emphasises the role of neuro-rehabilitation and physiotherapy treatment for mFND. Given that FND symptoms arise

due to disruptions in the body's equilibrium, psychobiological approaches are explored next.

#### 1.4.5 Psychobiological approaches

A physiological approach to FND considers the body's role, which is a complex entity of interrelated systems that can be disrupted when faced with internal or external stress. Integral to how our body responds to stress is the autonomic nervous system. This system controls the functions that are not voluntary but often reflect our emotional state (such as heart rate, pupil and blood vessel dilation, sweat glands, and bowel and bladder movement). The autonomic nervous system is subdivided into the sympathetic nerves (that determine how to react when faced with a threat) and the parasympathetic nerves (that exert unconscious control over organs when relaxed). In the face of sudden stress, the sympathetic nerves act quickly but transiently until the threat passes. However, under chronic stress, the sympathetic nervous system is suppressed (Kozlowska, 2013). This process disrupts the equilibrium between the body's interrelated systems (i.e. homeostasis). It can create harmful brain and bodily wear and tear (McEwen, 2004) that can result in a range of somatic, behavioural and cognitive symptoms that predispose us to illness (Kozlowska, 2013).

The body also responds to stress through the action of the Hypothalamic-Pituitary-Adrenal (HPA) axis, which integrates neurological and endocrine systems. The hypothalamus can secrete hormones, some of which bind to the pituitary gland. Cortisol plays a vital role in the metabolic, cardiovascular, immune, and behavioural responses to stress and regulates the HPA axis response's magnitude. Rising levels of cortisol further reduce the adrenocorticotropic hormone and cortisol release via the hypothalamus and pituitary gland. This negative feedback loop is essential to prevent an overactive response of the body's various systems to stress. The failure of the negative feedback loop when stress is chronic, and the failure of the adequate response of the HPA axis in the face of stress, is implicated in psychosomatic illness (Keynejad et al., 2019; Kozlowska, 2013). Indeed, there is a strong association between stress and the onset or exacerbation of various physical and mental health difficulties via early life traumas and later life events preceding symptom onset (Keynejad et al., 2019).

Keynejad et al. (2019) proposed a stress-diathesis model of FND, where biological susceptibility interacts with early-life adversity. A combination of risk and protective factors influences a person's cumulative susceptibility to FND. These factors relate to neurophysiology (such as interoception, motor planning/initiation), endocrine (such as HPA response), and psychological (such as hypervigilance) functions. They propose that greater biological susceptibility can lead to FND resulting from less severe and more recent stress. In comparison, FND precipitated by more severe stress is associated with lower biological vulnerability. The model highlights that FND is maintained by psychological responses. Recent research which has focused on the neurobiology of FND is now explored.

A range of psychobiological changes have been observed in people with FND, such as reduced activation in the sensory parts of the brain (Baek et al., 2017; Maurer et al., 2016), increased connectivity between the amygdala and the supplementary motor area of the frontal lobe (Espay, Maloney, et al., 2018), and heightened amygdala reactivity when shown affectively valenced stimuli (Aybek et al., 2015; Hassa et al., 2017; Morris et al., 2017; Szaflarski et al., 2018). However, difficulties arise when considering what these observed neurobiological changes in people with FND mean. Some have interpreted the lack of structural differences in the brain to connectivity issues between different areas of the brain (Carson et al., 2016).

- 14 -

Bègue et al. (2019) reviewed 29 papers on structural neuroimaging in FND and SSD patients. They found that some FND and SSD populations exhibit overlapping structural brain alterations. Similarly, Roelofs et al. (2019) explored neuroimaging in mFND and noted studies have started to find subtle structural brain changes in people with FND. They highlight emerging neurobiological theories implicating dysfunctional emotional processing, self-image and sense of agency in people with FND. Bègue et al. (2019) specifically reviewed the role of stress-related neuroplasticity in the development of FND. They highlighted how traumatic experiences have enduring neurobiological effects. In non-clinical populations, childhood maltreatment was associated with automatic, biased negative emotional processing and aberrant amygdala activations that were also present in people with FND.

Pick et al. (2019) reviewed 27 experimental studies of emotional processing using behavioural, psychophysiological and neuroimaging measures in conjunction with affective processing tasks. FND was associated with heightened preconscious ('bottomup') processing of emotionally significant stimuli and increased affective arousal, alongside disrupted 'top-down' regulation and interoception of bodily responses. Emotional processing was associated with hyperactivation of limbic and motor systems and increased interaction of these neurocircuits. These differences could result from a range of biological and psychological risk factors associated with FND. Taken together, the latest neurobiological research highlights that the brains of people with FND are behaving differently to control participants. However, the meaning behind this remains unclear.

#### 1.4.6 Summary

As presented, there are several ways that researchers have made sense of FND. Some have adopted a purely psychological understanding. For example, early models

- 15 -

and psychodynamic approaches highlight the role of early adversity and trauma and formulate that FND symptoms result from psychological distress that is either dissociated from awareness or unconsciously suppressed. Cognitive behavioural and somatisation approaches highlight the role of thoughts and behaviours in maintaining FND symptoms and identify a range of predisposing and precipitating factors contributing to the condition. However, these approaches are primarily evidenced by exploring specific psychiatric and psychological characteristics in people with FND, where methodological shortcomings mire research. Shortcomings include small sample sizes, a lack of conceptual consistency, inappropriate control groups (e.g. epilepsy control groups), and samples with a female bias (Brown & Reuber, 2016a)

The latest psychobiological research into FND provides insights into brain activity changes, functional connectivity and brain structure and the role of cognitive processes such as self-representation and agency and emotional processing (Pick et al., 2019). However, these ideas need to be treated with caution, given the speculative interpretation of neuroimaging (Logothetis et al., 2001). Most studies involve small numbers, with results between studies variable and not always reproducible (Bègue et al., 2019).

Current formulations of FND incorporate the spectrum of predisposing vulnerabilities, acute precipitants, and perpetuating factors that have been associated with FND (Bègue et al., 2019; Brown & Reuber, 2016b). This integrative theoretical understanding has implications in how FND is treated by indicating several areas that may be amenable to psychological intervention. For example, the ICM (Brown, 2016) highlights the importance of case formulation in choosing interventions that target factors contributing to the mental representations underlying symptoms. The model also suggests that only targeting cognitions may not be useful for all individuals with FND,

- 16 -

but rather other factors such as distress tolerance, emotion regulation, and interpersonal functioning should also be considered.

The heterogeneous nature of FND highlights a role for psychological approaches that consider cognitions (CBT) and approaches that take into account the individual's needs, defence, conflicts and relationship difficulties (e.g. psychodynamic therapy). Literature also highlights potential advantages in third-wave CBT approaches that move away from looking at the content of thoughts and draw instead upon acceptance and mindfulness approaches that support the improvement of transdiagnostic processes, such as emotional processing, acceptance, and psychological flexibility. The predictive coding framework of functional symptoms indicates that developing greater present awareness skills may also be beneficial. For example, attentional disengagement, topdown processing bias, and somatosensory distortions suggest that the ability for greater present awareness (i.e. mindfulness) would perhaps prove beneficial. The next section provides a brief overview of the main psychological interventions used for people with FND, based on psychodynamic and cognitive behavioural approaches.

#### 1.5 Psychological interventions for FND

Due to limited randomised controlled trial evidence, there are currently no official treatment guidelines for FND. Clinical practices for FND include patient education (Carson et al., 2011), physical interventions (Hall-Patch et al., 2010), such as occupational therapy (Gardiner et al., 2018) and physical therapy and rehabilitation strategies (Nielsen et al., 2017), as well as psychological interventions (Goldstein et al., 2010; LaFrance et al., 2014; Sharpe et al., 2011). Psychological interventions are traditionally considered the treatment of choice for FND. These interventions typically draw upon psychodynamic therapy or Cognitive Behavioural Therapy (CBT). Carlson

- 17 -

and Perry (2017) conducted a meta-analysis of psychological studies for NEAD. The authors found a 50% reduction in NEAD frequency by at least 50% in 83% of participants, with 47% of people being seizure-free post-therapy. They found no particular therapy to be more effective than others, highlighting that various approaches may have value.

#### 1.5.1 A psychodynamic approach

Psychodynamic interventions for FND draw upon the dissociative and psychodynamic theoretical understanding of FND (Breuer & Freud, 2009). These formulations posit that FND results from the person suppressing trauma or interpersonal conflicts in early life, which is then converted into FND symptoms. Kompoliti et al. (2014) drew upon this theoretical framework to explore psychotherapy for fifteen individuals with FND who were randomly selected to receive immediate or delayed psychodynamic treatment. The intervention involved making individuals aware of their unconscious phenomena and elucidating underlying conflicts. No significant improvement in mood or symptoms could be directly related to the intervention.

In contrast, Sattel et al. (2012) found that a brief course of Psychodynamic-Interpersonal Therapy (PIT) was effective in a Randomised Control Trial (RCT) of individuals experiencing 'Multisomatoform Disorder' including at least one FND symptom. Further studies have explored Brief Augmented Interpersonal Therapy (BAPIT), which contains somatic trauma therapy elements, explicitly adapted to address FND (Howlett & Reuber, 2009; Sattel et al., 2012). Drawing upon psychodynamic theory, BAPIT addresses childhood trauma or neglect common within the FND population (Reuber et al., 2007). BAPIT has been associated with significant improvements in psychological distress, mental health, physical health, and healthcare utilisation in patients with FND (Reuber et al., 2007). In individuals with NEAD, BAPIT is also associated with sustained improvements in seizure control and healthcare utilisation (Mayor et al., 2010).

#### 1.5.2 A cognitive behavioural approach

Later theories of FND have drawn from cognitive behavioural and related somatisation models of FND. CBT involves interrupting current patterns of thoughts and behaviour by identifying negative thoughts and illness beliefs and engaging in avoided activities to reduce any anxiety associated with them. Coping strategies such as relaxation exercises and distraction techniques are also developed as part of these interventions. Such CBT approaches have been trialled with the most common FND presentations, including NEAD (Goldstein & Mellers, 2016; LaFrance et al., 2014), mFND (Dallocchio et al., 2016) and functional dizziness (Schmid et al., 2018).

Several studies have suggested that CBT has positive effects on patients with FND. Goldstein et al. (2020) compared a CBT intervention to standard medical care to treat NEAD (both groups n = 60). They found superior seizure reduction in the CBT group post-intervention and a tendency to experience fewer seizures at three-month follow-up. LaFrance et al. (2014) studied nine individuals with NEAD randomised to CBT informed psychotherapy treatment for sixteen weeks and found a 51.4% seizure reduction and significant improvements in depression, anxiety and Quality of Life (QoL) compared to controls.

Goldstein et al. (2020) carried out one of the most extensive multicentre Randomised Controlled Trials (RCT) to date. They recruited 368 patients with NEAD from twenty-seven neurology and epilepsy services across the UK. Patients were randomly allocated standardised medical care or standardised medical care plus CBT. The authors found no statistically significant advantage of CBT compared with standard care alone to reduce monthly seizures. However, they did find improvements in several clinically relevant secondary outcomes following CBT, including health-related QoL, symptom inference, distress and somatic symptoms, which remained at 12-month follow-up.

O'Connell et al. (2020) examined CBT's effectiveness for mFND in a neuropsychiatric outpatient centre in the UK by exploring routine data collection from 98 patients with mFND between 2006 and 2016. Only a small subset of patients had pre and post-CBT scores related to symptoms, distress and QoL. However, significant improvements were found across scores. The authors found that the only predictor of symptom improvement was the acceptance of a psychological explanation of symptoms before treatment. A recent systematic review and meta-analysis by Revell (2019) explored CBT as an intervention for a wide range of FND symptoms. Based on nine high-quality studies, they found CBT significantly improved daily functioning outcomes, FND symptoms and depression and anxiety when compared to control groups.

#### 1.5.3 Third-wave CBT

CBT was the most popular psychological approach in the late 1980s and 1990s. However, critiques highlighted insufficiencies in the ability of the approach to adequately address the needs of disenfranchised or hard to treat clinical populations, as well as inadequate consideration of mechanisms of change through which symptoms improved (Linehan, 1993; Safran et al., 1988; Wierzbicki & Pekarik, 1993). These concerns spurred the development of diverse therapeutic approaches that included processes such as mindfulness, acceptance, cognitive defusion, emotions, metacognition, dialectics, contextual analysis, valued action and behavioural activation (Kahl et al., 2012). These approaches are distinct from primarily behavioural (first-wave) and cognitive (second wave) approaches and were subsequently termed 'third-wave' (Hayes, 2004).

Unlike its predecessors, third-wave CBT approaches are based on contextual concepts focused more on the person's relationship to thoughts and emotion than their content (Hayes, 2004). This shift from emphasising specific cognitive techniques aimed at distracting from unpleasant experiences or symptoms may be particularly beneficial for patients with FND. Villatte et al. (2015) argue that cognitive approaches focused on cognitive techniques and avoidance may paradoxically increase an individual's experiences via increasing vigilance (e.g. initiating or maintaining distraction) and through outcome monitoring (e.g. by evaluating the success or failure of control attempts). This process, in turn, causes insensitivity to other vital parts of their experience. In contrast, third-wave CBT focuses on developing meta-cognitive skills that support patients in observing their thoughts as mental events without becoming 'hooked' in their content. Being able to defuse from thinking leaves room for people to consider what is important to them and contributes to adaptive behaviour that decreases symptomatology.

Third-wave CBT approaches include ACT, Dialectical Behaviour Therapy (DBT), Mindfulness-Based Therapy (MBT), Meta Cognitive Therapy (MCT) and Compassion-Focused Therapy (CFT), among others (Hayes, 2004; Hayes, Villatte, et al., 2011). DBT was initially developed for patients diagnosed with Borderline Personality Disorder (BPD) and assumes shortfalls of emotion regulation skills (Linehan, 1993). As a result, DBT teaches an extensive range of skills in mindfulness, distress tolerance, emotion regulation and interpersonal effectiveness (Mckay et al., 2007). Similarly, MBT uses psychoeducation and encourages patients to practise mindfulness meditation (Ludwig & Kabat-Zinn, 2008). The main aim is to develop metacognitive awareness, where an individual can experience cognitions and emotions as mental events that pass

- 21 -

through the mind, which may or may not be related to external reality (Segal et al., 2002).

MCT was developed from traditional cognitive therapy and focuses on metacognition, which is an aspect of cognition that controls mental processes and thinking (Wells, 2011). This approach theorises that at the core of anxiety and depression is a cognitive attentional syndrome, which consists of repetitive cognitive processes such as worrying, rumination, flawed threat monitoring, cognitive and behavioural coping. MCT targets metacognition changes by teaching detached mindfulness, using attention training techniques to develop cognitive flexibility skills, and guiding cognitive and behavioural experiments to change metacognition. Finally, CFT encourages patients to care for their wellbeing, become sensitive to their own needs and distress, and extend warmth and understanding towards themselves (Gilbert, 2009).

#### 1.5.4 Acceptance and Commitment Therapy

ACT is a transdiagnostic approach designed to increase psychological flexibility, or the ability to behave consistently with one's values even in the face of unwanted thoughts, feelings, and bodily sensations (Hayes et al., 2006). In contrast, psychological inflexibility is characterised by experiential avoidance, cognitive fusion, self-as-content, lack of contact with the present moment, lack of values, and a lack of commitment to action. The ACT model conceptualises that many psychological and behavioural problems occur as a result of experiential avoidance or an unwillingness to experience unwanted internal events (such as thoughts, emotions, memories, and body sensations) and attempts to reduce the form, frequency, or situational sensitivity of these events (Hayes et al., 2006).

- 22 -

There is some evidence for ACT improving outcomes in chronic pain (Hann & McCracken, 2014) and growing evidence for ACT improving mental health conditions (A-tjak et al., 2015) and chronic diseases (Graham et al., 2016). However, this evidence is inconsistent, and studies are characterised by small samples and low-quality methods (A-tjak et al., 2015; Williams et al., 2020). Thus, indicating the need for higher quality research for ACT and these different clinical groups.

Recent research using single-case study designs has shown decreases in FND symptoms and distress (Graham et al., 2018; Graham et al., 2017), suggesting that an ACT approach may have value for individuals experiencing FND. Unlike other approaches which focus on FND symptoms to control or eliminate them, and related emotions and cognitions, ACT focuses on helping individuals move towards meaningful activities. Thus, an individual with FND may not experience symptom change, but therapy may still be effective (Graham et al., 2016).

Intervention according to the ACT model typically consists of three components that increase psychological flexibility: i) awareness and non-judgmental acceptance of all experiences, both negative and positive; ii) identification of valued life directions and iii) appropriate action toward goals that support those values (Hayes et al., 2011b). This process is facilitated through targeting specific aspects of psychological inflexibility such as acceptance (i.e. willingness to experience aversive emotions and other internal experiences without avoidance), cognitive defusion (i.e. relating to thoughts as just thoughts), present moment awareness (flexible attention to current experiences), and values (i.e. clarifying personally meaningful qualities of action) (Hayes et al., 2011).

#### 1.6 Research aims

This work evaluates the impact of third-wave CBT for people with FND using a multi-methods design. First, a scoping review explores the extent and nature of third-wave CBT for FND and the quality of evidence regarding its efficacy and effectiveness. Moreover, preliminary evidence of factors related to intervention feasibility, acceptability and effectiveness are explored. The review uses established transparent and systematic methods to collate, summarise, and report findings (Arksey & O'Malley, 2005; Peters et al., 2020). Next, the impact of a Clinical Health Psychology Service two-phase psychological intervention for FND is explored, focusing on exploring what therapeutic change is experienced by participants. Specific hypotheses are made concerning changes in pre and post-standardised outcome measures following each intervention phase. A SCED facilitates a more detailed exploration of changes across the ACT group intervention. Finally, a Change Interview captures the participant's experiences of the intervention, perceived therapeutic changes and how they made sense of these changes.

#### 2 A scoping review of third-wave CBT for FND

#### 2.1 Rationale

Third-wave CBT aims to change the individual's relationship to their psychological experiences and, consequently, adopt a transdiagnostic approach that transcends diagnostic categories (Hayes, 2004). Transdiagnostic processes such as difficulties with emotion regulation are essential skills addressed in third-wave CBT. This approach aims to reduce unhelpful and avoidant coping and encourage adaptive emotion regulation skills such as reappraisal, self-soothing and mindfulness (Shields et al., 2016). The broad focus on psychological experience and transdiagnostic processes means that third-wave CBT comprises a heterogeneous group of different therapeutic approaches. These include ACT (Hayes, Strosahl, et al., 2011), DBT (Linehan, 1993), MBT (Ludwig & Kabat-Zinn, 2008), and MCT (Wells, 2011). Connecting these approaches is a focus on strategies such as; mindfulness, acceptance, cognitive defusion, dialectics, contextual analysis, valued action and behavioural activation (Kahl et al., 2012).

Each of these third-wave CBT approaches has a growing evidence-base for various clinical populations. There is some evidence, albeit low quality, supporting ACT for improving outcomes in chronic pain (Hann & McCracken, 2014), mental health conditions (A-tjak et al., 2015), and chronic diseases (Graham et al., 2016). DBT has been shown to lead to decreases in suicidal behaviour and depression and improved anger control and healthcare utilisation for patients with a diagnosis of BPD (McMain et al., 2009; Neacsiu et al., 2012; Soler et al., 2009) and to impact intrapsychic and personality factors (Bedics et al., 2012). While MBT has shown changes in metacognitions for individuals with Obsessive-Compulsive Disorder (OCD), improved outcomes for patients with generalised anxiety disorders and high remission rates in treatment-resistant depression (Solem et al., 2009; van der Heiden et al., 2012; Wells et al., 2012). MCT has also shown reduced relapse rates and outcomes in depression (Kuyken et al., 2008), alcohol and drug use (Witkiewitz & Bowen, 2010).

Although there is a growing interest in third-wave CBT, little is known about third-wave CBT for FND. A preliminary search for existing scoping reviews and systematic reviews on the third-wave CBT for FND was carried out in June 2020 on the following bibliographic databases: PsycINFO, EMBASE MEDLINE. It revealed that no reviews had explored the relationship between third-wave CBT and FND, and only a small number of diverse studies have explored third-wave CBT for FND. From this preliminary search of the literature, it was established that a scoping review would allow the author to examine the extent and nature of studies on third-wave CBT for FND. A scoping review helps determine the value of undertaking a full systematic review, summarises and disseminates research findings and identifies gaps in the existing literature (Arksey & O'Malley, 2005). The review determines the quality of available evidence to enable practice recommendations to be made in the context of the evidence quality. The review also charts any preliminary evidence of factors related to intervention feasibility, acceptability and effectiveness and efficacy.

#### 2.2 Method

The present study consulted the Joanne Briggs Institute manual for scoping reviews (Peters et al., 2020) and adopts the five-stage framework of Arksey and O'Malley (2005), which involves (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising, and reporting the results.

- 26 -

## 2.2.1 Identifying the research questions

The current review explores the extent and nature of studies on third-wave CBT for FND and determines whether there is good quality evidence regarding their efficacy or effectiveness to facilitate practice recommendations. The extent and nature of thirdwave CBT interventions for FND are explored by describing the research designs, participant demographics, research interventions, and outcome measures. The literature is then critically appraised using standardised tools to identify potential sources of bias and research gaps to contextualise practice recommendations. Finally, establishing whether any preliminary factors relate to feasibility, acceptability, and effectiveness or efficacy of these approaches may help understand current trends and gaps in knowledge and identification of areas that may benefit from further exploration.

Feasibility is a concept that encapsulates ideas about whether it is possible to do something and refers to the state or degrees of the intervention being easily or conveniently delivered (Sekhon et al., 2017). Acceptability is a multi-faceted construct that refers to the perceived appropriateness, fairness, reasonableness, and intrusiveness of intervention for addressing a specific concern (Kazdin, 1981; Nastasi & Truscott, 2000; Reimers et al., 1992). In a healthcare intervention, acceptability reflects the extent to which people who are delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention (Sekhon et al., 2017). Finally, efficacy explores whether an intervention produces the expected result under ideal circumstances; effectiveness measures the degree of beneficial effect under 'real world' settings (Godwin et al., 2003).

Feasibility and acceptability are assessed by participant uptake, drop-out, nonresponse and deterioration rates in intervention studies, the practicality of the

- 27 -

intervention (e.g. duration, clinician involvement and expertise and adaptability of intervention across different contexts), and by qualitative descriptions of intervention experiences and satisfaction (Gadke et al., 2021). Effectiveness and efficacy will be measured by analysing the impact of the intervention on outcome measures. In summary, the review considers the following research questions:

1. What third-wave CBT interventions for individuals with FND have been reported?

2. What is the quality of the evidence for CBT third-wave therapies for FND?

3. Is there any preliminary evidence of factors related to intervention feasibility, acceptability and efficacy or effectiveness?

### 2.2.2 Identifying relevant studies

The search terms were developed and categorised based on two dimensions related to the review aims. One dimension was related to third-wave CBT (i.e. the intervention examined), while the other dimension related to FND (i.e. the clinical population). Initial scans of the literature were carried out to find keywords for each dimension. Once a preliminary list of words was collected, experts in the area were asked for their opinion and to identify any missed keywords related to the review aims. Examples of third-wave CBT approaches searched for included MBT, ACT and DBT. Examples of FND search terms included psychogenic, conversion disorder and nonepileptic seizure disorder (see Table 1).

Full details of the search strategy, including MeSH terms, are provided in Appendix A. The Boolean *OR* operator separated each search term, and each dimension was separated by the Boolean *AND* operator, outlined in Table 1. The following bibliographic databases were searched from the earliest available listing up to June 2020: PsycINFO, EMBASE, and MEDLINE, to identify potentially relevant documents. The abstract, title and keyword fields were searched in all databases to capture relevant studies. Due to limitations in resources, only English Language studies were included. The search strategy was drafted by an experienced librarian and further refined through discussion in supervision. The final search results were exported into EndNote, and duplicates were removed. The electronic database search was supplemented by carrying out a backwards and forwards citation search.

Eligibility criteria were developed to focus the scope of the review. Literature related to third-wave CBT interventions, delivered either by a trained clinician or supervised by a trained clinician. Self-help interventions were included if they were guided by weekly input from a clinician. If identified studies involved participants receiving additional treatment alongside a third-wave CBT intervention, they were included but highlighted as such. Literature could relate to intervention outcome studies or qualitative accounts of third-wave CBT interventions. Literature also had to relate to participants diagnosed with and experiencing FND. Studies with subgroups of patients who met the criteria for FND were included if separate data on FND participants could be extracted. There was no age specification placed on participants.

- 29 -

#### Table 1

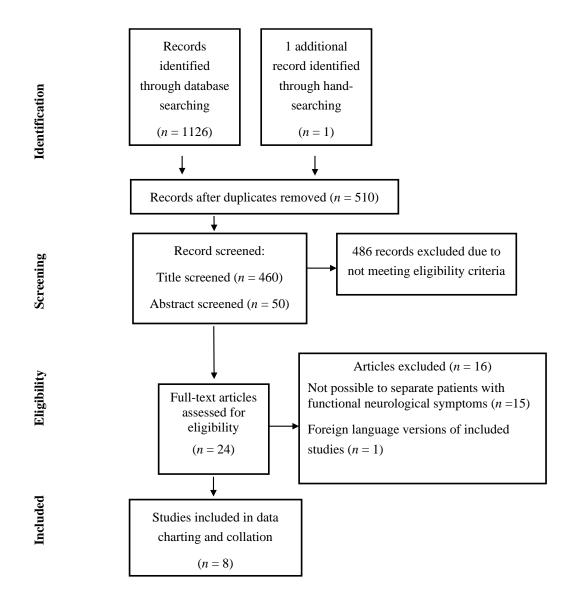
Key Search terms

	Search terms
AND	"bodily stress adj2 (syndrome* or disorder*))" OR "complex physical symptoms" OR "conversion disorder" OR "Dissociative Disorders" OR "dissociative adj2 (disorder* or convulsion* or seizure*))" OR "FND" OR "(functional adj2 (tic* or tremor* or stroke* or movement* or motor* or somatic* syndrome* or neurological* or disorder* or symptom* or seizure*))" OR "((functional or psychogenic) adj2 (paresis* or weakness* or twitching* or sensory disturbance*))" OR "Gait Disorders, Neurologic" OR "gait disorder*" OR "hysteric*" OR "(medically unexplained adj2 (physical* or disorder* or syndrome* or symptom*))" OR "medically unexplained symptoms/" OR "medically unexplained symptoms" OR "((movement or motor) adj (disorder* or symptoms*))" OR "NEAD" OR "((nonepileptic or nonepileptic) adj (attack* or seizure* or event*))" OR "medically unexplained symptoms" OR "((movement or motor) adj (disorder* or symptoms*))" OR "((nonepileptic or nonepileptic) adj (attack* or seizure* or event*))" OR "(nonorganic" OR "Psychophysiologic Disorders" OR "pseudoseizure*" OR "psychosomatic*" OR "persistent physical symptom*" OR "Somatoform Disorders" OR "somatoform*" OR "somati#ation*" OR "(unexplained adj2 (tremor* or weakness* or twitching*))"
	"Acceptance and Commitment Therapy" OR "acceptance and commitment therapy" OR "((behavioural or behavior) adj activation)" OR "(cognitive behavio* analysis system of psychotherapy or CBASP)" OR "(compassion focused therapy or compassion focussed therapy or compassionate mind or self-compassion)" OR "defusion" OR "(dialectical behavioural therapy or DBT)" OR "emotion* processing" OR "metacognitive therapy" OR "Mindfulness" OR "(mindfulness- based cognitive therapy or MBCT)" OR "(thirdwave or third-wave)"

# 2.2.3 Study selection

Based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) statement (Moher et al., 2009), articles were evaluated on whether they met the eligibility criteria by following three screening steps; title, abstract, and full text (see Figure 3). The last database search was conducted in June 2020; 1127 articles were identified, from which 510 duplicates were removed. All potentially relevant articles went through a two-step screening process. The first step was to exclude irrelevant articles by screening titles and abstracts. The second step was to filter out unrelated articles by screening full texts. Any studies where it was unclear whether inclusion criteria were met were discussed with the supervisory team.

#### Figure 3



Flow diagram of study identification and inclusion

Note. PRISMA reporting standards (Moher et al., 2009)

## 2.2.4 Data charting and collation

The lead author extracted data from all studies which met eligibility criteria. Data were extracted onto standard forms (Appendix B). Extracted information included the author, year of publication, description of the intervention, study design, data collected, participant characteristics, evidence of feasibility and acceptability and main findings. All data was charted using tables, and where categories in the data formed, they were

summarised descriptively and structured according to the review questions (Khalil et al., 2016). For example, information related to the intervention, such as the rationale for the third-wave CBT approach, intervention description, duration and facilitators and treatment fidelity and deviations, were charted and collated. This intervention information then informed exploration of preliminary factors related to intervention feasibility, acceptability, efficacy, and effectiveness.

## 2.2.5 Critical appraisal

This review explores the characteristics and methodological quality of third-wave interventions for patients with FND to identify potential sources of bias and understand research gaps to contextualise practice recommendations. Given the broad range of study designs extracted, a range of quality appraisal tools was initially considered. After piloting several tools, the Mixed Methods Appraisal Tool (MMAT, 2008) was chosen as it provided an overarching quality appraisal tool covering the diverse range of studies captured. It enables the appraisal of five study categories; qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive studies, and mixed methods studies. However, due to the design of studies identified, only the 'quantitative descriptive studies' category was used. This category consists of five different quality criteria, which are rated as either '0' (Yes), '1' (No) or '2' (cannot tell).

Notably, two of the quality items on the MMAT – 'is the sample representative?' and 'is there a risk of non-response bias?' – did not apply to the single-case designs included in this review. Non-response bias occurs when people who participate in a research study are inherently different from those who do not participate, which negatively impacts a sample's representativeness and skews outcomes (Hong et al., 2018). The single-case studies cannot be rated to these items due to the focus on one participant, and the items were subsequently marked as 'non-applicable'.

The MMAT allows for the use of additional quality appraisal tools to capture study designs not explicitly covered (Hong et al., 2018). Thus, for the single-case studies and case series, Morley's (2017) single-case appraisal guidelines were also used. These guidelines provide a minimum requirement for considering the quality of singlecase research using six different criteria designed to provide a descriptive account of studies. In the current study, a three-point rating was used to supplement the descriptive account. The six items were rated as either '0' (Yes), '1' (No) or '2' (Partial). This numerical rating was adopted from the RoBiNT (Risk of Bias in N-of-1 Trials) developed for SCED (Tate et al., 2008), which enabled an overall quality rating.

In addressing the research question 'What is the quality of evidence for third-wave therapies?' (See section 2.3.2), overlapping categories from the MMAT and Morley's (2017) guidelines are integrated under the same subheadings when providing descriptive detail to avoid repetition.

Inter-rater reliability. Inter-rater reliability can be defined as "the extent to which independent coders evaluate a characteristic of a message or artefact and reach the same conclusions" (Lombard et al., 2002, p. 589). Measuring this is important to establish a reliable estimation of study quality, with a low agreement between raters indicative of weakness in the critical appraisal process (Kolbe & Burnett, 1991). Consequently, each study was appraised by an independent rater, enabling inter-rater reliability to be calculated using Fleiss's kappa statistic, which considers the chance agreement between two or more raters (Fleiss, 1971). Both coders individually rated each of the studies against the quality criteria for the MMAT and, where appropriate, Morley's (2017) single-case appraisal guidelines (see Appendix C). Results were then compared, and disagreements were discussed between coders.

# 2.3 Summarising and reporting findings

Following the fifth stage of Arksey and O'Malley's (2005) framework for scoping reviews, the next sections summarise, report on, and discuss findings from the identified articles. The review explores the extent and nature of third-wave CBT for FND and determines whether there is good quality evidence regarding their efficacy and effectiveness by now presenting the findings for each of the research questions.

# 2.3.1 What third-wave CBT interventions for individuals with FND have been reported?

The search strategy yielded 1126 articles; 616 of these were duplicates. After screening and eligibility checks, eight articles detailing different third-wave CBT interventions for FND met eligibility criteria (see Figure 3). All articles outlined intervention studies; no qualitative articles were found. Table 2 summarises the data extraction table detailing key information from the studies included in the review. Here, the characteristic sources of evidence are described in relation to research design, research demographics and the research intervention to explore the scope and nature of third-wave CBT for FND.

# Table 2

# Data extraction table detailing key information from the studies included in the review

Study number, Authors, year	Recruitment	t Intervention Design type		Sample characteristics	Outcome measures Timepoints	Key findings
1. Barrett- Naylor, Gresswell & Dawson, 2018.	Through NEAD social media support group in the UK.	ACT guided self-help Six weekly 30-minute phone calls	case-series	N = 6 FND type: NEAD Age range: not reported Mean age: 45.3 yrs ( $SD = 15.86$ ) Gender: 5 females; 1 male	NEAD frequency, psychological health, psychological flexibility, and QoL All measures were collected just at; T1: Pre-intervention T2: Post-intervention T3: One-week follow- up T4: One-month follow- up S1-S6: NEAD frequency and psychological flexibility only	Psychological flexibility improved for all; reliable and clinically significant change for psychological flexibility, QoL and psychological health for 4 participants post-intervention, with QoL improvement remaining at follow-ups. Reductions in NEAD frequency for 4 participants, with 3 maintaining this at follow-up.
2. Baslet, Dworetzky, Perez, & Oser, 2015.	Through a medical centre in Chicago, America.	MBT programme 12 individual sessions	Consecutive case-series	N = 6 FND type: NEAD Age range: $18 - 59$ yrs Mean age: $39.7$ yrs Gender: 6 females	NEAD frequency, depression and psychological health. All measures collected just at; T1: Start of treatment T3: End of treatment (S12) S1-S12: NEAD frequency only	Average QoL improved from 2.59 (SD = $0.73$ ) at baseline, to 2.4 (SD = $0.76$ ) mid-intervention, and 2.14 (SD = $0.77$ ) post-intervention. All reported a decline in weekly NEAD frequency from baseline (median of 5.5 weekly events, mean of 18 weekly events) by the sixth session (median of 0.75 weekly events, mean of 2.25

						weekly events). The mean difference between pre (baseline) and post-treatment (12th session) was -14.98 weekly NEAD events. Three participants had remission of episodes based on weekly NEAD frequency at session 12.
3. Baslet, Ehlert, Oser & Dworetzky, 2020.	Patients with documented video-EEG diagnosis from Brigham and Women's Hospital, Boston, America.	MBT programme 12 individual sessions	Uncontrolle d trial	N = 26 FND type: NEAD Age range: not reported Mean age: 46.4 yrs Gender: 23 females, 3 males	NEAD frequency, intensity and duration, psychological health, QoL, somatisation and dissociation. All measures collected just at; T0: Baseline T1: Start of treatment T2: Treatment midpoint (S6) T3: End of treatment (S12) S1-S12: NEAD experiences only	NEAD frequency decreased by 0.12 episodes per week (95%, $CI = 0.2 - 0.04$ ) for every successive session ( $p = 0.002$ ). Thirteen patients reported no NEAD at the final session from the previous session and six described sustained cessation during the last four weeks of treatment. At last session median NEAD intensity significantly reduced to 3.74 ( $SD =$ 2.65) ( $p = 0.012$ ). From post- diagnosis appointment (T0) to last session, Qol improved ( $p = 0.002$ ).
4. Baslet & Hill, 2011.	Through an inpatient psychiatric hospital, America.	ACT-based group Three group sessions and two individual sessions	Single case study	N = 1 FND type: mixed FND Age: 31 yrs Gender: female	Qualitative changes in FND symptoms.	FND symptoms reported as not present by the end of treatment and at a one-month follow-up by authors.
5. Bullock, Mirza, Forte,	Patients receiving standard	DBT informed skills group	Naturalistic design	<i>N</i> = 19 FND type: NEAD	Sessional NEAD frequency collected.	A reduction of at least 50% from the baseline weekly seizure rate occurred in 9/17 (53%) completers.

& Trockel, 2015.	care from the Stanford University Department of Psychiatry, America.	Weekly 90 minute sessions of three consecutive repeating modules lasting 8-10 weeks		Age range: not reported Mean age: 44.5 yrs Gender: 18 females, 1 male	Six participants had complete cessation of seizure activity during the study. Using all available data from 19 participants over two years, mixed-effects regression model estimates indicated that from baseline to session 20.5 (average treatment time), the average seizure rate decreased by 66% (event rate ratio 50.34; 95%, CI = 50.19, 62). Statistically significant drop in average seizure frequency from 13.8 to 4.7 events per week ( $t = -3.76$ , $df = 17$ , $p =$ 0.002).		
6. Graham, O'Hara, & Kemp, 2018.	Through an NHS clinical neuropsycho logy department in Leeds, UK.	Individualise d ACT intervention 6-8 individual sessions	Consecutive case-series	N = 8 FND type: mixed Age range: 18-65 yrs Mean age: not reported Gender: most female, the number not specified	Symptom interference, psychological flexibility, and mood. All measures collected just at; T1: Start of treatment T2: Post-intervention	Five participants showed reliable improvements in symptom interference to a large magnitude (d = 1.02), 4 showed reliable improvements in mood to a large magnitude $(d = 1.70)$ . There was variation in psychological flexibility where improvement was at a medium magnitude $(d = 0.77)$ .	
7. Graham, Stuart, O'Hara & Kemp, 2017.	Through an NHS clinical neuropsycho logy department in Leeds, UK.	Individualise d ACT intervention 6 individual sessions	Single case study	N = 1 FND type: mFND Age: early twenties Gender: female	Symptom interference, psychological flexibility, and mood. All measures were collected just at; T1: Start of treatment T2: Post-intervention	Participant experienced a reliable and clinically significant improvement in symptom interference ( $RCI = 6.07$ ), mood ( $RCI = 5.91$ ; $CSC = 10.84$ ) and psychological flexibility ( $RCI =$	

						6.22; <i>CSC</i> = 22.76). FND symptoms almost entirely ceased.
8. Rancourt & Darkes, 2018.	Through a Primary Care-Mental Health Clinic in Florida, America.	DBT- informed psychotherap y 25 individual sessions	Single case study	N = 1 Age: 30yrs Gender: female FND type: mFND	Depression, PTSD, and alcohol intake All measures were collected just at; T1: Start of treatment T2: Mid-intervention T3: Post-intervention	Reliable and clinically significant improvement in PTSD (pre = 63; post = 51) and a reliable improvement in mood (pre = 26, post = 13). RCI not provided. In the final session participant using a walker and not in a wheelchair.

#### Characteristics of sources of evidence

*Research design.* Eight studies met the criteria for this review. As summarised in Table 2, these studies used diverse designs, clinical populations and measures. Three studies were single-case studies, three were case series, one used a naturalistic design, and another used a non-controlled trial design.

*Participant demographics*. The vast majority of participants across the studies were female, which appeared not to be intentional but somewhat representative of the female preponderance in FND (Asadi-Pooya et al., 2013; O'Connell et al., 2020). Ages ranged from 18 to 65 years. Sample sizes varied from single-case studies (Baslet & Hill, 2011; Graham et al., 2017; Rancourt & Darkes, 2018), up to a sample of 26 patients (Baslet et al., 2020), with full details of these different characteristics summarised in Table 2.

Four studies focused exclusively on NEAD participants (Barrett-Naylor et al., 2018; Baslet et al., 2015; Baslet et al., 2020; Bullock et al., 2015). Two single case studies reported on participants with mFND (Graham et al., 2017; Rancourt & Darkes, 2018). A further two studies reported participants with mixed FND presentations (Baslet & Hill, 2011; Graham et al., 2018). Mixed FND presentations included; arm tremor, leg weakness/ paralysis, propriospinal myoclonus, paraesthesia, visual disturbance, and syncope.

Several studies described participants having a range of comorbid psychiatric diagnoses and physical health difficulties. Baslet et al. (2020) provided a detailed account of participants' clinical characteristics; 88.5% (n = 23) of their sample reported current or past anxiety disorders, 80.8% (n = 21) depressive disorder, and 53.8% (n = 14) reported Post Traumatic Stress Disorder (PTSD); with a total of 23 of their participants (88.5%) reporting past psychiatric treatment. In comparison, some studies

did not provide details on broader participant characteristics (Barrett-Naylor et al., 2018; Graham et al., 2017).

Other studies provided only brief details on participants' demographics. For example, Baslet et al. (2015) described one patient with NEAD also had epileptic seizures, while Bullock et al. (2015) reported that two patients with NEAD also had epilepsy. Graham et al. (2017) noted that their participant 'Claire' had no comorbid diagnosis. Rancourt et al. (2019) explained that 'Jane' met the criteria for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) diagnosis of PTSD and major depressive disorder. Finally, Baslet and Hill's (2011) study of 'Annie' reported that she had a diagnosis of recurrent major depressive disorder, generalised anxiety disorder, and PTSD.

*Research interventions*. A range of third-wave CBT approaches was adopted, with sessions spanning from 3 to 26 sessions and delivered in varying formats – group sessions, individual sessions and guided self-help. Full details of the interventions are summarised in Table 3. Three studies focused on ACT interventions (Barrett-Naylor et al., 2018; Graham et al., 2018; Graham et al., 2017). Three studies used MBT (Baslet et al., 2015; Baslet et al., 2020; Baslet & Hill, 2011) and two used DBT-informed interventions (Bullock et al., 2015; Rancourt & Darkes, 2018).

# Description of the interventions

Authors, years	The rationale for third- wave CBT	Intervention description	Duration and facilitator	Treatment fidelity and deviations
1. Barrett- Naylor, Gresswell & Dawson, 2018.	Experiential avoidance of internal states, limited awareness, automatic (versus purposeful) behaviour, and heightened arousal implicated in NEAD addressed by ACT through psychological flexibility. Self-help hypothesised to be helpful, given psychological intervention, and face-to- face therapies can be experienced as aversive and precipitate seizure occurrence.	Six session ACT self-help intervention with weekly 30- minute phone calls to support material. The intervention was based on chapters from the book 'Get out of your head and into your life' (Hayes, 2005) and covered acceptance, cognitive defusion, self as content, mindfulness, values and committed action.	Six weekly 30 - minute phone calls. Trainee clinical psychologist.	No treatment deviations or treatment fidelity measures reported. The intervention adopted a manualised approach.
2. Baslet, Dworetzky, Perez, & Oser, 2015.	MBT corresponds well with NEAD, as the approach targets underlying psychological vulnerabilities, such as	Individual face-to-face MBT programme. Four modules; (1) psychoeducation and goal setting, (2) stress management training, (3) mindfulness	Four modules delivered over 12- hour sessions.	Timing for completion of each of the four core models was flexible. The frequency of sessions was flexible depending on patient availability. A weekly to biweekly frequency of sessions encouraged but not

	poor recognition and acceptance of emotional states.	training, and (4) emotion recognition, acceptance and behavioural regulation.	Facilitator not specified.	always possible. No treatment fidelity measures specified. The intervention adopted a manualised approach.
3. Baslet, Ehlert, Oser & Dworetzky, 2020.	MBT corresponds well with NEAD, as the approach targets underlying psychological vulnerabilities, such as poor recognition, acceptance and management of emotional states.	Individual face-to-face MBT programme. Five modules; (1) understanding your disease and treatment, (2) stress and management strategies, (3) mindfulness, (4) emotion management, and (5) reworking cognitions and relapse prevention.	12-hour sessions. Independent clinical social workers.	Attendance of weekly supervision. Manual checklists, notes and discussions determined compliance with elements of the programme. Thirteen participants required at least one additional session (seven participants had one additional session, five participants had two additional sessions, and one participant had three additional sessions). The average time between sessions 10.15 days ( $SD = 2.23$ ). The intervention adopted a manualised approach.
4. Baslet & Hill, 2011.	Increased avoidance and difficulties in emotion expression involve a disruption in the integrative capacity that may underlie FND. Mindfulness focused on acceptance redirects attention and behaviour choices toward high-value roles.	Group based MBT programme and individual follow-up sessions, covering; (1) lifestyle development associated with better management of stress (e.g. supportive relationships, interpersonal effectiveness, personal responsibility), (2) mindfulness practice and discussion, (3) uncontrollability of thoughts, feelings, and body sensations	Three group-based sessions, duration not specified. 2- hour individual sessions. Ward psychotherapist.	No treatment deviations or treatment fidelity measures reported. The intervention adopted a manualised approach for group sessions and an individualised formulation for one-to-one sessions.

		and controllability of actions, and (4/5) historical links to current life context.		
5. Bullock, Mirza, Forte, & Trockel, 2015.	Epidemiological characteristics of patients with FND similar to BPD, FND patients show a deficit in implicit to explicit processing of emotions. Subsequently, a DBT approach targeting emotional dysregulation may be useful for patients with FND.	DBT-Skills Training was psycho-educational and included; (1) distress tolerance, (2) emotion regulation, and (3) interpersonal effectiveness. Each module was preceded by one week of mindfulness training. Groups adhered to Marsha Linehan's 'Skills Training Manual for Borderline Personality Disorder' (Linehan, 1993).	Group held weekly for 90-minutes in three consecutive repeating modules lasting 8–10 weeks each. They were led by an intensively trained DBT therapist and two trainee level co- leaders.	Groups were videotaped and reviewed for adherence criteria by an outside DBT certified consultant. Process and content supervision occurred during weekly hour debriefings with consultant and co- leaders. The intervention adopted a manualised approach.
6. Graham, O'Hara, & Kemp, 2018.	ACT does not have prior assumptions on the causes of FND and emphasises patient's lived experiences of the disorder makes ACT applicable for the psychological heterogeneity within FND.	ACT intervention compromised assessment, formulation and treatment strategies.	<ul> <li>6 –8 individual one-hour fortnightly sessions.</li> <li>A clinical psychologist trained in ACT.</li> </ul>	The number of sessions could be extended based on need. No treatment fidelity measures reported. The intervention used adopted an individualised formulation approach.
7. Graham, Stuart, O'Hara & Kemp, 2017.	ACT via a process of psychological flexibility supports behaviours consistent with a person's	As described above in Graham, O'Hara, and Kemp, 2018.	Six sessions of ACT.	No treatment deviations or treatment fidelity measures reported. The intervention used adopted an individualised formulation approach.

	overarching values even in challenging, uncertain or immutable contexts and may have benefits in the context of FND.		A clinical psychologist trained in ACT.	
8. Rancourt & Darkes, 2018.	FND conceptualised as a maladaptive coping response to pervasive emotion dysregulation that occurs in response to a stressor. Note that affective stress and impaired emotional processing are implicated in the development of FND and BPD. Thus, DBT is useful as it targets the underlying mechanism of emotion dysregulation through relevant skills.	The intervention focused on increasing distress tolerance, emotional regulation, and interpersonal effectiveness skills. Distress tolerance skills included self-soothe activities, tolerating negative emotions, pros and cons, and radical acceptance. Emotion regulation skills included identifying and labelling emotions, opposite action, distress tolerance and problem-solving. Interpersonal effectiveness skills included assertiveness, effective interpersonal interactions and managing conflict.	25-hourly sessions, weekly or fortnightly, over eight months. Facilitator not specified.	No treatment deviations or treatment fidelity measures reported. The intervention used adopted an individualised formulation approach.

*Notes.* BPD = Borderline Personality Disorder

**Outcome measures**. All but one study (Baslet & Hill, 2011) used quantitative measures. Appendix D provides an overview and references for these outcome measures. Quantitative data was collected using pre-established and well-validated measures of a broad range of self-reported variables. Measures included; mood, psychological health, functioning and psychological flexibility, QoL, symptom interference and PTSD (see Table 2). Four studies also included idiographic measures of NEAD frequency, duration and intensity (Barrett-Naylor et al., 2018; Baslet et al., 2015; Baslet et al., 2020; Bullock et al., 2015). No idiographic measures of other FND symptoms were used.

*Measures of FND symptoms.* Improvement in FND symptoms was reported in five studies by measuring NEAD frequency or through qualitative reports of changes in symptoms (see Table 2). In all these studies, NEAD symptoms were reported through weekly self-reported idiographic measures of NEAD frequency. This included NEAD experiences, NEAD frequency diaries and logs (Barrett-Naylor et al., 2018; Baslet et al., 2015; Baslet et al., 2020; Bullock et al., 2015). Both daily and weekly measures of NEAD frequency were used (Table 2). In addition to weekly NEAD frequency, Baslet et al. (2020) measured weekly seizure duration and intensity using a 10-point Likert scale.

The single-case studies reported symptom improvement through qualitative descriptions of participants' self-reported experiences of symptom reductions (Graham et al., 2017; Rancourt & Darkes, 2018) or at one-month follow-up (Baslet & Hill, 2011). Graham et al. (2018, 2017) did not directly measure symptom change and instead reported changes in symptom interference by using the Work and Social Adjustment Scale (WSAS; Mundt et al., 2002). The WSAS is a 5-item self-report measure. The measure asks a person how their difficulties interfere with their ability to function

across work, home management, social leisure activities, private leisure activities, and close relationships, using a severity rating from 0 to 8.

*Measures of distress.* Six studies collected standardised and well-validated outcome measures related to distress (Table 2). Two studies exploring NEAD also collected Quality of Life (QoL) measures (Baslet et al., 2020; Barrett-Naylor et al., 2018), using the Quality of Life in Epilepsy-10 (QOLIE-10; Cramer et al., 1996). The QOLIE is a 10-item Likert-type scale measuring a range of health concepts related to epilepsy, such as emotional wellbeing, seizure worry, cognitive and social functioning. Baslet et al. (2020) also explored changes in a range of secondary outcome measures (mood, anxiety, dissociation, somatisation and QoL).

Baslet et al. (2015; 2020) and Barrett-Naylor et al. (2018) used the Depression Anxiety and Stress Scale-21 (DASS, Lovibond & Lovibond, 1995). The DASS is a 42item self-report questionnaire that measures depression (DASS-D), anxiety (DASS-A), and stress (DASS-S) levels over the preceding week. Barrett-Naylor et al. (2018) only used the DASS-A subscale, alongside the Beck Depression Inventory-II (BDI-II; Beck et al., 1996). The BDI-II is a 21-item self-report scale that measures depressive symptoms over the preceding two weeks, developed to assess the DSM-IV diagnostic criteria for depressive symptoms. Graham et al. (2017; 2018) used the Clinical Outcomes in Routine Evaluation-10 (CORE-10, Barkham et al., 2013), a 10-item measure of mood and distress. Rancourt and Darkes (2018) used the Patient Health Questionnaire-9 (PHQ-9: Kroenke et al., 2001), a 9-item measure of depression. These measures ask the respondent to report on the frequency that they have experienced symptoms of depression based on the DSM-IV diagnostic criteria. Rancourt and Darke also measured PTSD through the PTSD Checklist-Civilian Version (PCL-C; Blanchard et al., 1996), using a 17-item Likert item measure that corresponds to PTSD symptoms based on the DSM-IV diagnostic criteria.

*Measures of psychological flexibility.* Three studies of ACT interventions measured psychological flexibility as an outcome (see Table 2) using two different outcome measures – the Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011) and the Comprehensive assessment of Acceptance and Commitment Therapy processes (compACT; Francis et al., 2016). The AAQ-II was developed to measure psychological flexibility as conceptualised within the ACT model (see Section 1.5.5 An ACT approach). The measure consists of items rated from 1 ('never true') to 7 ('always true'). The AAQ-II has been criticised for its lack of validity, which is discussed further below in 'Appropriate measurements and sufficient timepoints' – Section 2.3.2. Subsequently, the Comprehensive assessment of Acceptance and Commitment Therapy processes (compACT; Francis et al., 2016) was developed to measure psychological flexibility. The compACT is a 23-item measure consisting of three subscales capturing the dyadic processes, which are 'openness to experience', 'valued action' and 'behavioural awareness'.

## 2.3.2 What is the quality of evidence for third-wave CBT for FND?

Studies were appraised according to the MMAT (2008) quantitative descriptive appraisal tool and, where appropriate, Morley's (2017) quality appraisal guidelines for single-case studies and case series; each article's final quality ratings are summarised in Table 4. Inter-rater agreement on quality was high: Fleiss's kappa statistic was found to be at 0.76, indicating an "excellent" agreement across final ratings (see Appendix C). The only disagreement between raters related to the Mixed Methods Appraisal Tool (MMAT) item 3 – 'are the measurements appropriate?'. Here two articles were rated as 'No' by the author, but 'Yes' by the independent rater, which is explained in more detail in 'Appropriate measurements and sufficient timepoints' below. The primary purpose of the critical appraisal process was to provide a descriptive exploration of studies' quality.

## Table 4

# Appraisal tools

Mixed Methods Appraisal Tool (MMAT) Version	Study number								
Quantitative descriptive methodological quality criteria	<b>S1</b>	S2	<b>S</b> 3	<b>S</b> 4	S5	<b>S6</b>	<b>S</b> 7	<b>S8</b>	
1. Is the sampling strategy relevant to address the research question?	Y	Y	Y	Y	Y	Y	Y	Y	
2. Is the sample representative of the target population?	Y	Y	Y	N/A	Y	Y	N/A	N/A	
3. Are the measurements appropriate?	Y	Y	Y	Ν	Y	Y	Y	Y	
4. Is the risk of nonresponse bias low?	С	С	Ν	N/A	С	С	N/A	N/A	
5. Is the statistical analysis appropriate to answer the research question?	Y	Y	Y	Ν	Ν	Y	Y	Y	
Morley (2017) Quality appraisal guidelines	<b>S1</b>	S2	<b>S</b> 3	<b>S</b> 4	<b>S</b> 5	<b>S6</b>	<b>S</b> 7	<b>S8</b>	
1. Clear specification of the experimental design and the rationale for using it	Y	Р	N/A	Ν	N/A	Р	Р	Р	
2. Clear definition and specification of the dependent variable(s) and evidence that its validity and reliability in this study has been accessed.	Υ	Р	N/A	Ν	N/A	Y	Y	Р	
3. Clear definition and description of the intervention who conducted it, the number and timing of the treatment sessions, and the attempts made to verify treatment integrity	Р	Р	N/A	Р	N/A	Y	Р	Р	
4. Sufficient data points in the baseline and intervention phases for the intended analysis, i.e. in visual analysis, the detection of the trend, variation, level, statistical analysis, and sufficient data points for the test's power.	Y	Y	N/A	N	N/A	Y	Y	Y	
5. Data analysis clear and a report in who conducted it and how	Р	Р	N/A	Ν	N/A	Р	Р	Р	
6. The full data set is produced in a high-quality graph or table	Υ	Y	N/A	Ν	N/A	Y	Y	Y	

*Note*. S1 – Barrett-Naylor et al. (2018), S2 – Baslet et al. (2015), S3 – Baslet et al. (2020), S4 – Baslet & Hill (2011), S5 – Bullock et al. (2015), S6 – Graham et al. (2018), S7 – Graham et al. (2017), S8 – Rancourt & Darkes (2018). Colour coding key: N = no/ not present, Y = yes/ present, P = partially present, C = cannot tell, N/A = Not applicable

Each area of the quality appraisal will now be addressed in the order presented in Table 4.

*Sampling strategy and representation.* The sampling strategies varied from targeted recruitment in a social media site to routine clinical practice to convenience sampling (see Table 2). While some studies recruited through convenience sampling and single locations, all strategies appeared relevant to the studies' aims. Barrett-Naylor et al. (2018) was the only study not to recruit from a clinical population but rather a community sample.

Several studies used convenience sampling that may have led to the over or underrepresentation of patients with specific characteristics (e.g. greater motivation, female preponderance) (Baslet et al., 2015; 2020; Barrett-Naylor et al., 2018; Bullock et al., 2015). These factors limit the studies' sample representativeness to broader FND populations and generalisability to males. Furthermore, across studies, small sample sizes reduced reliability through potentially increased variability and bias. However, the studies did not claim that their samples were more general than the subcategories they recruited from.

Appropriate measurements and sufficient timepoints. The quality of measurement varied across all studies (see Table 4). All single-case studies and case series, other than Baslet and Hill (2011), provided a clear definition and specification of the variables measured that was appropriate to the study's aims. Baslet and Hill (2011) provided only qualitative descriptions of change. None of the studies discussed whether their standardised measures had previously been used in FND populations. Some studies' measures had limited generalisability to a wider FND population. For example, Rancourt and Darkes (2018) used measurement based on the client's individualised formulation, which included alcohol intake and trauma symptomatology, which were not measured in other studies. Only Barrett-Naylor et al. (2018) and Graham et al. (2017, 2018) described the standardised outcome measures' validity and reliability.

Measurement issues were identified in Graham et al.'s (2017; 2018) studies due to measuring psychological flexibility using the Acceptance and Action Questionnaire-II (AAQ-11; Bond et al., 2011). The AAQ-II has been criticised for its lack of face validity. It is esoteric and hard to understand, particularly for those not socialised to the ACT model (Tyndall et al., 2019). This measure may have introduced a measurement error that confounded results. Due to the use of this contentious measure, the two Graham studies were marked as 'No' on the MMAT item three – 'are the measurements appropriate?' by the author, which was kept as the final rating. However, these items were marked as 'present' by the independent rater as it was felt that the measure was consistent with the studies' aims. Additionally, studies collecting participants' NEAD experiences, NEAD frequency diaries and logs, relied upon participants' accurate self-reports. These measures were not standardised and were used differently across studies.

Studies' data collection points varied, as summarised in Table 2. The highest quality-rated data points were those that collected weekly measures. They enabled greater ability to determine a causal relationship between the intervention and observed changes (Barrett-Naylor et al., 2018; Baslet et al., 2015; 2020; Bullock et al., 2015). However, Barrett-Naylor et al. (2018) was the only study that collected weekly timepoint measurements that supported inferences about the relationship between change and the intervention to be drawn. This was due to their interpretation of findings being on an individual level. Furthermore, this was the only study to collect follow-up measures to investigate whether changes were sustained.

Baslet et al. (2020) tracked changes in NEAD frequency at assessment and at all subsequent sessions, alongside collecting secondary psychological measures at four different time points. They were the only study to utilise a baseline measure, which

- 50 -

allowed the baseline to be compared to later measurements to judge effectiveness. Baslet et al. (2015) and Rancourt and Darkes (2018) collected pre, mid and postintervention measures. In comparison, Graham et al. (2017; 2018) provided lowerquality time points by using only pre and post-intervention measures. This pre and postdesign offered the least control of confounding variables. Still, it enabled reliable and clinically significant change calculations. All single-case studies and case series using quantitative measures used timepoints appropriate to their data analysis.

*Risk of non-response bias.* In the six studies that recruited more than one participant, it was hard to evaluate the risk of non-response bias due to the lack of reporting on the differences between responders and non-responders and drop-out rates. Studies provided limited information on participants who experienced deteriorations or no change following post-intervention. Baslet et al. (2020) did not give any details of participants experiencing deterioration or no change. Bullock et al. (2015) found that three participants reported worsening symptoms during the last week of intervention but provided no account for this. Baslet et al. (2015) reported that the two participants who experienced the least improvement had distinct characteristics, with a history of alcoholism and recurrent depression that was not present in others. This mirrored Graham et al.'s (2018) case series, where authors reported that participants who experienced the least change had comorbid mental health issues and more severe FND symptoms.

Baslet et al. (2020) was the only study to examine participants' drop-out rates. Out of 144 participants initially recruited, 103 dropped out. The authors noted that noncompleters tended to be younger and from ethnic minority groups. Bullock et al.'s (2015) report on drop-out rates was limited. Out of the 21 participants who enrolled, 19 completed at least one module of the four-module programme. Further details were not provided. Drop-out was low for Barrett-Naylor et al. (2018), who described only one

- 51 -

participant not completing their intervention. In comparison, Graham et al. (2018) and Baslet et al. (2015) did not report drop-out rates. The lack of reporting on drop-out rates makes it impossible to explore sample bias that could lower the intervention's generalisability.

*Statistical analysis*. Statistical analysis included calculation of reliable and clinically significant change, median regression, and mixed-effect model analysis. Overall statistical analyses were all described in sufficient detail, and all appeared appropriate for answering the research questions. The highest quality statistical analysis was Baslet et al.'s (2020), with the largest sample and comprehensive collection of outcome measures across timepoints. These factors increased validity and enabled more sophisticated data analysis using group statistics. Barrett-Naylor et al.'s (2018) SCED had a good analysis compared to other studies. Here, visual analysis of key-dependent variables across the intervention enabled participants to serve as their control to track changes. This was carried out alongside exploring reliable and clinically significant change of standardised measures pre and post-intervention.

A lower quality statistical analysis was found in Bullock et al.'s (2015) study due to their use of group-level statistics. They used data collected across a two-year time point, which did not account for the varying length of time participants participated in the group, thus, significantly limiting their findings. Single-case studies and case series collecting quantitative data, provided well-presented graphs or tables that gave a greater understanding of the results. Except for Baslet and Hill's (2011) descriptive study, all case studies and case series reported data; however, none explicitly stated who had conducted the analysis.

*The rationale for the design*. All single-case studies and case series provided specification of the experimental design, except for Baslet and Hill (2011), who offered a solely descriptive account of change. This descriptive account was less

- 52 -

methodologically robust and did not enable any conclusions about the intervention's effectiveness. Only one of the studies provided an explicit rationale for their design – Barrett-Naylor et al. (2018), whose SCED enabled participants to serve as their control. None of the study designs took into account confounding variables, such as concurrent treatment, which lowered all the studies' ability to conclude intervention effectiveness.

Information related to the intervention. The single-case studies and case series provide varying levels of detail about the intervention used, outlining the intervention and the number of treatment sessions (see Table 3). Six studies detailed who had conducted the intervention (Baslet et al., 2011, 2020; Barrett Naylor et al., 2018; Graham et al., 2018, 2017; Rancourt & Darkes, 2018). Baslet and Hill (2011) provided a detailed description of their intervention but did not provide information on the group sessions' duration. Graham et al.'s (2018) case series explored treatment integrity by excluding potential participants who had not received the full treatment protocol. Rancourt and Darkes (2018) assessed treatment integrity by videotaping sessions.

**Summary of critical appraisal.** Applying the MMAT and Morley's (2017) quality assessment guidelines enabled a descriptive exploration of literature that, on balance, indicates that Baslet et al.'s (2020) study provides the highest quality evidence for third-wave CBT effectiveness. This is due to the study's comparatively large sample size, time-specific and manualised intervention, numerous time-points (including a baseline measure), valid measurements and high-quality data analysis, albeit in a mostly female sample with high drop-out rates.

The next highest quality studies are Barrett-Naylor et al.'s (2018) study on six volunteers and Bullock et al.'s (2015) study of nineteen participants recruited in a clinical setting. Both adopted a manualised approach and focused on NEAD outcomes. However, Barrett-Naylor et al. (2018) had the added strength of collecting secondary outcomes at clearly specified time points across their short intervention that enabled

- 53 -

tracking of change. In contrast, Bullock et al.'s (2015) statistical analysis of NEAD frequency over two years reduced the level of information that could be drawn from their results. However, their larger clinical sample offers higher ecological validity and subsequent generalisability to broader FND populations than Barret-Naylor et al.'s (2018) small sample recruited on a social media website.

Graham et al. (2018) and Baslet et al. (2015) offer lower quality data. Neither benefit from numerous data points or a larger sample. Graham et al. (2018) measured pre and post-intervention change. However, Baslet et al. (2015) tracked change across three time-points, although unlike Graham et al. (2018), who measured several variables, they only provide NEAD count. Graham et al. (2017) and Rancourt and Darkes (2018) also offer relatively low-quality evidence in their single-case studies. Rancourt and Darkes (2018) provided an in-depth description of their 26-session intervention and collected outcome measures over three time points. However, their outcome measures are perhaps less generalisable to the broader FND population, in contrast to those used by Graham et al. (2017). Finally, the lowest quality study was Baslet and Hill's (2011). Here, the authors provide an in-depth account of their intervention but used no quantitative measures, leading to results being open to research bias.

Overall, the quality assessment process indicates that the literature for third-wave CBT for FND is low quality and mired by methodological difficulties. The process of applying MMAT and Morley's quality criteria highlights the diversity of the studies identified within this scoping review. It will be drawn upon to contextualise findings in the next sections.

# 2.3.3 Is there any preliminary evidence of factors related to intervention feasibility, acceptability and efficacy or effectiveness?

**Factors related to intervention feasibility and acceptability.** Data charting identified three themes relating to the feasibility and acceptability of the third-wave CBT interventions: replicability versus individualisation; clinical versus community samples and; willingness and barriers.

*Replicability versus individualisation.* The first factor related to intervention replicability versus individualisation. The interventions studied ranged on a scale from replicable (manualised) to individualised (formulation driven) approaches. Five studies used a manualised intervention with varying adaptation levels to FND participants (Barrett-Naylor et al., 2018; Baslet et al., 2015; 2020; Baslet & Hill, 2011; Bullock et al., 2015). Baslet et al. (2015, 2020) tailored their MBT programme to participants' NEAD diagnosis. They included a focused session on understanding FND symptoms. These studies appeared to have evolved from Baslet and Hill's (2011) case study, which reported a four-session manualised MBT group-based intervention within an inpatient setting.

Barrett-Naylor et al.'s (2018) ACT self-help material was not adapted for participants and was taken directly from a book. Here, participants read the material at home, with minimal input. Similarly, Bullock et al.'s (2015) lower quality study did not specify any adaptions in their manualised DBT programme held on a rolling basis. However, their group-based intervention exposed participants to others experiencing NEAD.

Three studies described interventions driven by individualised formulation (Graham et al., 2017, 2018; Rancourt & Darkes, 2018). Although there are differences in the interventions' lengths, the two ACT interventions were between six to eight sessions, which contrasted with the DBT case study lasting twenty-six sessions. However, this could be weighed within the context of the participants' severe FND presentation, comorbid mental health difficulties and costs of repeated utilisation of inappropriate health care services.

The studies with comparatively higher quality used time specified manualised methods, running between 6-12 sessions. Manualised approaches offer higher feasibility than individualised approaches, and the lack of difference in outcomes between manualised and individualised approaches suggests that they are effective. A manualised approach is more straightforward to replicate across settings and requires less clinical expertise (Nezu & Nezu, 2008).

*Clinical versus community sample.* A second preliminary factor related to acceptability and feasibility was differences between a clinical versus community sample. There were differences in the samples used within the studies (see Table 2)— seven studies recruited from clinical populations. In contrast, Barrett-Naylor et al. (2018) used a community sample rather than a clinical sample. It is unclear how representative and subsequently acceptable their volunteer sample is to a broader FND population.

*Willingness and barriers*. The final preliminary factor related to willingness and barriers to engagement. Two studies identified potential barriers to engagement related to participant characteristics or experiences. In the highest quality study, Baslet et al. (2020) provided a detailed analysis and breakdown of their twenty-four non-completers demographics, as well as broader drop-out rates during recruitment. Those that did not complete the intervention were younger, tended to belong to ethnic minorities, and had fewer years of education. The most commonly cited reason for dropping out was due to difficulties accessing the sessions. The only other study to describe drop-out characteristics was Bullock et al. (2015). They noted that two participants dropped out

at the start of the group because they felt 'different' from the other group members, which they did not expand on.

Several authors described barriers to engagement regarding the necessity of accepting a psychological explanation of FND. Graham et al. (2017, 2018) and Barrett-Naylor et al. (2018) hypothesised that ACT's focus on the individual's values (rather than their FND symptoms), rather than FND, might enable engagement through a focus on lived experiences within an uncertain context. For example, in Graham et al.'s (2017) single-case study of 'Claire', the intervention was shaped around her values and explored the outcome and function of her behaviours concerning these values.

In contrast to the ACT studies, Rancourt and Darkes (2018) DBT approach shared an explicit formulation that FND symptoms are a coping strategy for psychological distress. The authors hypothesised that supporting participants to interpret problematic behaviours as learnt responses decrease judgment and stigmatisation and provide individuals with the opportunity to feel validated and supported. They evidenced this process in their detailed case study of 'Jane', who did not believe her paralysis was psychologically driven at the start of the intervention. She slowly shifted her perspective to be more open to a psychological understanding throughout the intervention. The only other study using a DBT approach provided limited evidence of patient acceptability (Bullock et al., 2015). Here, the authors suggested participant willingness was evident through completion rates, ease of recruitment, implementation, and positive exit intervention responses but provided minimal detail of these factors.

Barrett-Naylor et al. (2018) were the only study to collect evidence of participants' experiences of engagement in their intervention through the use of a Change Interview. This semi-structured interview explores participants' experiences of the intervention, any changes they experienced, and what they attributed to these changes. The interview

- 57 -

results presented lacked detail but indicated that participants found the intervention acceptable, accessible, and led to meaningful changes.

There was a recognition of the potential barriers to ascribing psychological explanations for FND symptoms reported by the authors within all the studies, which was addressed differently, dependent on the intervention's theoretical orientation. Across studies, there was a lack of direct qualitative accounts of the participants' intervention experiences. Indeed, Barret-Naylor et al. (2018) was the only study to give participants a voice, albeit limited.

**Factors related to intervention efficacy and effectiveness.** None of the studies had sufficient quality to evidence efficacy; subsequently, only effectiveness will be explored. Perhaps due to the studies' diverse nature, no specific intervention factors appear to be related to intervention effectiveness. Three categories became apparent when charting the study effectiveness data, which related to study outcomes. These categories were: FND symptom change; QoL and distress changes; and psychological flexibility change. Each factor is presented below.

*FND symptom change*. A reported reduction in FND symptoms or FND interference was associated with intervention effectiveness (see Table 2). Baslet et al. (2020) found that median NEAD frequency decreased for every subsequent session. Furthermore, 52% of participants (n = 13) reported no NEAD occurrences at the last session. These findings suggest promise for the 12-session MBT programme's effectiveness. Bullock et al.'s (2015) naturalistic study explored the impact of their rolling DBT group intervention by participants keeping a weekly NEAD frequency diary. Using group statistics across the data collected over two years, over half of the participants (n = 9) experienced decreased NEAD frequency of at least 50%. However, the group intervention most effectively reduced NEAD frequency when offered in conjunction with a DBT orientated individual psychotherapy. Their data was aggregated from participants who attended different group programme parts for varying lengths over two years. These factors limited the evidence of the intervention's effectiveness.

Baslet et al. (2015) and Barrett-Naylor et al. (2018) also found a decline in weekly NEAD frequency. Barrett-Naylor et al. (2018) found that this reduction remained for four out of six participants at a one-month follow-up. Their SCED enabled participants to serve as their control. However, the study's small and selective sample makes conclusions on the intervention's effectiveness limited. All case studies described qualitative improvements in mFND, with Baslet and Hill (2011) also describing improvements in NEAD. These qualitative accounts came from the researcher's observation rather than through any formal measurement. Graham et al.'s (2018, 2017) ACT interventions found some participants experienced reliable symptom interference reductions (five out of eight in the case series).

All studies found either reduced NEAD frequency, improved FND symptoms and reductions in FND symptom interference for some participants. Positive outcomes occurred in the context of the low quality of research and varying third-wave CBT approaches duration and delivery across studies. There is a lack of objective measures of these changes in the single-case studies, leading to conclusions being open to significant research bias. The use of group statistics in small and underpowered samples, alongside lack of control group, baseline and follow-up measures and existing concurrent therapy, makes any inferences on the effectiveness of third-wave CBT in reducing FND symptoms tentative.

*QoL and distress changes*. A second preliminary factor related to intervention effectiveness was QoL and distress improvements. The highest quality study by Baslet et al. (2020) found the only measure to reach statistically significant improvement was QoL (measured by QOLIE-10; Cramer et al., 1996). Similarly, Barrett-Naylor et al.'s

- 59 -

(2018) found that four participants also experienced reliable and clinically significant improvement on this measure of QoL, which remained at follow-up periods.

Distress was measured across six studies and revealed a mixed picture with improvements found for some participants. Baslet et al. (2020) found no changes in distress measures. While Baslet et al.'s (2015) results suggested a slight improvement. However, the authors explained that psychopharmacological changes happened during the intervention to address depression, anxiety, and insomnia. They were the only authors to acknowledge the potential impact medication may have had on confounding results.

Barrett-Naylor et al. (2018) found that four participants experienced reliable and clinically significant improvements in distress, which remained at one-month follow-up for two participants. Graham et al.'s (2018) lower quality case series also collected pre and post-outcome data on distress and found a large improvement in mood. Furthermore, two lower quality single-case studies found reliable and clinically significant improvements in standardised distress measures (Graham et al., 2017; Rancourt & Darke, 2018).

The two most robust studies reported reliable and clinically significant improved QoL outcomes for some participants with NEAD (Barrett-Naylor et al., 2018; Baslet et al., 2020). Barrett-Naylor et al. (2018) found four out of six participants experienced reductions in NEAD episodes. Baslet et al. (2020) found half of the participants (n = 13) reported NEAD cessation in the final session, with a NEAD frequency decrease of 0.12 episodes per week.

The interventions diverged significantly in intervention length, content and delivery. The findings for post-intervention improvements in distress outcomes were inconsistent. Four low-quality studies explored distress using ACT, guided self-help ACT and DBT. Again, studies had varying durations, but all found post-intervention

improvements in distress outcomes for some participants. In the higher-quality study by Barrett-Naylor et al. (2018), distress outcomes were also improved. However, the highest quality study by Baslet et al. (2020) found no improvements in distress outcomes. It is unclear whether the observed post-intervention improvements in QoL and distress outcomes result from placebo or non-therapeutic factors, regression to the mean or a range of other potentially confounding variables, such as participant history.

*Psychological flexibility change*. A further preliminary factor linked to effectiveness was psychological flexibility improvements. The three ACT studies that were of varying quality found improved psychological flexibility for the majority of participants. In the most robust of these studies, Barrett-Naylor et al. (2018) found an improving upward weekly trend in psychological flexibility measured by the compACT throughout the intervention and at follow-up. The development of psychological flexibility was found to be a cumulative process. However, Barrett-Naylor et al. (2018) found one participant who reported improvements in psychological flexibility using the compACT also experienced deteriorations in the AAQ-II. The authors reasoned that the worsening of the AAQ-II was a likely artefact of the measure's lower face and discrimination validity.

Graham et al.'s (2017) case study of 'Clare' showed reliable and clinically significant improvement post-intervention on the AAQ-II. Graham et al.'s (2018) case series found improvements of a medium magnitude in psychological flexibility using the AAQ-II, with reliable improvement evident in four participants. However, they found a deterioration in psychological flexibility for two participants. Unlike those who experienced improvements, these participants showed no improvement in symptom interference or mood measures. They were also described as 'distinct' from other participants, as they reported 'extremely severe' functional impairment. Overall, ACT interventions studies found some participants reported improved psychological flexibility associated with reduced distress, FND symptoms and interference and improved QoL. However, the studies are methodologically limited. They have small samples and a lack of control, baseline measures, and potential instrumentation issues (i.e. AAQ-II), making it impossible to draw any causal relationship from the intervention.

Summary of findings. This review examined the extent and nature of studies on third-wave CBT for FND and explored preliminary factors related to intervention feasibility, acceptability and effectiveness. The review identified eight low-quality intervention studies using varying quantitative designs. Studies used DBT, MBT and ACT interventions delivered to people experiencing various FND presentations, although mainly NEAD. Effectiveness was most commonly assessed through NEAD frequency and standardised QoL and psychological flexibility measures. The majority of these studies were carried out as part of routine clinical practice, offering high ecological validity. However, the quality was impaired by small and highly selective samples that were predominantly female, case series lacking multiple baselines, a lack of follow-up measures, and a reliance on self-report measures.

There is currently limited evidence of the feasibility and acceptability of thirdwave CBT. The literature indicated that there might be particular feasibility in adopting manualised third-wave CBT that can be replicated across clinical contexts by facilitators with varying skills mixes (Nezu & Nezu, 2008). All but one study reported from a clinical sample, suggesting feasibility within this setting. Only one study provided detailed information on non-completers, who tended to be younger, from an ethnic background, and have fewer years of education. The two reasons for participant dropout related to difficulty accessing sessions or feeling 'different' from other group members. Authors identified that ascribing a psychological explanation for FND could be a barrier to psychological treatment, which was addressed differently, depending upon the intervention's theoretical orientations. Across studies, there was a lack of direct qualitative accounts of the participants' intervention experiences.

No specific intervention factors related to intervention effectiveness. Intervention effectiveness was indicated by improvements in FND symptoms and symptom interference, with the most robust evidence for reducing NEAD frequency. Some improvements were also found for standardised QoL, distress and psychological flexibility measures, with the lowest improvement rates in distress. However, the lowquality evidence makes it impossible to know whether changes were due to the intervention or other confounding factors.

## 2.4 Discussion

This review explored the extent and nature, and quality of evidence regarding third-wave CBT effectiveness for people with FND. Eight diverse intervention studies were found, and no qualitative research. Overall, the quality assessment process indicated that the literature for third-wave CBT for FND is low quality and mired by methodological difficulties.

Charting of the interventions' feasibility and acceptability involved exploring uptake, drop-out, non-responder rates, and participant experience and satisfaction. Here the evidence was limited. Only Baslet et al. (2020) described characteristics of noncompleters being younger, from ethnic backgrounds, and with fewer years of education, consistent with the broader literature on adherence to mental health interventions (Olfson et al., 2009). Most studies did not report on uptake, drop-out and non-responder rates, and participant experience and satisfaction, making it impossible to compare these variables between studies. Notably, the lack of reporting on non-responders and deterioration rates is a common problem in general psychotherapy literature (Radcliffe et al., 2018). In the few studies that provided details on non-responses or worsening, participants were described as having more severe FND symptoms of a longer duration and comorbid mental health difficulties. This finding corresponds with research exploring predictive factors of poor outcomes for people with FND, which includes a longer time with the diagnosis (Asadi-Pooya et al., 2019), having a previous psychiatric diagnosis (McKenzie et al., 2010) and other evidence of psychopathology (Reuber et al., 2004).

No differences were found in acceptability between using an individualised formulation driven approach or a time-specific manualised approach. However, when considering feasibility, there may be advantages to adopting a manualised approach. For example, manualised approaches can permit treatments to be easily replicated, which underlines evidence-based practice (a guiding principle for healthcare in the NHS) (Nezu & Nezu, 2008). A manualised approach can also facilitate staff training and play an important role in providing support and structure to less experienced practitioners (Wilson, 1998). Furthermore, manualised approaches can enhance treatment integrity and offer a minimum quality assurance. For example, a meta-analysis of psychotherapy outcomes found that the use of treatment manuals reduced variability in treatment outcome across therapists, particularly with inexperienced therapists (Crits-Cristoph et al., 1991). However, the acceptability of manualised treatments has been questioned, highlighting that they can be perceived as prescriptive and rigid (Addis & Krasnow, 2000). Flexibility can be increased using a modular approach or by specifying the session format but allowing the session content to be guided by the patient's current problems (Henin et al., 2001).

This review found several authors had identified factors related to either willingness or barriers to engaging in third-wave CBT. For example, ACT studies

- 64 -

described the advantage of not requiring direct discussion of FND but instead focusing on what is personally meaningful for the patient and being guided by their goals and values. Thus, addressing the barriers to engagement imposed by psychological explanations of FND, where patients can feel that their symptoms are not being taken seriously (Carson et al., 2012). A focus on personally meaningful goals was also identified to increase willingness to engage in individualised DBT. Barrett-Naylor et al. (2018) also purported that their self-help format offered increased acceptability for some, as the approach can be used alone, in a safe and familiar setting, at one's own pace, and without the need for a broader acceptance or discussion of the diagnosis with others. However, here acceptability was surmised by the author's opinions and not the experiences of the participants. Strikingly across the intervention studies, there was a lack of participants' qualitative experiences of the intervention, how they made sense of the intervention and how it impacted them.

By charting the studies' effectiveness, improvements were found in FND symptoms and symptom interference with the most robust evidence for reducing NEAD frequency. Additional standardised QoL, distress, and psychological flexibility measures also revealed improvements, although inconsistently. No specific intervention factors were found to relate to intervention effectiveness. Overall, the low-quality evidence makes it impossible to know whether the observed improvements were due to the intervention, non-specific therapy factors, regression to the mean, placebo effects, or other confounding factors.

These outcome findings echo those of systematic reviews on third-wave CBT approaches for different clinical populations. For example, Graham et al.'s (2016) systematic review of eighteen ACT intervention studies for long-term health conditions found a pattern of improved QoL and distress (both in six studies), but due to the low quality of research, could not make any firm conclusions regarding the effectiveness of

- 65 -

ACT. Similarly, Robinson et al.'s (2019) systematic review of nineteen studies of thirdwave CBT for long-term neurological conditions found promise in this approach addressing emotional difficulties associated with neurological conditions. However, this was also amidst a range of methodological issues paralleling those found within the current review.

Billones et al.'s (2020) systematic review on Mindfulness-Based Interventions (MBI) for medically unexplained conditions identified twenty-four studies of comparatively higher quality, with nineteen RCTs and five case-controlled clinical studies. The authors found MBI had a middle to large effect sizes on symptom severity (d = 0.82), pain intensity (d = 0.70), depression (d = 0.62) and anxiety (d = 0.67). Unlike the current review, due to using studies with more robust methods, they were able to identify four intervention components critical for effectiveness. These factors were; psycho-education to understand symptoms better, the practice of awareness, the non-judgmental observance of experience in the moment, and compassion for oneself.

#### 2.4.1 Strengths and limitations

Several limitations are implicit in this review due to the search strategy. Non-English language papers were excluded due to resource constraints, which may have led to a language bias and relevant literature not being included. This review also specified a third-wave CBT intervention and FND population as part of the electronic database search strategy. As a result of this restrictive search strategy, potential sources of information may have been missed, particularly when considering feasibility and acceptability. A broader search strategy could have explored either FND or third-wave CBT and concepts of feasibility and acceptability, alongside searching broader sources, such as Google search using key phrases and hand searches of websites and forums. This search may have provided more contextual information about the intervention procedures, outcome measures, and techniques (Arian et al., 2010; Shanyinde et al., 2011) and information on individuals with FND experiences and attitudes towards thirdwave CBT interventions. More details on experience and context could have been incorporated into intervention study findings to give an in-depth and balanced view of the value of third-wave CBT for people with FND (Sekhon et al., 2017).

The lack of qualitative literature on third-wave CBT and FND may have been an artefact of the restricted search terms and sources, which led to this review's focus solely on intervention outcomes (i.e. does this work?), not the intervention process (i.e. can this work? how does this work?), which is addressed by feasibility research (Orsmond & Cohn, 2015). Additionally, the search terms may have limited details on participants' self-reported satisfaction with the intervention. However, Carter (2008) note that intervention acceptability requires a wider focus than just the participants, as acceptability is distributed among the system, interventionists, and participants. Subsequently, each of these subsystems needs to be explored when evaluating intervention acceptability. A search strategy that enabled the capturing of clinicians' views or NHS contexts (e.g. neurology departments or FND services) might have also provided a more rounded exploration of acceptability.

Due to the scoping review's focus upon intervention studies, two appraisal tools were used to provide a more in-depth exploration of study quality. The decision to use the MMAT enabled the use of one overarching criterion. The use of Morley's (2017) case study appraisal guidelines meant that while some criteria overlapped with MMAT, quality appraisal factors specific to the case studies and case series were captured. These tools enabled a more consistent critical appraisal, which was found to have high interrater reliability.

The limited literature meant that this review explored studies focused on specific subtypes of FND, specifically either NEAD or mFND. While it is argued that these

- 67 -

different subtypes share common mechanisms (Paola et al., 2014) and researchers have identified similarities (Hopp et al., 2012), significant differences have been found between the presentations. Compared to patients with mFND, patients with NEAD tend to be younger, more likely to report childhood abuse and stressful life events and experience alterations in consciousness (Driver-Dunckley et al., 2011; Hopp et al., 2012). The limited data in this review did not find differences in how FND subgroups responded to the intervention. However, it may be that different subtypes of FND respond in different ways to various interventions and would benefit from separate investigations on the effectiveness of different therapies.

## 2.4.2 Addressing gaps in the literature

The review has identified significant literature gaps concerning third-wave CBT interventions for people with FND, such as no qualitative studies and low-quality intervention studies that lack participant's qualitative experiences. These literature gaps can inform future work in the area.

**Research recommendations.** Several recommendations can be made for intervention studies. First, future intervention studies using case series could include the use of multiple baselines pre-intervention. Baseline measures would make it possible to identify patterns that indicate threats to internal validity, such as maturation, instrumentation issues, and testing before the intervention. Moreover, to assess changes' longevity, follow-up measures are vital and could be administered at multiple follow-up points.

Standardised outcome measures could also be collected on a sessional basis if appropriate and be selected to capture theoretically related process measures that are model-specific. Model-specific measures may be more sensitive to picking up on change and provide a greater understanding of what intervention factors can impact change processes. Additionally, research would benefit from capturing participants' direct experiences of the intervention and change experienced using qualitative methods such as the Change Interview (Elliott, 1999; Elliott et al., 2001). Again, this may provide a further understanding of how different intervention components work and greater insight into patient acceptability. Acceptability is essential in designing, evaluating and implementing healthcare interventions (Sekhon et al., 2017).

An important part of assessing the intervention acceptability involves considering factors such as participants' attitudes towards the intervention, appropriateness, suitability, convenience, and perceived effectiveness of the intervention, which is best captured through qualitative accounts (Sekhon et al., 2017). Subsequently, qualitative research and mixed-method designs are essential in voicing the participant's perspectives that can provide a sociocultural context that informs how interventions are designed and delivered in different contexts in a way that generates patient acceptability across a range of socioeconomic and geographical groupings (Sekhon et al., 2017). Ayala and Elder (2011) recommend focus groups and interviews to assess intervention materials' acceptability in cultural appropriateness, context, presentation, and delivery. This approach can provide a deeper understanding of reactions to the intervention that increases willingness or act as a barrier to engagement and shape future work.

This review has also highlighted the need to provide more detailed reporting on uptake, drop-out, non-responder and deterioration rates at different intervention stages. Future research may also benefit from detailing participant information and characteristics to contextualise findings. For example, this information could provide greater insight into acceptability by supporting identifying factors contributing to dropout, non-response or deterioration rates. Participant information could include concurrent treatments (e.g. psychopharmacological or physiotherapy intervention) that could confound results—as well as the collection of information on physical and

- 69 -

psychological comorbidities that may impact therapeutic outcomes. It is also recommended that future intervention studies consider how to ensure fidelity to the model being used. Video-recorded sessions would ensure adherence to the model and evaluate the therapist's interactions and skills during sessions.

Feasibility studies implemented before conducting outcome-focused studies could enable a focus on how an intervention can be implemented and evaluated and provide the opportunity to test interventions in practice settings, consider real-world barriers and facilitators to implementation, and address cultural or linguistic relevance (Bowen et al., 2009; Kazdin, 2018). Without this preparatory work, outcome-focused intervention studies can be negatively impacted by quality issues (e.g. inadequate measures, treatment integrity, sample size), as well as issues around compliance, acceptability, recruitment issues, which could be predicted and remediated through feasibility studies (Eldridge et al., 2016).

**Practice recommendations.** The evidence suggests that for some patients with FND, third-wave CBT interventions are effective. However, within the limited literature, it is unclear who may benefit and when best to offer the intervention. Preliminary evidence suggests lower effectiveness for those with greater chronicity of symptoms, comorbid mental and physical health difficulties, younger people, identifying as being from an ethnic background, and having fewer years of education.

The limited evidence suggests a particular promise for MBT programmes for patients with NEAD and formulation-driven ACT approaches for patients with mFND. Further work is required in investigating whether it is beneficial to adopt time specified and manualised third-wave CBT for patients with FND that can offer higher feasibility. While third-wave CBT approaches share key commonalities, differences in their focus and delivery need to be considered within an individualised formulation. It may be that different subtypes of FND respond in different ways to various interventions.

- 70 -

This review indicates that real-world research within clinical settings is possible. Clinicians working with patients with FND are advised to consider how they can contribute to the evidence base. A broad range of methodological designs can be adopted. Perhaps the most methodological robust and feasible within an NHS context are SCEDs. Here, patients can serve as their controls and high-quality regular data collection before, during and after the intervention can explore the unique contributions of different parts of the intervention that may contribute to therapeutic change. Moreover, collecting patient's qualitative experiences will help establish feasibility and acceptability and aid understanding of how the intervention works and for whom.

Given the current low-quality evidence available for third-wave CBT for FND, it may be that other therapeutic modalities are more appropriate for treating FND. However, third-wave CBT interventions can still be drawn upon flexibly. They emphasise the importance of working with transdiagnostic processes, such as supporting an individual in moving from experiential avoidance towards acceptance of their experiences and providing useful skills to become more present-focused and better able to identify and manage emotions. Furthermore, an ACT perspective may have particular utility in a clinical setting that requires a multi-disciplinary approach. It can be used and translated across professional groups to provide a coherent and joined-up approach focused upon increasing personally meaningful activity without discussing the cause of symptoms.

## 2.4.3 Future direction and conclusion

**Future direction.** This review outlines the significant gaps within the literature and the need for further qualitative research focusing on patients' experience and higher-quality research that can be shaped by feasibility research focused upon understanding research processes. Future research would benefit from considering how

- 71 -

to capture participants' direct experiences of the intervention and change, which can shed further light on the acceptability of third-wave CBT approaches and potential intervention factors that contribute to change. Finally, future research would benefit from further exploring the effectiveness or efficacy of various third-wave CBT, using different durations and delivery formats for different subpopulations of individuals with FND. Ultimately, to conclude the efficacy of third-wave CBT for FND, RCTs are needed.

**Conclusion.** A small number of published studies have applied third-wave CBT in different formats across several FND presentations. There is limited detail provided on factors related to feasibility and acceptability, highlighting the need for feasibility studies and qualitative research to help develop higher-quality intervention studies that shape acceptable and effective interventions. There was some evidence that third-wave CBT may improve NEAD frequency and QoL, mood, and psychological flexibility. However, studies are of low quality, and there have not been RCTs of third-wave CBT for FND. Therefore, third-wave CBT is currently not well established for use in FND.

# 3 An evaluation of the impact and experiences of a two-phase psychological intervention for FND

## 3.1 Introduction

This study evaluates the impact and experiences of patients attending a Clinical Health Psychology Service treatment pathway for FND, consisting of two intervention phases: 1) assessment and formulation, and 2) an ACT group.

The impact of this two-phase psychological intervention is explored using pre and post-standardised outcome measures for each intervention phase and for participants attending Phase 2, a Single Case Experimental Design (SCED), which included a daily survey. The daily survey aimed to track change and identify whether the intervention's specific components were linked to change. Finally, all participants took part in a Change Interview (Elliott, 1999; Elliott et al., 2001) that captured their qualitative experiences of the intervention, the therapeutic changes they perceived experiencing and how they made sense of this. This study is the first to use a SCED to explore an ACT group intervention for FND and collect interview accounts of patients' experiences of a psychological intervention for FND.

#### 3.1.1 Research aims and hypotheses

Evaluation of the impact and experiences of the two-phase psychological intervention is explored by looking at changes in standardised measures, SCED data, and participants' descriptions of their experiences. The study aims to bring these sources of data together to explore effectiveness. Specifically, reliable and clinically significant improvements in standardised measures and improved SCED data trends were evaluated. Several hypotheses are made for the changes expected in standardised measures and SCED specific measures following each intervention phase. It was hypothesised that following assessment and formulation (Phase 1):

H<sub>1</sub>: There will be reliable and clinically significant improvements in distress, symptom interference and QoL measures.

H<sub>2</sub>: There will be reductions in participants' threatening illness representations (controllability, treatability and coherence).

It was hypothesised that following the ACT group (Phase 2):

H<sub>3</sub>: There will be reliable and clinically significant improvements in distress, symptom interference and QoL measures following Phase 2.

H<sub>4</sub>: There will be reliable and clinically significant improvements in emotion processing and psychological flexibility measures associated with improvements in distress, symptom interference, QoL measures, and greater use of ACT processes.

H<sub>5</sub>: Daily FND experiences of FND symptom severity, interference and distress will improve as the ACT group progresses.

## 3.2 Method

## 3.2.1 Overview

First, the design for the research is presented, followed by a description of the research procedure. This description provides context to the measures used to evaluate change. Following an overview of the measures used, their administration timepoints are outlined. This information is presented alongside participant information and an overview of the actual data collected. Data collection was interrupted by a pandemic, which resulted in the Change Interviews being a standalone measure for some participants. The design description is followed by a presentation of the ethical considerations, clinical and research inclusion and exclusion criteria, and finally, data analysis.

#### 3.2.2 Design

**Rationale.** The design of the study centres on a single-case series method. It had been intended that participants would be tracked across the two-phase intervention with standardised measures at specified time points and that a daily survey would be collected during Phase 2. The design was influenced by Hermeneutic Single-Case Design, as outlined by Elliott (2002). It included a Change Interview at the end of the intervention. Due to the disruption caused by the pandemic, the intervention and daily data collection stopped during the second group.

Quantitative and SCED measures. Pre and post-standardised outcome measures were used for both intervention phases. A SCED collected a daily survey for those attending the ACT group (Phase 1). A SCED helps explore new treatments where the population studied is small or heterogeneous by exploring comparisons between the same person's behaviour (or response to measures) at different times. The design was used to identify the ACT group's components associated with therapeutic changes (Morley, 2017). This SCED explored an established clinical intervention offered in a psychology service. Given the small sample and lack of control group for the ACT group, an alternative design of pre and post-evaluation for Phase 2 would have considerably reduced the ability to reach any conclusions about the ACT group's effectiveness and exploration of change mechanisms.

**Qualitative measure.** Qualitative interview data was collected using a Change Interview template to capture any changes following each phase. The Change Interview summary and any reported changes are briefly summarised for each participant in the SCED. The Change Interview transcripts have also been analysed to provide a broader picture of participants' intervention, their perceived experiences of change, and how they made sense of this change.

# 3.2.3 Description of procedure and intervention

The study procedure was shaped around a pre-existing clinical intervention offered to patients with FND. All participants were referred to the Clinical Health Psychology Service under the FND treatment pathway and attended initial assessment and formulation sessions with a Clinical Psychologist. The sessions are carried out on a one-to-one basis with a Clinical Psychologist and can take up to six one-hour sessions. The sessions aim to generate a shared understanding of how the patient's FND symptoms may have developed and factors that may maintain or exacerbate symptoms. The assessment acts as a screening process for Phase 2 (the ACT group). Patients assessed as clinically suitable are invited to attend the seven-session ACT group.

Before attending assessment and formulation sessions, patients were posted a set of routine, standardised outcome measures to complete with their appointment letter and asked to bring these measures completed to their first appointment with the clinician. Patients were also asked to repeat these measures at the end of Phase 1. At this stage, patients were given the option to consent to their routine clinical measures being accessed anonymously. Those offered the ACT group were also asked for their consent to participate in the SCED and Change Interview.

Clinicians asked all patients taking part in the ACT group to complete standardised outcome measures at the start and the end of the group as part of routine clinical care. These measures were posted out with invites to the group, with instructions to bring completed to the first group session. Otherwise, clinicians asked patients to complete these measures at the start of the first group session and the final group session. In both groups, the researcher was briefly present at the start of the first session to introduce the research and answer any study questions. Patients who took part in the SCED had the choice of completing the daily survey through a paper-based survey provided weekly by clinicians or through an online survey link sent via email or text by the researcher. Furthermore, four-week follow-up standardised outcome measures were posted to consenting participants at the end of the group by the psychology service together with a pre-paid and addressed envelope to post back to the department. The three participants who completed the first seven-week ACT group consented to complete a Change Interview one to two weeks after the final group session.

The second ACT group recruited a further five participants to complete the SCED and Change Interview. However, the group ended abruptly due to the pandemic. Subsequently, these five participants completed a Change Interview focused upon their experiences of Phase 1 (assessment and formulation). The researcher held these interviews over the phone, which were recorded and then transcribed by the researcher.

**ACT group description.** The ACT group consisted of seven weekly two-hour sessions, with fifteen-minute breaks, with a group of up to eight individuals and two facilitators. The group draws upon ACT techniques to increase psychological flexibility, such as exploring participants' overarching values and encouraging individuals to initiate actions that support their values (Dahl, 2015). The development of the openness and awareness aspects of psychological flexibility is facilitated by mindfulness and perspective-taking to assist committed action. Moreover, group facilitators are creative in using relational framing (i.e. purposefully creating new relationships between words and other stimuli). Relational framing help make the conditions in which new psychologically flexible behaviours might occur (Villatte et al., 2015).

Each group session targeted areas of the ACT Triflex ('Opening up', 'Being present' and 'Doing what matters'). Different sessions had a particular focus on one aspect of the tri-flex. ACT processes are not conceptualised to work sequentially, and

- 77 -

therefore, they can theoretically be introduced in any order (Blackledge & Barnes-Holmes, 2009). The first group session introduced ACT with a focus on 'Being present'. The next group session introduced 'Doing what matters' and explored values and the concept of choice point, alongside continued mindfulness exercises. The third group session introduced an understanding of emotions and body awareness, focusing on mindfulness and values-based action and building a compassionate relationship. The fourth session introduced 'Opening up', which included a discussion of emotional regulation and related techniques.

The fifth session focused upon defusion and associated methods before moving back to 'Doing what matters' through exploring self-as-context and value-based actions. The final two sessions re-capped the group's content and provided time for evaluation and completion of routine, standardised outcome measures. The introduction of different processes within the various sessions aimed to enable a clearer understanding of participants' responsivity to particular processes or techniques, which would otherwise have been obscured. Table 5 summarises each group session's topic, skill focus, key aims and home practice.

# Table 5

# Group session topic, skill, key focus and home practice

Session	Topic	Skill focus	Key focus	Home practice			
1	Understanding diagnosis and symptom	<ul> <li>Explanation of FND model</li> <li>Introduction of ACT, including choice point and values</li> </ul>	• Being present	Mindfulness practice and mindfulness     diary			
	management	<ul> <li>Introduction of present moment awareness</li> </ul>					
		• Mindfulness – mindful breathing exercise					
2	Doing what matters	• Mindfulness – body scan, soothing rhythm breathing	<ul><li>Being present</li><li>Doing what</li></ul>	Mindfulness practice and mindfulness diary			
		• Explanation of values and defining them	matters	<ul> <li>Choosing a value-based action step and taking it while noticing external and internal barriers</li> </ul>			
		Choice point		• Thinking about a challenging situation, recognising 'choice point' and moves 'away' and 'towards' values			
3	Understanding emotions and	• Mindfulness of body and breath exercise	• Building a compassionate	Mindfulness practice and mindfulness     diary			
	body awareness	<ul> <li>Identifying internal and external barriers to value lived</li> </ul>	relationship with self	• Continuing value-based action			
		<ul> <li>Recognising, accepting and opening up to emotions</li> </ul>	• Understanding emotional experience	• Practice sensory grounding exercise			

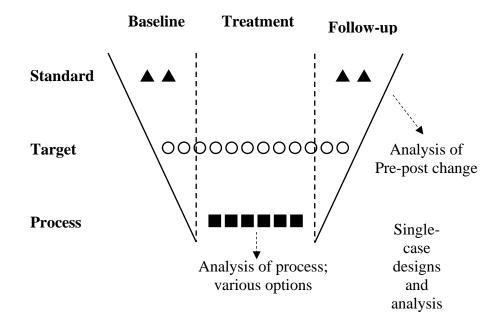
4	Opening up	<ul> <li>The window of tolerance, avoidance and emotional regulation techniques (e.g. mindfulness exercises, grounding and soothing rhythm breathing)</li> <li>Opening up (e.g. 'quicksand' metaphor and 'struggle switch')</li> </ul>	<ul> <li>Understanding emotional experience</li> <li>Opening up</li> </ul>	<ul> <li>Mindfulness practice and mindfulness diary</li> <li>Practising grounding exercise – 'dropping anchor'</li> <li>Practising soothing rhythm breathing</li> </ul>
5	Defusion	<ul> <li>Understanding defusion and exercises         <ul> <li>dropping anchor exercise and three</li> <li>N's (Noticing, Naming, and</li> <li>Neutralising)</li> </ul> </li> </ul>	• Defusion	<ul> <li>Mindfulness practice and mindfulness diary</li> <li>Continuing valued-based action</li> <li>Noticing and observing daily thoughts</li> </ul>
		• Mindfulness – leaves on the stream, 3- minute mindfulness		that hook, practising defusion techniques
6	Value-based action and self-	• Introducing self-as-context (e.g. mountain meditation)	• Self-as-context	Mindfulness practice and mindfulness     diary
	as-context	• Reflecting on value-based action		• Continuing soothing rhythm breathing
		• Discussion on choice point and internal and external barriers to valued living		• Continuing value-based action and reflecting on thoughts, feelings and consequences
7	Review session	Summary of all areas Triflex: • Being present		
		• Opening up		
		• Doing what matters		

## 3.2.4 Measurement

**Selection of measures.** Measure selection included standard, target and process measures (collected at different time points and varying frequencies), as outlined in the Treatment Assessment Funnel (Morley, 1996) illustrated in Figure 4.

#### Figure 4

The Treatment Assessment Funnel (adapted from Morley, 1996)



The measures selected are presented below in the grouping of standard, target and process measures. The majority of the measures were collected as part of routine clinical practice and covered eight broad domains, summarised in Table 6. Standardised outcome measures captured clinical distress, symptom interference, illness understanding, emotion processing and psychological flexibility. It was planned that Phase 1 data on these measures would provide baselines for the SCED. However, this was not possible due to data collection problems. The SCED specific daily target measures were collected across the ACT group and captured participants' experiences of FND and use of ACT processes; this was created specifically for the research. In terms of process measures, an ACT fidelity measure was used by facilitators to measure adherence to ACT concepts. The change interview was intended as a process measure for the SCED, but in the final study was used to capture participants' experiences in both intervention phases.

## Table 6

Measures used and rationale

	Domain	Measure	Reason
	Clinical distress	PHQ-9	Measure of low mood
		GAD-7	Measure of anxiety symptoms
	Symptom interference	WSAS	Measure of symptom interference
Standard measures	Health status	EQ-5D-3L	Measure of health status and QoL
	Illness understanding	B-IPQ	Measure of cognitive and emotional representations of illness
	Emotion processing	EPS-25	Measure of emotional processing
	Psychological flexibility	CompACT	Measure of psychological flexibility
	FNS experiences	Daily survey of FND experiences	Daily survey of symptoms, interference and distress
Target	FND impact	WSAS	Measure of symptom interference
measures	Behaviour change	Daily activities and positive changes	Measure of participant's daily engagement in ACT processes, other techniques and positive changes
Process	Process measures	Change interview	Measure of participant's experiences of group and change
measures	ACT fidelity measure	The ACT fidelity measure	Measure of ACT group adherence to the ACT model

**Standard measures.** Several standardised outcome measures were used to capture general wellbeing and functioning, illness perception, emotion processing, and psychological flexibility. Due to their length, these measures are not designed for repeated use over a short time frame. Standard measures were administered at the start and the end of each intervention phase. Below is a description of each standard measure used.

*Physical Health Questionnaire (PHQ-9; Kroenke et al., 2001):* is a measure of depression based on the standard DSM-IV diagnostic criteria and used as a routine clinical measure. The 9-item self-report measure asks the person to report on the frequency that they have experienced nine symptoms of depression from 0 ('not at all') to 3 ('nearly every day') over the past two weeks. Higher scores indicate more severe symptoms. A score of 5 indicates mild symptoms, 10-15 indicates moderate symptoms, 15-20 indicates moderately severe symptoms, and a score of 20 above indicates severe depression. A PHQ-9 score  $\geq$ 10 has a sensitivity of 88% and a specificity of 88% for major depression (Kroenke et al., 2001).

*Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006):* is a measure of anxiety symptoms based on the standard DSM-IV diagnostic criteria and used as a routine clinical measure. The 7-item self-report measure asks the person to describe the frequency that they have experienced seven symptoms of anxiety from 0 ('not at all') to 3 ('nearly every day') over the past two weeks. Higher scores indicate higher anxiety levels. A score of 10-15 indicates moderate anxiety, and a score of 15 and above indicates moderate to severe anxiety. The GAD-7 has excellent internal consistency, good test-retest reliability and strong criterion validity (Spitzer et al., 2006).

*Work and Social Adjustment Scale (WSAS; Mundt et al.,2002):* is a measure of symptom interference ascribed to FND and used as a routine clinical measure. The 5-

item self-report measure asks a person how their difficulties interfere with their ability to function across work, home management, social leisure activities, private leisure activities, and close relationships, from 0 ('not at all') to 8 ('very severely'). Scores range from 0 to 40, with higher scores indicating more significant symptom interference. The WSAS has an internal scale consistency ranging from 0.70 to 0.94 and a test-retest correlation of 0.73 (Mundt et al., 2002).

*EuroQol-5D-3L (EQ-2D-3L; Brooks et al., 2013):* is a routine clinical measure of health status that provides a simple, generic measure of health and quality of life for clinical and economic appraisal. EQ-5D is a preference-based measure of health status widely used in clinical trials, observational studies and other health surveys. The EQ-5D measures five dimensions; (1) mobility, (2) self-care, (3) usual activities, (4) pain/ discomfort, and (5) anxiety and depression. A person is asked to rate these dimensions for the day using three severity levels ('no problems', 'moderate problems', 'severe problems'). Respondents also self-rate their health on a vertical, visual analogue scale. The endpoints are labelled 'best imaginable health state' and 'worst imaginable health state'. This information provides a quantitative measure of health outcome as judged by the person. This measure offers two scores, one reflecting the participant's overall health status through responses on the five items and a second score reflecting their self-reported health status.

Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al., 2006): is a measure of cognitive and emotional representations of illness ascribed to FND and was a routine clinical measure. The 9-item self-report measure asks a person to rate questions from 0 to 10 about their perceptions of different illness dimensions. Dimensions cover the illnesses' consequences, control, treatment control, timeline, illness concern, coherence, identity and emotional representation. A final open-ended

- 84 -

question asks the person to rate the importance of three self-generated causations for their illness. Scores range from 0 to 60, with higher scores indicating greater overall illness threat. The BIPQ has good psychometric properties, including concurrent, predictive and discriminant validity (Broadbent et al., 2006).

*Emotional Processing Scale- 25 (EPS-25; Baker et al., 2007, 2010):* is a measure of emotion processing styles and shortfalls and was used as a routine clinical measure. The 25-item measure covers five subscales; suppression, signs of unprocessed emotions, unregulated emotion, avoidance and impoverished emotional experience. Different statements are rated over the past week, from 0 ('completely agree') to 9 ('completely disagree'). Two open questions also ask the person to recall the strongest positive or pleasant emotion and the strongest negative or unpleasant emotion they have experienced over the past week. Higher scores indicate more significant difficulties with emotion processing. The EPS-25 has been used in patients with NEAD (Novakova et al., 2015) and in patients with mixed FND (Williams et al., 2018). The measure was found to have an internal consistency of 0.92 in fifty patients with NEAD (Novakova et al., 2015). The measure has also been shown to have satisfactory, test-retest reliability and correlates well with the Toronto Alexithymia Scale (TAS-20) and the Courtauld Emotional Control Scale (Baker et al., 2007).

*Comprehensive assessment of Acceptance and Commitment Therapy processes* (*compACT; Francis et al., 2016*): is a measure of psychological flexibility as conceptualised within the ACT model and was introduced as a research specific measure. The 23-item measure consists of three subscales capturing the dyadic processes; 'openness to experience', 'valued action' and 'behavioural awareness'. Items are rated from 0 ('strongly disagree') to 6 ('strongly agree'). Scores can range from 0 to 60, with higher scores indicating greater psychological flexibility. In this study, the total psychological flexibility score was derived by computing the sum of item responses and exploring each of the three subscales. The compACT has an internal consistency of 0.91 and converges and diverges in theory-consistent ways with other measured variables (Francis et al., 2016). The three-factor structure, reliability and validity of the compACT have been demonstrated in an independent sample (Bayliss, 2018).

**Target measures.** Target measures tend to be brief and taken frequently, focusing on the intervention's elements explored in the SCED. A daily survey was created in consultation with previous patients who had attended the ACT group for FND. The daily survey measured participants' FND symptom severity, interference and distress using a 10-point Likert scale (see Table 7). This measure was adapted from a chronic pain study case-series daily survey by Roche et al. (2017). Daily practice of ACT processes taught in the group was measured with the following options; 'formal mindfulness', 'informal mindfulness', 'valued-based action', 'other', or 'none of the above'. Space was left for participants to provide details if they selected 'other', and participants had the option to provide additional information using an open text box. Participants were then asked whether they had made any positive changes using an open text box. The daily survey was designed and administered via free internet software (Online Surveys), piloted before administration.

#### Table 7

#### Daily survey

Functional Neurological symptoms	
How bad are your functional neurological symptoms today? (1 - not at all bad, 10 - the	

- How bad are your functional neurological symptoms today? (1 not at all bad, 10 the worst it can be)
- 2. How much are your functional neurological symptoms stopping you from doing what you want to do today? (1 great functionality, 10 it is stopping me from doing anything)
- 3. How much distress is your functional neurological symptoms causing you today? (1 it is not causing me any distress, 10 most distress)

	Daily activities
4.	<ul><li>Please select the techniques that you have used today:</li><li>formal mindfulness;</li></ul>
	• information mindfulness;
	• value-based action;
	• none;
	• other (please explain).
5.	Have you made any positive changes today?

6. Is there anything you want to add?

Process measures. A Change Interview was used to explore participants'

experiences of the intervention and change for both intervention phases.

*Change Interview (Elliott, 1999; Elliott et al., 2001):* participants were interviewed after either Phase 1 or Phase 2 using an adapted semi-structured Change Interview (see Appendix H). This interview captures participants' experiences of the intervention, changes experienced and provided opportunities to give feedback. The Change Interview also caught contextual issues to rule out any other alternative plausible explanations of change (Elliott, 2001).

The 45 to 90-minute interview explored the changes a participant had noticed since attending the psychological intervention and whether they attributed these changes to helpful and unhelpful aspects of the intervention. Participants are asked to identify changes, including any changes for the worse, and prompted to consider changes in thoughts, feelings, actions, or ideas. Participants then rate these changes according to

how 'expected' they were, how 'likely' they would have occurred without therapy, and how 'important' the change was for them. Participants are also asked what they thought had caused the various changes, both outside and within the intervention. Finally, participants were asked to consider what had been helpful about the intervention and what was hindering, unhelpful, negative or disappointing for them. These areas of questioning helped to evaluate the credibility and validity of the quantitative data collected.

**ACT group adherence measure.** An adherence measure was completed at the end of each ACT group session by facilitators, described below.

The Acceptance and Commitment Therapy fidelity measure (O'Neill, 2018): measured the ACT fidelity within the group. The measure consists of 24-items structured around the therapist's stance, with ACT consistent and inconsistent items. At the end of each group session, the two facilitators rated their delivery of the group using ratings ranging from 0 ('this behaviour never occurred') to 3 ('therapist consistently enacts this behaviour'). The measure has moderate to excellent inter-rater reliability (*ICC* = 0.73) and high content validity (O'Neill, 2018). Higher scores indicate a therapist's greater adherence to the ACT model. Ideally, this rating is provided by an observing ACT expert. However, given service constraints, this was not possible.

**Measurement time-points.** It was initially planned that the various measures described would be implemented at the time points illustrated in Figure 5 for each participant. Unfortunately, disruptions in data collection meant this was not possible.

#### Figure 5

	Phase 1: Assessment and formulation pha	ase	
	• Session 1	Pre-measures (PHQ-9, GAD-7,	
	• Session 2	EPS, B-IPQ, WSAS, EQ-5D	
	• Session 3 - 6 (optional)	CompACT)	
Ą		Post/ Pre-measures – repeated	
thw:	Phase 2: ACT group	twice if time delay in starting the	
pat	Thase 2. ACT group	group (PHQ-9, GAD-7, EPS, B-	
lent		IPQ, WSAS, EQ-5D, CompACT)	
Complete treatment pathway	• Session 1	ACT-FM	
olete t	• Session 2	ACT-FM	
Comp	• Session 3	ACT-FM	
•	• Session 4	ACT-FM Daily	0
	• Session 5	ACT-FM	5
	• Session 6	ACT-FM	
	• Session 7	Post-measures (PHQ-9,	
		GAD-7, EPS, B-IPQ,	
		WSAS, EQ-5D, CompACT)	
	Optional feedback session	Change interview	
	• Four-week follow-up measures	Post-measures (PHQ-9, GAD-7, EPS, B-IPQ, WSAS, compACT, daily measures)	

## Types of measure used and timepoints

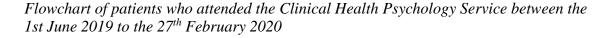
## 3.2.5 Recruitment and service context

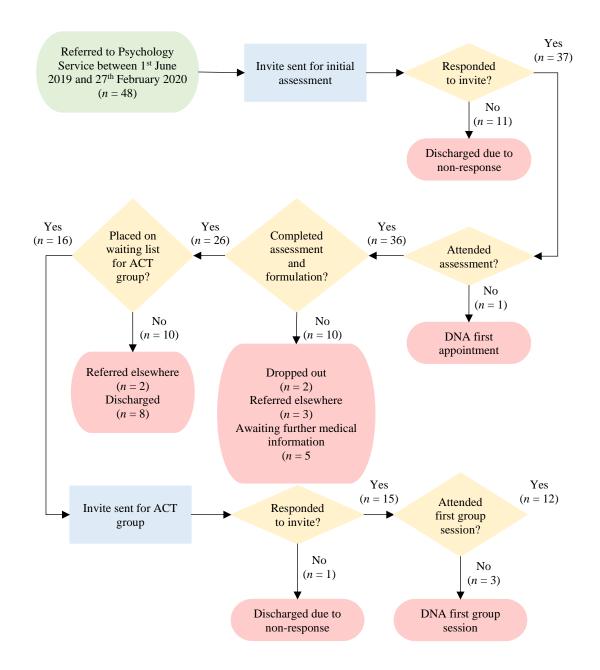
Clinical recruitment occurred between June 2019 and February 2020. Figure 6 provides a flow chart of the patients with FND who attended the Clinical Health Psychology Service between the 1st June to the 27th February 2020. The recruitment process adopted a two-stage approach. Patients who completed the initial assessment and formulation (Phase 1) were asked whether they consented to their routine, standardised outcome measures being accessed for analysis. While six agreed, low completion of measures resulted in three complete data sets being collected for Phase 1. The patients who provided standardised outcome measure data for Phase 1 were separate from the patients who completed the SCED in Phase 2.

Participants for Phase 2 of the pathway were recruited from an ACT group that started in October 2019 and finished in December 2019. The Change Interviews were completed within two weeks of the group's end date. Nine patients were offered places in this group. However, three of these patients did not attend the ACT group from the start. Out of the six patients that started the group, only three completed the full course. The reasons for drop-out related to one participant feeling too young within the group and two experiencing significant stressors unrelated to the group. The three patients who finished the group completed the SCED and Change Interview.

A second ACT group started in February 2020 and came to an abrupt end in March 2020 due to the pandemic. Six patients attended this group, and five consented to participate in the SCED and Change Interview. The premature end of the group stopped data collection. However, four of the five participants in this group completed the Change Interview related to their experiences of Phase 1 (assessment and formulation).

#### Figure 6





**Participants' pathway information.** All participants were recruited from the twelve patients identified as starting the ACT group in Figure 6. Table 8 summarises the data collected for each participant. Four participants completed Change Interviews related to their experiences of Phase 1. Three of these participants also completed pre and post- measures for Phase 1. Three participants completed the SCED for Phase 2,

and a Change Interview focused on their ACT group experiences. These participants did not have available pre and post-data measures for assessment and formulation (Phase 1).

## Table 8

The data provided by participants

I.D.	Pre-post P1	SCED data	Change Interview	Follow-up measures
P1	Y	Ν	Y (Phase 1)	N/A
P2	Y	Ν	Y (Phase 1)	N/A
P3	Y	Ν	Y (Phase 1)	N/A
P4	Ν	Ν	Y (Phase 1)	N/A
P5	Ν	Y	Y (Phase 2)	Ν
P6	N	Y	Y (Phase 2)	Y
P7	Ν	Y	Y (Phase 2)	Ν

*Note*. N = Not collected, Y = Yes, collected, N/A = Not applicable

Out of the four participants who attended Phase 1, three attended four sessions. One participant attended six sessions, as summarised below in Table 9.

## Table 9

The number of assessment and formulation sessions attended by participants

I.D.	S1	S2	S3	<b>S</b> 4	S5	<b>S</b> 6
P1	А	А	А	А	А	А
P2	А	А	А	А		
P3	А	А	А	А		
P4	А	А	А	А		

*Note.* A = Attended session

Out of the three participants that completed the SCED for the ACT group, two missed one or more of the ACT group sessions, as summarised in Table 10.

## Table 10

The number of ACT group sessions attended by participants

I.D.	S1	S2	S3	S4	S5	<b>S</b> 6	<b>S</b> 7
P5	А	А	М	А	А	А	А
P6	А	А	М	М	А	А	А
Ρ7	А	А	А	А	А	А	А

*Note*. A = Attended session, M = Missed session

# 3.2.6 The participants

Participant demographics are summarised in Table 11. Minimal detail has been provided to preserved anonymity.

## Table 11

## Participant demographics

I.D.	Participant's age group*, sex and ethnicity	FND symptoms/ comorbidities	Duration of symptoms	Relation status
P1	Female, 30s, White British	NEAD Other neurological condition	1 year	Married
P2	Female, 40s, White British	Functional tremor, mind blanks, pains in muscles	15 years	Married
P3	Female, 50s, White British	Fainting/ passing out	3 years	Single
P4	Female, 40s, White British	Functional tremor, pains in muscles	2 years	Single
P5	Female, 20s, White British	Severe right arm weakness and pain	3 years	Single
P6	Male, 30s, White British	Motor sensory difficulties, muscle weakness and pain, comprehension and memory difficulties and migraines.	2 years	Married, lives with family
P7	Male, 30s, White British	Motor sensory difficulties, muscle weakness and pain and migraines (associated with dissociative episodes and memory issues)	8 years	In a relationship, lives with partner

*Note.* \* Participants were classified by decade into five age groups (i.e. 20s, 30s, 40s, 50s and 60s)

#### 3.2.7 Ethical considerations

The East of Scotland Research Ethics Service approved this study (see Appendix E). Several ethical issues were considered:

*Informed consent.* Participants were informed about the research verbally and provided with a patient information sheet (see Appendix F and Appendix G). Written consent was collected at least 48-hours later, leaving time for reflection. Group-attending participants also had the opportunity to meet the primary researcher in person to ask questions or raise any concerns. Informed consent was gathered by the clinicians and stored securely at the Clinical Health Psychology Service department.

*Right to withdraw.* It was made clear to participants that they could withdraw from the study at any time and that this would not impact the treatment that they received. They could withdraw through contact with the clinicians or researcher.

*Confidentiality*. The research was conducted following the Data Protection Act (1998). Participants were allocated a unique identifying code enabling data to be collected and stored confidentially. All details were stored on secure services, and any emails containing data was sent via a secure network.

*Incentive to participate.* Participants attending the ACT group completed a daily survey, alongside a Change Interview at the end of the group, which might have been burdensome. Previous patients who had attended the ACT group were consulted for their opinion regarding this. They highlighted the importance of keeping measures as brief as possible. They also believed that a financial incentive for taking part in the research would not be appropriate. They described feeling that patients would be incentivised by having the opportunity to contribute to research that supports effective FND treatment. Thus, participants were only offered compensation for the costs of travelling to take part in the Change Interview, where relevant.

- 94 -

### 3.2.8 Inclusion and exclusion criteria

Participants were attending the Clinical Health Psychology Service two-phase psychological intervention for FND. Inclusion criteria for patients attending the clinical service included an FND diagnosis and being eighteen years old or above. For this study's research component, participants had to be deemed to have the capacity and provide informed consent.

As this study focused upon a clinical intervention, exclusion criteria were set by clinicians rather than by the researcher. For example, participants were not invited to the ACT group if they did not express an interest or willingness. Similarly, some participants were referred elsewhere when clinicians felt participants' needs were best met in primary or secondary mental health care services. Furthermore, insufficient understanding of English or additional requirements that prevented the patient from benefitting from a group setting was an exclusion criterion for the ACT group. Research exclusion criteria were set for participants who took part in the SCED. Daily survey completion rates of below 50% meant data were excluded from the analysis. Participants missing more than two out of seven group sessions were also excluded from data analysis. No participants met these exclusion criteria.

### 3.2.9 Data analysis

**Pre and post-intervention analysis.** The Reliable Change Index (RCI; Kaplan, 2014) and Clinically Significant Change (CSC) are both psychometric criteria. The RCI indicates whether a change in score is significantly greater than a difference recorded due to a random measurement error and, therefore, is likely to result from the intervention (Jacobson & Truax, 1992). The RCI is calculated using a function of the standard deviation and the reliability of the measure used. Changes were assessed to see

if they were reliable and of 'clinical importance' using the CSC, indicating meaningful improvement or deterioration using the measures' clinical cut-offs (Evans et al., 1998).

The RCI for all standardised outcome measures was calculated using the appropriate data if available (see Table 12). This data was not available for the EPS-25 and B-IPQ. The B-IPQ has different norms depending on the clinical population it is used on, and to date, this information is not available for FND. For the other outcome measures, psychometrics from relevant validation studies and data from literature using the samples deemed similar to an FND sample were used, such as those with mixed mental health samples. The CSC was used where the clinical cut-off scores for measures were available. It was not available for the EPS and B-IPQ. The CSC made it possible to determine whether the magnitude of change from the start to the end of each intervention phase was reliable and clinically significant (Evans et al., 1998; Jacobson & Truax, 1992).

#### Table 12

#### RCI calculations

Measure	RCI	CSC
PHQ-9	5.83	≥5
GAD-7	4.59	≥4
WSAS	10.78	$\geq 8$
compACT score	-	$\geq \! 18$

*Note.* Psychometric data is from the following sources; PHQ-9 (Kroenke et al., 2010), GAD-7 (Toussaint et al., 2020), WSAS (Zahra et al., 2014), and compACT (Francis et al., 2016).

**SCED analysis.** The SCED data should be evaluated using multiple methods to increase interpretation confidence (Lane & Gast, 2014). Subsequently, the effectiveness and causality of the ACT group were assessed using the following methods:

1. Comparing standardised outcome measure scores across different time points of the treatment pathway, using the RCI and CSC criteria (Jacobson & Truax, 1992), as outlined above.

2. FND Symptom severity, Interference, Distress and activity data across the intervention was displayed in graphs to allow for visual inspection (Morley, 2017). The effect of the intervention was also evaluated by examining changes in patterns from the start to the end of the ACT group (Morley, 2017).

3. Hermeneutic Single-Case Efficacy Design (HSCED; Elliott, 2002) explores SCED data and guided the synthesis and interpretation of study data. Quantitative and qualitative data were combined to help decide whether changes could be attributed to the effects of the intervention.

Quality standard for SCED. The ACT group followed a session plan to ensure standardisation. However, the facilitators exercised clinical flexibility, as participants were encouraged to ask questions and share their experiences. Two Clinical Psychologists delivered the ACT group, both with considerable experience in the area. The facilitators used an in-session checklist to ensure that the intervention was delivered consistently and completed the ACT-fidelity measure together immediately following each session. As shown in Table 13, the facilitators rated themselves as overwhelmingly ACT consistent and indicated minimal occasions where they were ACT inconsistent. The research supervisors also checked the visual analysis and qualitative data from the obtained results to ensure accuracy.

#### Table 13

	Therapist stance		Open response style		Aware response style		Engaged response		Total	
	con	inc	con	inc	con	inc	con	inc	con	inc
1	4.5	1	1	0	9	1	0	0	14.5	2
2	6	0	7	0	9	1	0	0	22	1
3	9	2	4	0	3	1	6	0	22	3
4	9	2	6	0	5	1	9	0	29	3
5	9	0	9	0	9	1	9	0	36	1
6	6.75	1	8	0	8	1	9	0	31.75	2
7	0.75	0	8	0	9	1	5	0	22.75	1
Total	45	6	43	0	52	7	38	0	190	13

#### ACT fidelity measure

*Note*. Con = ACT consistent, inc = ACT inconsistent

Thematic analysis. The qualitative data from the Change Interviews for participants who were part of the SCED is presented descriptively for each participant, alongside their quantitative measures. Here it was noted that data was rich enough to warrant further analysis. Subsequently, thematic analysis (Braun & Clarke, 2006) was chosen given the Change Interview's focus (see Appendix H) on participants' experiences of the intervention, their perceived changes, and how they made sense of these changes.

Thematic analysis is a qualitative research process used to organise, analyse and describe patterns within complex data sets (Boyatzis, 1998). It is often considered independent of theory and epistemology and can be adapted flexibly to a broad range of data (Braun & Clarke, 2006, 2013). Before data analysis, interviews were transcribed with the participant's identifiable information removed. These transcripts were then printed out in their entirety to enable analysis. A mixed approach was adopted to study data, with both a deductive and inductive approach used to code the data.

During the initial stages of data analysis, a deductive approach was used to draw codes and themes directly from the data, where data was collected without any influence from the researcher's theoretical interest in the topic area (Braun & Clarke, 2006). However, the interview data was rich enough to warrant an inductive analysis. Subsequently, these codes and themes were then considered in the broader theoretical literature in the latter stages of the analysis (Braun & Clarke, 2006).

Braun and Clarke (2006) developed a six-stage systematic approach to thematic analysis. The first stage of this method requires the researcher to familiarise themselves with the data by transcribing and re-reading the text passages. The researcher transcribed all interviews and spent additional time familiarising themselves with the whole data set. The second stage of thematic analysis involves identifying codes within the data set. Here transcripts were printed in their entirety, and codes began to be recognised and scribed directly to the transcript. The researcher intentionally did not narrow the coding process's focus to ensure that the identified codes were data-driven. Stage three is concerned with the development of themes from the coded data. Here individual codes were clustered into preliminary broader themes and sub-themes (see Appendix I).

During stage four, the themes were reviewed and refined based on the strength of data available for each theme and whether the themes 'work' as a complete data set. During this stage, the preliminary themes that had significant overlap were clustered to ensure that the themes were distinct from each other but communicated the participants' experience in its entirety. Once a satisfactory thematic map was developed, stage five involved deciding the names and definition for each theme that was concise and encapsulated the essence of the data that contributed to that theme. The final step involved the production of the report summarising the themes developed from the initial data set.

- 99 -

Quality standard for thematic analysis. At each stage of the thematic analysis process, the data, codes, and themes were discussed with the research supervisors. This process provided a critical analysis of the analytic process. It ensured that the themes were sufficiently refined and suitable to give a clear and concise account of the data. This process enabled different perspectives on the codes and themes that emerged from the data and provided a critical approach to the analysis process. If there was disagreement regarding code or theme, the researcher and supervisor discussed until consensus was reached. An independent researcher was also asked to assess the identified themes. An agreement was made across the themes to combine the data from participants in both intervention phases, given the significant overlap in themes. Furthermore, at each stage of the data analysis, codes and themes were grounded within the transcripts' raw data.

## **3.3 Results**

## 3.3.1 Overview

Three analyses of the data sets are now presented. First, pre and post-standardised outcome data collected for participants attending either Phase 1 or Phase 2 are examined in relation to hypothesises 1 and 2. Next, the SCED for the three participants who attended the ACT group, alongside key details from the Change Interview, is presented in order to address hypotheses. Third, a thematic analysis of the Change Interview data for participants attending either Phase 1 or Phase 2 is presented.

# 3.3.2 Changes across a two-phase psychological intervention for FND

Changes in standardised measures following each intervention phase are presented for the following hypotheses:

- There will be reliable and clinically significant improvements in distress, symptom interference and QoL measures following both phases.
- Following Phase 1, there will be reductions in participants' threatening illness representations (controllability, treatability and coherence).

The final two hypotheses will be addressed in 'SCED analysis' – Section 3.3.3.

#### Phase 1 pre and post-measures

*Changes in distress measures.* Out of the three participants who completed the outcome measures for Phase 1, only Participant 1 (P1) experienced reliable and clinically significant improvement in mood (measured by the PHQ-9) and anxiety (measured by the GAD-7). Participant 2 (P2) and Participant 3 (P3) experienced reliable and clinically significant worsening in their mood. P2 also experienced a reliable and clinically significant worsening in anxiety (see Table 14).

*Changes in symptom inference.* Following Phase 1, two participants experienced post-intervention reliable and clinically significant worsening in symptom interference (P1 and P3) (measured by the WSAS) as recorded in Table 14. The third participant (P2) remained in the severe range.

*Changes in QoL*. Following assessment and formulation (Phase 1), all three participants' overall health rating remained similar across the two-time points. Self-rated health status improved slightly for one participant (P1) and worsened for two participants (P2 and P3) (see Table 14).

*Changes in threatening illness beliefs.* Two participants (P1 and P2) experienced improvements in overall illness threat. Exploring relevant items indicated improvements in treatment control (P1 and P2), personal control (P2) and illness coherence (P1), as illustrated in Figure 7. However, P3 experienced a worsening.

#### Phase 2 pre and post-measures

*Changes in distress measures.* In Phase 2, only Participant 5 (P5) experienced reliable and clinically significant improvements in mood, anxiety, and post-intervention. No reliable and clinically significant change in mood or anxiety were observed in Participant 6 (P6) and Participant 7 (P7) (see Table 15).

*Changes in symptom inference*. Following the ACT group (Phase 2), two participants experienced worsening in symptom interference (P5 and P7), which was reliable and clinically significant change P7 (measured by the WSAS). The third participant (P6) remained in the severe range post-intervention and at follow-up (see Table 15).

*Changes in QoL.* Following the ACT group, all three participants' overall health rating did not change. Participants' self-rated health status improved slightly for P7 but worsened for the other two participants (P5 and P6) (see Table 15).

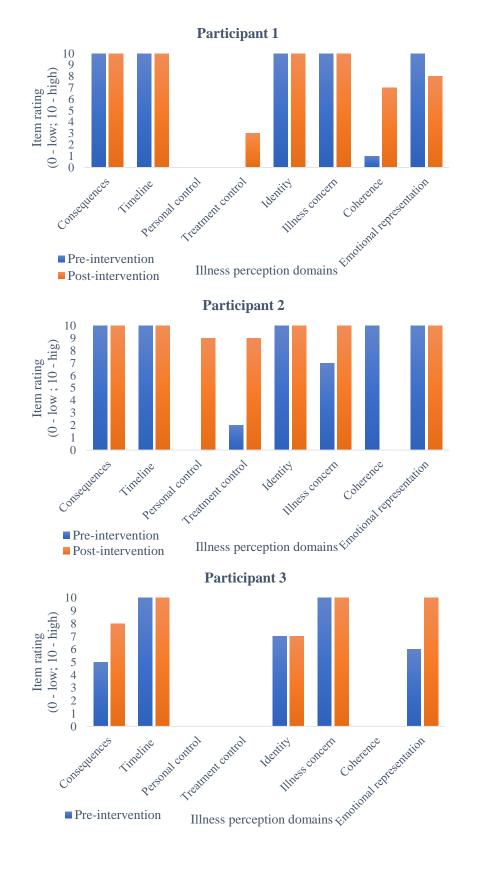
# Table 14

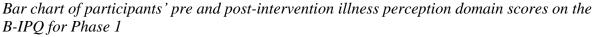
0 0	c	1 1, 1	1 · · · · · · · · · · · · · · · · · · ·	
Nummary of scores	tor narticinants	who completed pre and	i nast_moasuros tar ti	<i>ie assessment and formulation</i>
Summer y Of Scores	joi paracipanas		i posi-measures jor m	

	Participant 1			Participant 2			Participant 3		
Measures	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
PHQ-9	22	16	-6*!	13	21	+8**!	1	12	+11**!
GAD-7	21	15	-6*!	13	18	+5**!	3	1	-2
WSAS	30	38	+8**!	27	28	+1	4	16	+12**!
EQ-5D-3L	9 20%	9 25%	+5%	12 65%	10 3%	-2 -62%	9 50%	12 5%	+3 -45%
B-IPQ	58	46	-12	59	68	+9	58	48	-10
EPS	3.6	4.84	+1.24**	6.24	5.2	-1.04*!	4.84	4.92	+0.08
compACT	36	61	+25*	56	67	+11	86	99	+13

Notes. \*significant reliable change (RCI criterion at 0.05 level), ! clinically significant change, \*\*significant reliable change in the non-predicted direction (worsening); Sev = Severe range, V-hi = Very high, M/se = Moderate severe, Mod = Moderate, H-av = High average; PHQ-9 = higher scores indicate a worsening; GAD-7 = higher scores indicate a worsening; WSAS = higher scores indicate a worsening; EQ-5D-3L rating = higher scores indicate a worsening; EQ-5D-3L self-rating = higher percentage indicates an improvement; B-IPQ = higher scores indicate a worsening; EPS = higher scores indicate a worsening; compACT = higher scores indicate an improvement.

## Figure 7





# Table 15

	Participant 5			Participant 6				Participant 7			
Measures	Pre	Post	Change	Pre	Post	Change	F/u	Change	Pre	Post	Change
PHQ-9	19-	12	-7*!	24	21	-3	25	+4	21	20	-1
GAD-7	19	13	-6*!	21	18	-3	21	+3	17	18	+1
WSAS	32	29	-3	33	36	+3	40	+11	19	31	+12**!
EQ-5D-3L	11 33%	10 7%	-1 -26%	11 26%	10 7%	-1 -19%	-	-	10 40%	10 67%	- +27%
B-IPQ	59	57	-2	62	62	0	64	+2	55.5	58	+2.5
EPS	6.86	4.6	-2.26*!	6.5	6.5	0	8.4	+1.9**	5.8	7.56	+1.76**
compACT	34-	64	+30*	49	51	+2	43	-8	37	58	+21*

Summary of scores for participants who completed pre, post- and follow-up measures for the ACT group

Notes. \*significant reliable change (RCI criterion at 0.05 level), ! clinically significant change, \*\*significant reliable change in the non-predicted direction (worsening); Sev = Severe range, V-hi = Very high, M/se = Moderate severe, Mod = Moderate, H-av = High average; PHQ-9 = higher scores indicate a worsening; GAD-7 = higher scores indicate a worsening; WSAS = higher scores indicate a worsening; EQ-5D-3L rating = higher scores indicate a worsening; EQ-5D-3L self-rating = higher percentage indicates an improvement; B-IPQ = higher scores indicate a worsening; EPS = higher scores indicate a worsening; compACT = higher scores indicate an improvement.

## 3.3.3 SCED analysis

The SCED analysis is next presented on an individual basis for participants who attended the ACT group, and it considers the following hypotheses for each participant;

- Participant's experiences of FND symptom severity, interference and distress will improve as the ACT group progresses.
- There will be reliable and clinically significant improvements in emotion processing and psychological flexibility following associated with improvements in distress, symptom interference, QoL, and greater use of ACT processes.

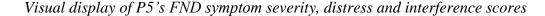
#### Participant 5

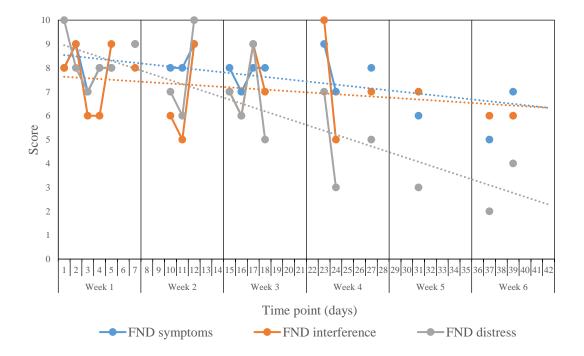
**Overview of the participant.** P5 is a female in her twenties, experiencing severe right arm weakness and pain. She attributes these symptoms to an accident three years earlier that involves ongoing litigation. While attending the group, she reported living by herself and not working. P5 attended six out of the seven group ACT sessions. She missed session three that covered 'understanding of emotions and body awareness'. Her adherence to completing the daily survey was approximately 50%, 22 out of the 43 daily surveys were completed. Caution has been taken in interpreting her results, given this incomplete data set.

**Target measures.** Figure 8 provides a visual plot of P5's self-reported FND symptom severity, distress and interference across the group. While there is sparser data in weeks 4 and 5, the plots reveal a downward trend in all measures as the group progresses. The most visible change across time is in distress, which reduced across the intervention, as illustrated in the downward trend lines. Her distress was as high as 10 in the first week and dropped as much as eight points on the group's final week, with a

final score of 3. There are variations within the data, with the most extensive variation in symptom interference, which drops five points from day 24 to 25. The least variation in scores is on the symptom severity measure, which is as high as 9 in the first week and falls to 5 in the last week. Her responses suggest that she was distinguishing between her experiences of FND symptoms, distress and interference.

# Figure 8





**Standard measures.** P5's standardised outcome measures are now described. Follow-up measures were not obtained for P5. Thus, only pre and post-ACT group measures are presented.

*Emotional Processing Scale-25 (EPS-25):* Pre-intervention P5 scored 'High' to 'Very High' on the EPS total (score = 6.84, 95%) and across the subscales, indicating difficulties with emotional processing. Post-intervention, the EPS total score and subscales reduced to the 'Average/ High Average' range (score = 4.6, 70-75%),

indicating that the intervention reduced emotional processing difficulties. The 'Suppression' and 'Controllability' scale showed the greatest improvements.

*Comprehensive Measure of Acceptance and Commitment Therapy (compACT):* P5's score on the compACT revealed increases in psychological flexibility (pre = 34, post = 64). The greatest change was on 'Valued Action', which was the only subscale to show reliable clinical changes.

*Brief Illness Perception Questionnaire (BIP-Q):* There were minimal changes pre to post-intervention (pre = 59, post = 57). These scores showed that her threatening illness beliefs remained stable. Pre and post-intervention, the most important factor she felt caused her FND symptoms remained the same with (1) car accident.

*Distress measures:* Scores showed improvement on the PHQ-9 and GAD-7 that reduced from a 'Moderate/ Severe' range to a 'Moderate range' (PHQ-9 pre = 19, post = 12; GAD-7 pre = 19, post = 13), this indicated reliable but not clinically significant change.

*Adjustment measures:* There was minimal change in symptom interference, measured by the WSAS, which was in the 'Severe' range pre and post-intervention (pre = 32, post = 29).

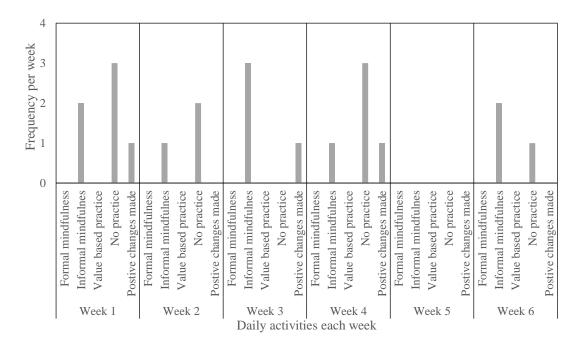
*Quality of life:* There was minimal change in overall health status (pre = 11, post = 10). However, P5 reported a 31% rise and subsequent improvement in her perceived health rating, rated at 64% post-intervention.

Use of ACT processes. Over the forty-two days of the ACT group, P5 provided activity responses on twenty-one days. On nine of these occasions, she reported not using any ACT processes. She reported using informal mindfulness exercises on eleven occasions but no formal mindfulness or value-based practice. She described making three positive changes, including socialising with a friend, eating out and going for a walk. P5's use of ACT processes is summarised visually by summing their occurrence each week (see Figure 9). Due to the missing data, it is not possible to make comparisons between these weekly events.

There was an option to leave further comments within the survey, which she did on nine occasions. Her remarks related to the difficult experiences that she had experienced that day. For example, on day one, she described the 'distress of meeting other people with FND'. On four occasions, she described feeling exhausted and sleeping excessively, and she reported having a bad migraine on another day. She also noted her mood as 'being up and down' and experiencing 'high pain and low mood' on two different occasions.

## Figure 9

## Visual display of P5's weekly use of ACT processes



**Change interview.** P5 commented on several helpful aspects of the ACT group. She described no changes in her FND symptoms. Still, she felt that she managed her mood and stressful situations better following the group. She reported three important changes; managing her feelings of panic better and going out more, having different ways of thinking, and feeling less alone (see Table 16). She attributed these changes to the various skills that she learnt, particularly 'choice point' that enabled her to 'take a step back' from her thinking and be more 'positive'.

She attributed feeling less alone to meeting others with FND and feeling 'understood' and 'encouraged' by group members. She also described feeling better in herself, in part, due to a change of living circumstances that provided her with more physical help. P5 commented on several unhelpful aspects of the group. Unhelpful aspects included experiencing anxiety before the first group session and a lack of information on what to expect. She also spoke of the first group session being a shock, as she met others with the condition, which impacted her mood. She described feeling a sense of loss when the group came to an end. P5 made several suggestions on how the group could be improved, such as more information before the first group session through a leaflet or meeting people who had previously attended.

#### Table 16

importance			
Changes	Change was:	Without therapy, change was:	Importance of change:
Skills to stop my panic getting worse; going to the supermarket alone	Expected	Very unlikely	Extremely
Using the choice point to have different ways of thinking about things	Surprised	Very unlikely	Very

Very unlikely

Very

*P5* Change Interview, changes rated by expectancy, likelihood without intervention and importance

## **Participant 6**

Not feeling so alone

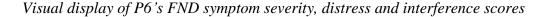
**Overview of the participant.** P6 is a male in his forties, experiencing a range of symptoms associated with FND over the past three years. His symptoms included; motor sensory difficulties, muscle weakness and pain, comprehension and memory

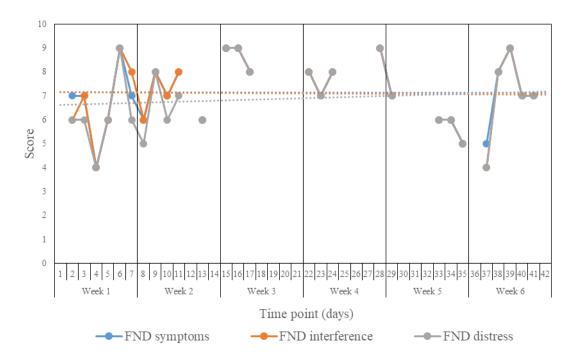
Surprised

difficulties and migraines. He was on long-term sick leave and living at home with his partner and children. Due to ill health, he missed two consecutive weeks of the group, session 3 ('understanding emotions and body awareness') and session 4 ('opening up'). His adherence to completing the daily surveys was 60%, with thirty-one out of the forty-three collected. The missing data, particularly in week three and four, when he did not attend the group, makes interpretation of this data tentative.

**Target measures.** Overall, there appear to be no changes in his FND symptom severity, distress and interference post-intervention (see Figure 10). When there is information recorded over consecutive days, there are notable variations in scores. Such variation is also evident in his scores within the final week of the intervention. The scores of nine in both week 3 and 4 indicated that he was experiencing high levels of FND difficulties during these times. His pattern of responses suggests he scored the same ratings for his FND symptom severity, interference and distress, except for the first week and a half of the group.

## Figure 10





**Standard measures.** P6's standardised outcome measures are now described in turn. Follow-up measures were obtained for P6. Thus, pre and post standardised measures, and one-month follow-up measures are detailed.

*Emotional Processing Scale-15 (EPS-25):* Pre-intervention P6 scored 'Very High' on the EPS total (score = 6.5, 95%) and across the subscales, indicating difficulties with emotional processing. Post-intervention, his EPS total score remained unchanged. However, his scores increased slightly on all subscales, other than Controllability. Similarly, at one-month follow-up, his scores increased somewhat (score = 8.4, 95%), indicating a worsening on this measure, although remaining in a 'Very High' range.

*Comprehensive Measure of Acceptance and Commitment Therapy (compACT):* P6's score on the compACT pre-intervention of 49 revealed no reliable clinical changes post-intervention with a score of 51. His score reduced to 43 at one-month follow-up, indicating a reduction in psychological flexibility. However, this was not a reliable change.

*Brief Illness Perception Questionnaire (B-IPQ):* There were no changes postintervention on the B-IPQ total score of 62. Pre-intervention, he ranked the three most important factors that he believed caused his FND symptoms as; (1) long-term stress, (2) lack of 'me' time and space, and (3) family and work pressures. Post-intervention, the order but not content of his rankings changed; (1) extreme stress over time, (2) family issues, and (3) no 'me' time. At one-month follow-up, his score increased slightly (score = 64), and his rankings remained similar, with; (1) family, (2) stress, and (3) no me time.

*Distress measures:* Scores revealed slight post-intervention improvements on the PHQ-9 and GAD-7, which remained in the 'Severe' range and did not represent a reliable and clinically significant change. Both these scores worsened slightly at one-

month follow-up and remained in the 'Severe' range. (PHQ-9 pre = 24, post = 21, and f/u = 25; GAD-7 pre = 21, post = 18, and f/u = 21).

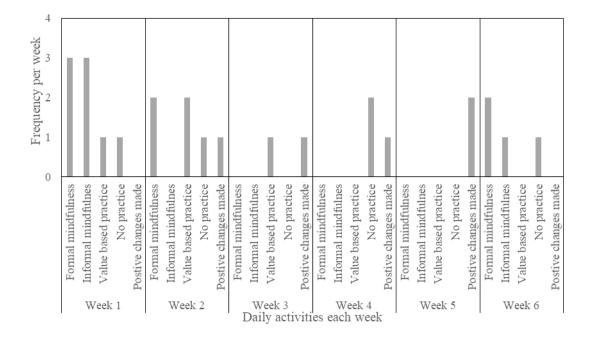
*Adjustment measures:* There was minimal change in symptom interference, measured by the WSAS, which was in the 'Severe' range across measurement time points (WSAS pre = 33, post = 36, and f/u = 40).

*Quality of life:* There was minimal change in overall health status (pre = 11, post = 10). However, P6 reported a 19% worsening in their self-reported health rating, which fell from 26% to 7%. Follow-up was not obtained on this measure.

Use of ACT processes. Over the 42 days of the ACT group, P6 provided activity responses on twenty-two days, illustrated in Figure 11. He reported using informal mindfulness on four occasions, formal mindfulness on seven occasions and used value-based processes on three occasions. He also described using 'other' techniques on two occasions, both related to having 'quiet time with no plans'.

He reported making five positive changes between week 2 and 5, which involved spending time with family and friends, retail therapy, eating out, relaxing and reflecting. There was an option to leave further remarks within the survey, which he did on four occasions. His comments were themed around the day's difficult experiences, including bereavement, feeling 'chronically fatigued', feeling 'not in control', and a stressful event related to employment.

#### Figure 11



#### Visual display of P6's weekly use of ACT processes

**Change interview.** P6 described several beneficial aspects of the ACT group. He described no changes in his FND symptoms but felt that the group had created several positive changes. The most important change that he reported was being able to 'slow down' and 'put himself first'. He also described resting more, being able to 'take a step back', 'ground' himself and making a decision not to go back to work (see Table 17). He attributed these changes to several skills that he learnt, including mindfulness and breathing exercises, cognitive defusion techniques (such as 'leaves on the stream') and 'choice point'. He also spoke of the benefits of having 'others to talk to' and how gaining support helped him be 'kinder' on himself and feel that 'it is not just me'.

P6 commented on several unhelpful aspects of the group, such as a lack of information on what to expect, which caused him anxiety. He suggested an outline of the session structure would have helped manage his anxiety. He also indicated that the group could be made longer. Finally, P6 spoke of struggling when the group came to an end and 'feeling abandoned' and unsure what to do next.

#### Table 17

*P6 Change Interview, changes rated by expectancy, likelihood without intervention and importance* 

Changes	Change was:	Without therapy, change was:	Importance of change:
Slowing down and putting self-first	Surprised	Unlikely	Extremely
Resting more	Surprised	Unlikely	Very
Taking a step back	Surprised	Unlikely	Very
Be able to ground self/ increase inner calm	Surprised	Unlikely	Very
Deciding not to return to work again	Surprised	Unlikely	Very

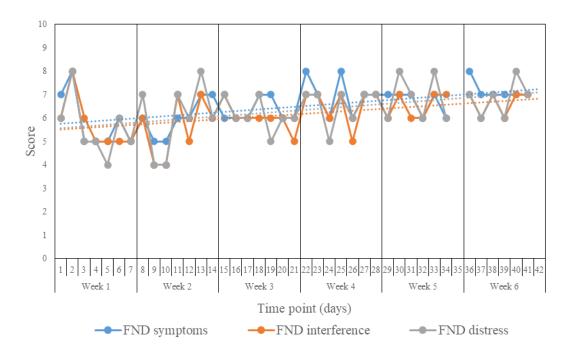
#### Participant 7

**Overview of the participant.** P7 was a male in his thirties. He had experienced symptoms associated with FND for eight years. His symptoms included motor sensory difficulties, muscle weakness and pain and migraines (associated with dissociative episodes and memory issues). He was not working and lived with his partner. He missed no group sessions and missed only two of the forty-three daily surveys sent.

**Target measures.** There appears to be a slight upward trend and worsening in his FND symptom severity, interference and distress as the group progresses (see Figure 12). His experiences of FND difficulties, particularly distress, appear to increase immediately following the first group session then fluctuate until day 10. However, from here onwards, his experiences of distress and inference worsen. His FND symptoms are worse in week four and six, whilst he rated his distress as highest in week five and six. His responses suggest that he was distinguishing between his experiences of FND symptoms, distress and interference.

#### Figure 12

Visual display of P7's FND symptom severity, distress and interference scores



**Standard measures.** P7's standardised outcome measures now described in turn. Follow-up measures were not obtained. Thus, pre and post-measures are described.

*Emotional Processing Scale-25(EPS-25):* Pre-intervention P6 scored 'High/ Very High' on the EPS total and across the subscales (score = 5.8, 90-95%). These scores indicated difficulties with emotional processing, which worsened into the 'Very High' range post-intervention (score = 7.56, 95%). The greatest worsening was on the 'Emotion Experience' subscale. He rated highly for the items 'feelings did not belong to me' and 'hard to work out if felt ill or emotional' throughout.

*Comprehensive Measure of Acceptance and Commitment Therapy (compACT):* P7's score on the compACT revealed improvements in psychological flexibility (pre = 37, post = 58). The only subscale demonstrating a reliable clinical improvement was 'Valued Action'. *Brief Illness Perception Questionnaire (BIP-Q):* There was a slight increase in threatening illness beliefs (pre = 55.5, post = 58). Pre-intervention, he ranked the three most important factors that he believed caused his FND as (1) car accidents, (2) history of being bullied and (3) assault. Post-intervention, these factors stayed similar, but the order changed; (1) assault, (2) history of being bullied and (3) car accidents.

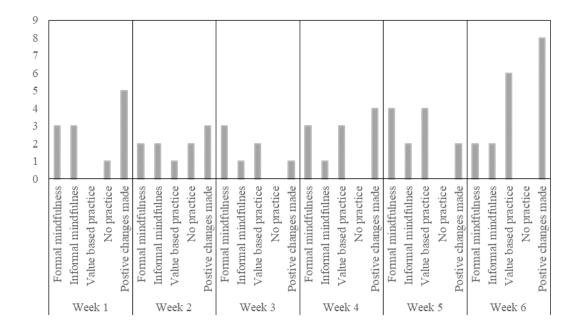
*Distress measures:* His score on the PHQ-9 and GAD-7 was in the 'Severe' range both pre and post-intervention (PHQ-9 pre = 21, post = 20; GAD-7 pre = 17, post = 18).

*Adjustment measures:* His score on the WSAS pre-intervention was in the 'Moderate' range. This worsened post-intervention to a 'Severe' range, indicating a reliable and clinically significant worsening (pre = 19, post = 31).

*Quality of life:* There was no change in overall health status (pre and post = 10). However, P7 reported a 27% rise in their perceived health rating, rated 67% postintervention.

Use of ACT processes. Over the forty-two days of the ACT group, P6 responded on thirty-six of these days, summarised in Figure 13. He reported using informal mindfulness on eleven occasions, formal mindfulness on seventeen occasions and using value-based processes on sixteen occasions. Only in week two did he report two days when he did not use any form of practice. He also described using 'other' techniques on three occasions, which included listening to podcasts (n = 2) and playing a game on his phone. Throughout the intervention, he reported making twenty-three positive changes. These changes included going out despite experiencing pain, helping a family member, doing chores, waking up earlier than usual, identifying areas of improvement, focusing on formal mindfulness and physiotherapy. Other positive changes included using his walking stick, although noting that it made him 'feel old', to walking more than usual, going shopping (based on values), meeting up with family, and attending the psychological intervention session. There was an option to leave further comments within the survey, which he did on eleven occasions. His comments related to the struggles he had experienced. He reported struggling to focus on mindfulness, find time, go out for a walk and not finding his phone game relaxing. Other comments described his difficult experiences of the day, including pain, depression and struggling with physiotherapy.

## Figure 13



Visual display of P7's weekly use of ACT processes

**Change Interview.** P7 commented on several beneficial aspects of the ACT group (see Table 18). He described no changes in his FND symptoms. Still, he felt he was managing his mood and stressful situations better following the group. He reported extremely important changes in his 'thought process'. These changes involved not getting 'hooked into thoughts' and experiencing less negative and more positive thoughts, and feeling better able to manage difficult situations. He attributed these changes to a range of 'tools', including several cognitive defusion techniques, and gaining a greater understanding of FND.

P7 also spoke of finding the routine of having the group helpful, alongside meeting others. He also described experiencing increased dissociation episodes due to the group and likened this to a medication side effect. He spoke of the group's unhelpful aspects, relating to a lack of information on what to expect and not always being comfortable when paired up for exercises. He felt that receiving more details would have been helpful and shorter but more regular breaks. He thought he was given too much information and could struggle to take this in.

#### Table 18

*P7* Change Interview, changes rated by expectancy, likelihood without intervention and importance

Changes	Change was:	Without therapy, change was:	Importance of change:
Change in my thought process, not getting hooked into thoughts	Surprised	Very unlikely	Extremely
Less negative, more positive thoughts	Surprised	Very unlikely	Extremely
Managing more situations better (i.e. social situations)	Surprised	Very unlikely	Extremely

# 3.3.4 Change Interview analysis

In this final section of this results chapter, Change Interview data will be presented to explore participant's descriptions of intervention acceptability for each intervention phase, followed by a description of the themes that emerged from the thematic analysis summarising participants' experiences of the interventions and change.

# 3.3.5 Acceptability of the intervention

*Phase 1, Assessment and formulation sessions:* Four participants attended the assessment and formulation sessions (ranging from three to six appointments) and three ACT group sessions before the group was suspended due to the pandemic. All

participants described these sessions as a helpful, informative and positive experience. This was despite one participant describing initial apprehension due to past painful experiences of psychological intervention. Two participants initially believed either they had been misdiagnosed with FND or did not have the diagnosis.

Three participants described experiencing positive changes due to the sessions (see Table 19). The participant who did not describe experiencing changes reported that they found the sessions helpful in providing clarification and confirmation in their understanding of FND by an expert. Unlike the other participants, this individual had known her diagnosis for many years. Participants attributed the changes they experienced to the skills and support they received from sessions. The three participants who reported experiencing changes also indicated experiencing challenges while attending sessions. Challenges included a deterioration in a health condition, ongoing employment issues and mental health difficulties. Furthermore, all participants experienced different levels of adjustment and distress related to a newly emerging pandemic, which placed significant restrictions on their day-to-day life and resulted in the abrupt end of the ACT group and uncertainty on when this would re-commence.

All participants reflected upon how, within assessment and formulation, despite talking about painful topics, they found this necessary for moving forward and that sessions had helped address distressing issues. All participants spoke positively of their interactions with the psychologists, who were described as good at what they do, friendly, and non-judgemental. These interactions created a safe space where participants felt listened to, expressed their feelings, and asked questions. Only one participant reported worsening FND symptoms following the intervention related to increased seizure frequency. However, they attributed this to a deterioration in a comorbid health condition. While no participants reported any unhelpful experiences, two participants commented on the individual sessions' environment being hindering, either due to the noise of building work or the uninviting appearance of corridors.

*Phase 2, ACT group:* Three individuals completed the full ACT group and completed the Change Interview related to their experiences. Mirroring the high acceptability of Phase 1, all participants spoke of finding the group helpful and feeling better due to the group. All described a range of positive changes resulting from the group, summarised in Table 19, which participants attributed to having a safe space, gaining increased understanding and new skills. Participants spoke highly of the value of meeting other people with FND, which helped them to feel understood, less alone and more connected.

Only one participant spoke of experiencing adverse effects at the end of the ACT group, related to increased 'brain fog' and dissociation. They attributed this to "thinking too hard" due to having new tools and likened this to medication's side effects. One participant described feeling upset following the initial session due to seeing others with FND. Another participant found it hard to think about their FND and how it impacts their life while also acknowledging that this was important. All three participants described finding the ending of the group difficult and daunting. As captured in the quotes below;

"you have learnt but, it's a bit, it's still daunting. . . it's kind of like here you go we brought you some new things to do, but it's... you're on your own" (P5)
"I have got all this support and input, and now I am done and left to get on with it by myself... that feels difficult. . . I am not sure what this Thursday will look like" (P6)

# 3.3.6 Experiences of the intervention and change

Participants reported positive changes in both intervention phases. The changes experienced by participants who attended different intervention phases overlapped in three super-ordinate themes: (1) safe space, (2) increased understanding, and (3) new ways of thinking. Figure 14 visually summarises these key themes and subthemes. There are clear links between these themes.

All participants spoke of experiencing the sessions as a safe space that provided validation and affirmation, which seemed crucial in aiding understanding and new ways of thinking. Participants spoke of increased understanding, which included understanding FND, self-awareness, and new skills acquisition. Furthermore, all but one participant spoke of gaining new ways of thinking that resulted from changes in understanding. New ways of thinking included relating to thoughts, increased coping, greater acceptance and increased self-compassion. Given the differing focus of assessment and formulation (Phase 1) and the ACT group (Phase 2), some of the subthemes related more clearly or were exclusive to these different phases. These main themes are now described with supporting quotes to elaborate.

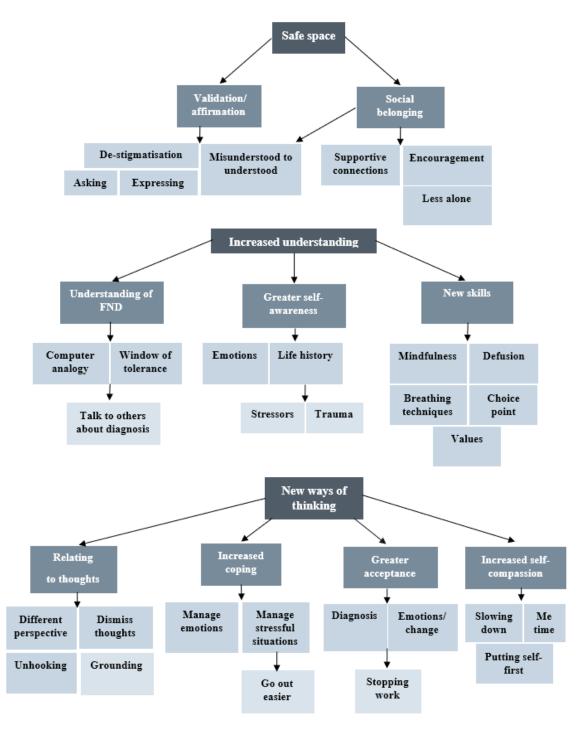
# Table 19

# Participant's responses to Change Interview questions

	Changes	Intervention	Surprised by changes	Without intervention	Importance of changes	Ext event
P1	<ul><li>Greater understanding of FND</li><li>Disclosing diagnosis to others</li><li>Going out more</li></ul>	Ax/ formulation	Surprised by all	Very unlikely for all	Very important for all	Deterioration in a health condition
P2	• No changes reported	Ax/ formulation	-	-	-	-
P3	<ul> <li>Putting self-first</li> <li>More me time/ relax time</li> <li>Slowing down</li> </ul>	Ax/ formulation	Surprised by all	Very unlikely/ unlike for all	Very important for all	Chronic stressors/ mental health difficulties
P4	<ul> <li>Looking at things differently</li> <li>Greater understanding of FND</li> <li>Reduced anxiety</li> <li>Increased self-care</li> </ul>	Axt/ formulation	Surprised/ Very surprised	Unlikely for all	Extremely important/ Very important	Chronic stressors/ mental health difficulties
P5	<ul><li>Skills to stop getting panic worse</li><li>Feeling less alone</li><li>Different ways of thinking</li></ul>	Full ACT group	Expected/ Surprised x 2	Very unlikely for all	Extremely/ Very important	Change in living circumstances
P6	<ul> <li>Putting self-first</li> <li>Resting more and slowing down</li> <li>Taking step back</li> <li>Inner calm and grounding</li> <li>Not returning to work</li> </ul>	Full ACT group	Surprised by all	Unlikely for all	Extremely/ Very important	Acute external stressors (family crisis, bereavement)
P7	<ul> <li>Not getting hooked by thoughts</li> <li>Less negative thoughts, more positive thoughts</li> <li>Managing stressful situations better</li> </ul>	Full ACT group	Surprised by all	Very unlikely for all	Extremely important for all	-

*Notes*. Ext event = influential external events during the intervention. Ax/ formulation = assessment and formulation

## Figure 14



Thematic map of changes due to the two-phase psychological intervention

**Safe space.** All seven participants spoke of experiences related to having a safe space, captured within the two subthemes <u>validation and affirmation</u> and <u>being part</u> <u>of a group</u>.

*Validation and affirmation.* Six participants spoke of experiencing validation of their FND experiences or affirmation of their understanding of FND, which is illustrated in the following quotes:

"through the sessions, I have realised that, no, this is something that is really going on in my brain ... I can't control this, and at the moment it is controlling me..." (P1)

"[psychologist] said things that I needed to hear. . . " (P4) "I have had the FND for so long. . . knowing what I understand about my condition and then speaking to a clinical psychologist in relation to my condition, and that what I understood was actually correct helped. It makes you feel a bit better, especially when you have been talking to people who do not know what they are on about" (P2)

The six participants described how this validation and affirmation led to feeling **<u>understood</u>**, contrasted with previous experiences of feeling <u>**misunderstood**</u> or not believed or even abandoned, both by professionals and family, as captured in the following excerpts:

"I have been taken to A&E a few times, and the Doctors don't have a clue what to do, they put you through scans that you don't need and don't know what you are saying. . . [family member] didn't get it, she was saying well if you sit down, it will hurt more, and she wasn't getting it, she didn't understand how it felt" (P5) "it has been such a difficult path to finding out what is wrong with me... I feel like no one believed me for a long time..." (P6)

"I have been made to feel very let down by Doctors in the past, and sometimes, erm I feel if I go to a doctor, everything is blamed on the FND, but you are allowed to have other illnesses, alongside FND" (P2) "trying to explain NEAD to your employer is embarrassing, it is degrading, because a lot of people just think, oh you are making this up, or oh you are just a little bit dramatic. . . patients suffering from FND symptoms do feel like they have just been abandoned and left to their own devices and that is tough... whereas if it was a cancer treatment, we know that there is a step by step pathway for cancer treatment, but then with FND sometimes there is not a clear pathway" (P1)

One participant who attended individual sessions (Phase 1) described how the experience of validation and affirmation supported a process of <u>de-stigmatisation</u> of FND that helped them process their diagnosis:

"The name dissociative seizures, I absolutely hate that term because of the stigma that it has with mental health. . . when I was first diagnosed, I thought oh God it is due to my mental health. . . [symptoms] are not a sign of weakness and not a sign of stress... I had previously been told that it was stress, but actually, there were multiple factors there in the background... for me, it was just a revelation and it helped me process my diagnosis" (P1)

Having a safe space where people experienced validation and affirmation was described by four participants as enabling them to <u>ask questions</u> and <u>express</u> <u>themselves</u>. For example:

"being able to ask questions, you know, every week I would go in, and sometimes I would feel really stupid asking a question, but actually it was really reassuring that other people have asked these questions as well, and other people have experienced that. . . just to have that sounding board and having someone non-judgemental, oh it was just incredible you know... For all the times that she listened and explained. . . for me it was just what I needed, a safe space, an opportunity to ask questions, an opportunity to learn, and an opportunity to express how it is affecting me" (P1) "It was really helpful because erm [psychologist] was really nice, she sat and listened . . . [psychologist] was good, very easy to speak too, she made you feel at ease" (P3)

*Social belonging.* The three participants who attended the ACT group spoke of specific benefits related to being part of a group with others experiencing FND, such as creating **supportive connections** through their interactions with others, which lasted beyond the group itself, illustrated in the following quotes:

"I have enjoyed the group, normally I would not go out and interact with people that I do not generally know. . . but with the regularity with coming to the group every week you kind of got to know them, so you opened up a little bit more, and at the end, those of us that were left have exchanged numbers and set up a WhatsApp group" (P7)

"You do not feel so alone. . . meeting other people as well and being able to keep in touch with them helps" (P5)

"been able to meet other people and have support... that connection has been important... it has helped me be kinder on myself and feel more supported... we have a WhatsApp group, and we message regularly in that" (P6)

These participants linked these supportive connections to receiving **encouragement** that supported them in creating change:

"we are keeping each other's spirits up. And you know, make sure everything is okay... we are constantly priming each other with other tools that we can use..." (P7) "it has been nice having the WhatsApp group and having people who understand what you are experiencing encouraging you... as well being able to encourage others. . . we message ideas from the group and encourage each other ... " (P6) "...there was a little task for each week that kind of pushed me to go out and into the supermarket because I thought right by the next time I go, I want to be able to tell everybody that I have done it, and that kind of push, erm, felt like what I needed really. . . having other people that maybe makes you a bit braver I think" (P5)

Linked with a sense of social belonging, all three participants in the ACT group described **feeling understood** by peers and **less alone**:

"they may not have the exact same thing as you. . . but they have an understanding of what you are going through, so it is easier to discuss with them" (P7) "When I told the group. . . because they have had the same pain, so they were like oh well why don't you try this and try doing different things, and it was just having someone there who gets it. . . I think the biggest part that I have got from the session is meeting people with, erm, the same thing" (P5)

*"it can be difficult to explain to people what functional neurological symptoms mean to others, but we have all had a shared understanding of what it is, and it was good... the group has helped me feel like it is not just me" (P6)* 

**Increased understanding.** Six participants spoke of experiencing increased understanding, linked to increased understanding of <u>FND</u>, greater <u>self-awareness</u> and <u>learning new skills</u>.

*Understanding of FND.* Five participants described having a limited understanding of FND before the intervention. They found it helpful to gain an increased understanding, which is captured in the following quote:

"Before coming to the group, I had a limited idea of what FND was, what my condition was, and what it was doing to me. So, in the first lesson introduction of what is FND, it made me want to learn more about my condition, rather than walk away from it not knowing. . . by getting to grips with the condition, your anxieties move and start to dissipated" (P7)

One participant described understanding FND better through a **computer analogy**:

"I understand it a lot more. . . it did help you know, so many years with this disease and not knowing what it was. . . she explained your brain is like a computer. . . and things come to you, and it comes crashing... it is like the information in my brain is hard. . . so maybe my software is triggering the computer in my head" (P4)

Another participant attending individual sessions described the **'window of tolerance'** helpful in understanding FND:

"she [psychologist] was good, and she was able to say you know people with different characteristic traits or different experiences are more likely [to have FND]... and I think the thing for me that was most significant for me was understanding the window of tolerance, and just having that kind of awareness of yourself is just, I mean, it was really, really helpful" (P1)

This participant also described how through being able to understand their diagnosis, they were more able to **talk to others about their diagnosis**:

"being able to educate my friends and family has made me feel like actually... do you know what I can trust these people to tell them, I can tell this is why what is going on and not to panic. . . understanding and being able to explain to people has been a really big transformation for me because my friends and family have never heard of it" (P1)

*Greater self-awareness.* Three out of the four participants who attended the assessment and formulation sessions spoke explicitly of gaining greater self-awareness, which included increased recognition of **emotions** and the role of **life history**. For example, one participant explained:

"when [psychologist] explained it, it made it obvious that actually... in your subconscious, you can be stressed without realising that you are stressing and that is what I was struggling with" (P1)

All four participants who attended Phase 1 spoke of experiencing a range of longterm and acute stressors, for example:

"it helped... because we have gone through a lot in the past twenty years my family, we have not seemed to have a break" (P2) "I have just been born into a challenging life after I got to a certain age, and that is just what I feel like it is one big challenge... sometimes I beat the challenge, and sometimes I don't... we are not all winners" (P3)

Two participants described their experiences of talking about their life history, including experiences of **trauma** and adversity as a painful experience, but helpful in creating awareness, illustrated below:

"We talked about some of my history. . . how something that affects you as a child, could be symptomatic of what goes on in your subconscious now, I erm was abused. . . and nobody knew about it. . . I feel relieved that I was able to say it out loud" (P2) "I just did not want to associate any of this, my current circumstances with the past, so that was a tough realisation I guess. . . it gives me a focus for the future, so although it is negative, as it was difficult and painful, you know it is better than not having a realisation" (P1)

*New skills.* All participants who experienced changes, in part, attributed this to the learning of new skills:

"I have got some techniques to use, so now I am thinking right, I will try to go out with that meal with friends. I will try it because I have back up and from the things I have learnt" (P5)

"By coming to the group, it keeps the routine going, but also giving us new tools to work with and help with putting those tools into practice" (P7)

These new skills included mindfulness, breathing, defusion, choice point and the identification of values. Participants spoke of finding different combinations of these skills helpful, for example:

"Most helpful things is the techniques, so like the mindfulness, breathing and the choice point. . . so like giving you the ideas of how to help yourself, and more positive thinking" (P5)

The most common skills spoken about was **mindfulness** and **breathing techniques**, where everyone who discussed these techniques described experiencing benefits, for example:

"I guess that breathing and mindfulness has helped me. . . just giving myself time. . . those activities have helped me decide on not going back to work. . . practising the mindfulness exercises has given me a new perspective" (P6) All three participants who attended the ACT group spoke of using cognitive defusion techniques, which contributed to changes in thought processes, illustrated below:

"it is by giving us the tools to do the changes to the thought process, you know it was not expected at all. . . the thing that I tend to use a lot is the leaves on the streams. . . with leaves on the stream I find I am able to take control of my own thoughts" (P7)

"with everything that is going on, I feel more able not to get caught up with it and hooked into the thoughts... so the leaves on the stream has helped me to get a little less caught up with all the stress" (P6)

"I found it a bit childish. . . you know your brain is constantly active all the time and then to turn around to it and say thank you it seems a bit strange. . . but it helps" (P5)

These three participants who attended the ACT group also described the benefits of using **choice point** and connecting with their **values**:

"Working on the values of what is important to you. . . I still have not managed to get my independence back to going out on my own, but it is something that I have been working towards" (P7)

*"choice point has been helpful... it has helped me think about what I can do next. . . it has helped me think about what really matters" (P6)* 

"the choice point really stands out to me as something that was useful in being able to take a step back and think about what matters..." (P5) New ways of thinking. Six participants spoke of experiencing new ways of thinking. These changes are captured within the four subthemes <u>relating to thoughts</u>, <u>increased coping</u>, <u>acceptance</u> and <u>being kinder to self</u>.

*Relating to thoughts.* Five participants described how changes in managing their thoughts led to different perspectives, for example:

*"just like a different perspective. . . it has made me stop and think about it properly and what I am going to get out of it, as well as thinking more about the positive side of it" (P5)* 

Another participant described feeling able to see the bigger picture and unhooking from difficult thoughts:

"I find it has helped me think about things a bit differently... I guess to see a bigger picture and not just keep on doing the same old thing. I feel more able not to get caught up with it and hooked into the thoughts..." (P6)

While another participant described more easily dismissing thoughts:

"One thing that changed for me is my thought process. . . now when I get a thought, I will quickly think it through and then just kind off, yeah thanks, I do not need to dwell on that one. . . dismissing the thoughts. . . it is like there is a barrier and they are not getting in" (P7)

*Increased coping.* Six participants also described experiencing increased coping, which was related but distinct to managing thoughts. For four participants, this increased coping included being better able to manage emotions, for example:

"mood-wise, I think I am managing to manage it a bit better" (P5)

"instead of you know letting it all get on top of you, instead of smothering it, I let it [emotions] out" (P4)

Two of these participants described being able to use **grounding** to manage their emotions better:

"I struggled so much... she was dropping anchor with me, and I just felt much better" (P4)

"panic. . . it will be a case of okay I will try to throw it out, even though I can feel my heart rate increasing, it is like I am not focusing on a specific thought and allowing myself to continue with what I do" (P7)

Alongside feeling better able to manage emotions and using grounding, six participants spoke of being able to cope and **manage stressful situations** more effectively, illustrated below:

"without the change in the thought process, I would not be able to cope with as much or manage situations as easily. . . the group helped more along the lines of anxiety and how to cope with stressful situations. . . I would not be able to cope with as much or manage situations as easily" (P7) "I am about to finish one of my jobs to see if that helps. . . " (P3)

Three participants described being able to go more out more easily, for example:

"It is getting better. I am finding it easier to go out" (P7)

"I have been able to walk to the supermarket on my own. . . I pushed it, did it, felt proud of myself, and it has given me more of that, well, if I do push myself a bit, I could build up to more different things. . . I have been able to go out for a walk by myself, which I was not able to do before" (P5) This change was particularly significant for one participant, who explained:

"before sessions, I became quite recluse. . . I was frightened, I would have a seizure or that they would judge me, or that I was just faking it. . . I am a chatty person, and I am outgoing, and it was really hard to drop what I considered was my normal life" (P1)

Another participant described going out following individual sessions despite their fear:

"I am still scared... it is always weird and at the back of your mind... if I go shopping or anywhere by myself it is always there, am I going to have one" (P5)

*Acceptance.* Another facet related to participants' descriptions of new ways of thinking was accepting both the diagnosis and emotions. Acceptance of diagnosis led to changes in work for two participants. Three participants who attended Phase 1 described struggling to accept their **diagnosis**:

"I would not accept that I had FND... you know I have been fighting through the hospital for years" (P4)

Another participant explained that they were still unsure of whether they had the diagnosis:

"she [psychologist] is going to see if the neurologist can fit me it... to explain... It was one of his juniors, and they could not wait to get rid of me" (P3)

For two participants, difficulties in accepting their diagnosis were linked to negative rumination related to the lack of control, uncertainty and unpredictability of their symptoms, for example: "I would feel one day fine for a few days, and then it all comes crashing down again. . . I did not want it, you know. . . I was always fighting, and I am still confused, why am I feeling this pain – is it this, is it that, and my head goes a little bit, so I question myself. . . I don't know if it is me doing it, don't know if I overthink because I do not want to be in pain" (P4)

"emotionally it is quite a difficult to cope with... you know it is a frightening thing, and for a person that likes to be in control and come across as got together, it is a horrible thing to experience. . . I really like to be in control and have a plan, and I am very independent... not being able to drive, that is the hardest thing I think... because that was my coping mechanism driving" (P1)

Three participants described how assessment and formulations sessions helped them to accept or be more open to an FND diagnosis:

"Something had to switch inside me, erm, because I had to break that wall down before I could understand what was going on. . . when I first came in, I was in denial, and I think I went from denial into acceptance. . . I think the work has to come from me, which I think is what I have gathered from the sessions. . . I realised that I had to do the work, so I have to maybe give a change to my lifestyle or the way that I see the diagnosis" (P1)

Similarly, one participant also spoke of sessions helping them accept their emotions:

"I would not admit to my anxiety... but she got me to understand things" (P4) While another participant spoke of sessions helping them accept **change**: Three participants described how increased acceptance was linked to **stopping work**, as illustrated below:

"I push myself too much, and I know I got to stop... I know I have . . . It is tiring, it is time for me to resign now. . . I just cannot get it, you know why, it is just a fourhour job, and I just cannot do it" (P4)

"It feels like a huge shift for me in accepting that I can no longer work rather than fighting against it. . . I kept fighting to get back to what I was doing... but it was making me ill. I was going to work feeling in pain, and I was wiped out when I got home. . . this group has helped me to think about it and come to a decision... why would I go back to work and make myself unwell again?" (P6)

*Increased self-compassion.* The final subtheme related to new ways of thinking was increased self-compassion. Five participants described being kinder to themselves by **slowing down, having more time** to themselves, and **putting themselves first**. Examples of different ways participants' described increased self-compassion included:

"You are rushing about, and you haven't got a minute. . . now I think, no slow down and take your time. . . it does affect your health and that, yeah I was very surprised by that. . . she said no you need to take time out. . . take more time to relax and take care of me, which I have started doing. . . I found her very helpful. She started making me think on the one to ones, yeah bugger it, I do not care what they say now, it is my time, I need my time and that, so yeah, I have started doing that" (P3) "you know, she taught me about how-to self-care. . . that works a hell of a lot" (P4) "one of the main changes I have made is slowing down and giving myself permission to slow down. . . rather than doing things. . . I am kinder to myself..." (P6)

## 3.4 Discussion

**Overview.** This study used multiple data sources to evaluate the impact of a two-phase psychological intervention for FND. This was explored in terms of changes in standardised and target measures and interviews of participant's experiences of the intervention. First, the findings regarding the change in Phase 1 (assessment and formulation) are outlined and discussed, followed by a discussion of Phase 2 (ACT group) findings. Here, pre and post-data and SCED data are described in relation to the Change Interviews. These findings are then explored using Elliot's (2002) hermeneutic single-case design (HSCED) and considered in the context of relevant literature and the limitations and strengths of the study. Next, the findings related to similar literature. The limitations and strengths of this approach are also presented. Finally, the scoping review findings on third-wave CBT interventions for FND and the multiple data sources from the two-phase psychological interventions are considered together. This summary is followed by consideration of the overall implications of this thesis, including clinical and research implications.

### 3.4.1 Phase 1 findings

The impact of the assessment and formulation was explored through pre and poststandardised outcomes measures for three participants, alongside four participants' qualitative accounts of their experiences of this intervention and perceived therapeutic change. Pre and post-change findings are now discussed regarding the two hypotheses made about the expected changes after assessment and formulation. Relevant Change Interview data is also considered.

First, it was hypothesised that reliable and clinically significant improvement would be observed for standardised distress, symptom interference and QoL measures. However, results disconfirmed this, with one participant (P1) experiencing improvements in distress measures and two experiencing worsening (P2 and P3). Two participants (P1 and P3) also experienced significant clinical worsening for symptom interference, and two participants (P2 and P3) experienced a reduction in overall health status.

Participants' qualitative accounts perhaps help provide context for these findings. The two participants who experienced worsening in distress measures described exploring historical trauma, losses and judgment linked to their FND experiences within the context of feeling understood by the clinician. Literature on patients' psychological assessment and formulation experiences indicates that people can gain increased awareness and understanding of their difficulties, feel understood and accepted and gain a sense of relief. However, this process of increased awareness can have implications for a person's sense of identity, which can cause distress (Redhead et al.'s, 2015) and perhaps this contributed to the worsening distress measures for two participants.

During assessment and formulation, the participants' FND illness beliefs were explored, and information on FND and its treatment was provided. Accordingly, it was hypothesised that there would be reductions in threatening illness representations. Here, findings were mixed, with two participants (P1 and P3) experiencing an overall decrease in threatening illness perceptions—related to an increased understanding of FND and a belief that treatment could help. In contrast, another participant (P2) experienced increased threatening illness representation related to an increased perception of the consequences and emotional impact of FND, alongside an increase in distress measures. This participant had their FND diagnosis significantly longer than other participants and was the only participant who experienced reliable and clinically significant emotion processing improvement. It may have been that improvements in emotion processing and perhaps reduced experiential avoidance came at the cost of increasing distress.

Overall, for assessment and formulation, changes in standardised outcome measures were unexpected and included worsening overall health status, symptom interference and distress measures for two participants and increased threatening illness perceptions for one. However, participants reported positive experiences of the sessions and experiencing therapeutic changes attributable to the intervention. For example, some participants described receiving validation and affirmation and having the opportunity to ask questions and express themselves, which enabled an increased understanding and acceptance of FND, greater self-awareness, increased selfcompassion, and better stress management.

## 3.4.2 Phase 2 findings

The ACT group's impact was explored for three participants who completed pre and post-standardised outcomes measures, a daily survey and a qualitative Change Interview on the experiences and perceived therapeutic change. The pre and postchange findings are presented, followed by SCED findings explored further through hermeneutic single-case efficacy design (HSCED; 2002), which explores these quantitative measures alongside the Change Interview.

**Pre and post-change findings.** For the ACT group (Phase 2), it was also hypothesised that reliable and clinically significant improvement would be observed for distress, symptom interference and QoL measures following. Again, the findings were unexpected. There was a lack of change for several standardised measures across participants. Only one participant (P5) experienced reliable and clinically significant improvements in distress measures. There was an unexpected reliable and clinically significant worsening in symptom interference for another participant (P7). This participant reported experiencing "a lot more brain fog" following the group, which they compared to the side effect of medication.

The fourth hypothesis anticipated that there would be reliable and clinically significant improvements in emotion processing and psychological flexibility measures associated with improvements in distress, symptom interference, QoL measures, and greater use of ACT processes. This hypothesis held only partly true for one participant (P5), who experienced reliable and clinically significant improvements in emotion processing and distress measures and a reliable improvement in psychological flexibility. However, the other two participants experienced a worsening in emotion processing and no change in distress, and one participant (P7) experienced a reliable and clinically significant worsening in symptom interference but a reliable significant improvement in psychological flexibility. No associations were found between the use of ACT processes and other measures. The measure of psychological flexibility showed reliable improvement for two out of three participants (P5 and P7), linked only to the 'valued action' subscale, reflecting the ACT group's focus on increasing value-orientated behaviour.

**SCED findings**. The ACT group SCED collected a daily survey of participants' FND symptom severity, interference and distress, and ACT processes. This allowed testing of the final hypothesis made – daily FND experiences of symptom severity, interference and distress would improve as the ACT group progresses. Again, this was disconfirmed. Although data completion levels were problematic, two participants completed approximately 50% of daily surveys, compared to a third participant's almost

- 141 -

full data completion (P7). This participant also reported the most consistent use of ACT processes across the intervention. A visual summary of their data revealed a slight worsening across FND experiences as the intervention progressed. There was no change in measures other than a reliable and clinically significant worsening in symptom inference and emotion processing and significant clinical improvement in psychological flexibility.

For the two participants with approximately 50% adherence to the daily survey, one participant's (P5) results showed a trend indicating improved FND experiences, particularly for distress. This finding was associated with reliable and clinically significant improvements in distress, psychological flexibility and emotion processing measures, but not increased ACT processes. The final participant's (P6) daily survey revealed a lack of change in FND experiences, with symptom severity, interference and distress appearing unchanged and largely indistinguishable. This participant experienced no reliable or clinically significant changes in measures, although there was a trend of worsening in distress, symptom inference and psychological flexibility measures. They reported using more ACT processes than P5. In the next section, these unexpected findings from the SCED are explored further using Elliott's hermeneutic single-case efficacy design (HSCED; 2002).

**Elliott's hermeneutic single-case design.** Elliott's approach is now presented to evaluate the ACT group's findings and explore links between the intervention and outcomes. The method applies scientific rigour to examine factors within and outside of the intervention to explain observed changes and consider a lack of change or worsening through the standardised outcome measures and qualitative data. The starting point of the HSCED is to identify evidence behind the intervention being the primary cause of change (Elliott, 2002). This involves establishing clear links between the therapy process and outcomes by asking participants what caused changes and how

likely these would have occurred without the intervention (i.e. Change Interviews). Next, if possible, the intervention stages are mapped to outcomes to identify any early change in stable problems following the intervention's introduction. This is followed by an analysis of process measures and comparing them with target and standard outcome measures.

#### **Evaluating evidence that the intervention caused changes.**

*Retrospective attribution.* All three group participants reported multiple changes following the intervention during the Change Interview process that were rated as unlikely to have happened without the intervention. They all attributed these changes to being 'Very likely' due to the intervention and spontaneously attributed changes to specific intervention components. For example:

- Participant 5: "I have noticed a change because of different things really... like the different things they taught us in the sessions... I have been using that when out and about"
- Participant 6: "Breathing and mindfulness exercises have helped me slow down (...) leaves on the stream has helped me get a little less caught up with all the stress (...) has helped me think about things differently."
- Participant 7: "Gives new tools to work with and put these tools into practice and maybe linking a couple of those tools together. So for me thanking the thoughts, I never really got the gist of it or understood it fully, but if you kind of work it in with leaves on the stream, for example, every time you see the thought, you can say thank you, and put it on the leaf and allow it to go."

All three participants also attributed the changes that they had experienced to gaining a sense of peer affiliation:

Participant 5: " having other people that maybe makes you a bit braver."

Participant 6: "having others to talk to has helped. It has helped me be kinder on myself and feel more supported."

As well as an increased sense of routine:

Participant 7: "normally, I would not go out and interact with people that I do not know well, but with the regularity of coming to the group each week (...) I felt more relaxed around people (...) got that routine which is something that I now kind of need."

Overall, support for intervention effectiveness is found for each participant. Change Interview comments linked changes to the group's specific components, meeting others and gaining a routine.

*Outcome to process mapping*. Participants linked changes to specific intervention processes and events. However, the symptom interference outcome measure (WSAS) directly linked to FND experiences revealed no change. The psychological flexibility measure revealed clinically significant improvement for participant 5 and participant 7 due to changes in the 'Valued action' subscale. There were also reliable but not clinically significant improvements in distress measures for participant 5.

*Process to outcome mapping.* Data from the daily survey (FND symptom severity, interference and distress) was graphically displayed to map any changes following the introduction of different weekly ACT components. Participant 5 and participant 6 only had 50% adherence to the daily surveys weighted towards the intervention's front end, making it impossible to identify whether changes in FND experiences corresponded to specific intervention events and processes. Participant 7 had almost full adherence to the daily survey, but there was no evidence of FND experience changes related to intervention events and processes found.

*Early change in stable problems.* Change can be attributed to the intervention when it coincides with a shift in long-standing difficulties compared to baseline. Unfortunately, multiple baseline measures were not available. Subsequently, it was not possible to assess for early change in stable problems. There was evidence that FND was chronic for all participants, with symptoms varying between 2 to 8 years.

*Event-shift sequences*. It is assumed that important events should precede a stable shift in participants' target problems during the intervention. This pattern was not observed in participant 6 and participant 7. There was evidence of shifting patterns in participant 5's target measures. However, important missing data and high variability during the second half of the group made it impossible to link changes to specific intervention components.

#### **Evaluating non-treatment explanations for change**

*Non-improvement or trivial change*. Where possible, the RCI was calculated for measures to ensure a reliable and clinically significant change. Participant 5 experienced reliable and clinically significant improvement in distress and emotion processing measures. Participant 5 and participant 7 experienced a reliable improvement in psychological flexibility, and participant 7 also experienced QoL measure improvement.

Overall, there is minimal evidence for reliable and clinically significant change other than psychological flexibility improvement for participant 5 and 7 and improvement on distress and emotion processing measures for participant 5. These findings were at odds with the participant's Change Interview, which indicated important changes.

*Negative changes.* The only reliable and clinically significant worsening following the ACT group was reported by participant 7 on symptom interference (WSAS measure), which was described in their Change Interview:

Participant 7: "more clouded, a lot more brain fog, so I will have moments where I will dissociate, and it feels like my head's all fuzzy".

They attributed this worsening to a 'side-effect' of the group due to: *"thinking too hard"*.

Participant 7 also experienced a reliable worsening on the emotional processing scale post-intervention, which was perhaps impacted by the adverse 'side effects' they reported experiencing. Notably, participant 6's emotional processing scale remained unchanged post-intervention but indicated a reliable worsening at one-month follow-up, which fitted with an overall worsening across measures for this participant.

*Relational artefacts.* Relational artefacts were considered as a potential explanation for the changes reported in the Change Interview. First, data was analysed for evidence of the 'hello-goodbye' effect. This effect describes a tendency to emphasise distress at the start of the intervention to justify the need for treatment and is followed by an exaggeration of improvement at discharge, to show gratitude or justify the wish to end therapy (Elliott, 2002). Additionally, the interviews were explored for evidence of any participants failing to disclose any difficulties or disappointments with the intervention due to social desirability (Gale, 2000).

Change Interviews were conducted by a researcher rather than clinicians, which enhanced validity. During the Change Interview, all participants commented on both positive and negative aspects of the intervention. There was no dynamic of wanting to please the researcher evident. Additionally, participants' answers about specific factors within the intervention were full of personal detail. Based on the detailed, differentiated nature of the qualitative data, it did not appear that participants reported changes during the Change Interview or within the outcomes that were inflated. *Expectancy artefacts.* Another source of bias in attributing the change to interventions is participants' expectations or wishful thinking. However, none of the participants' comments indicated this being present. On the contrary, a couple of participants commented on their unfulfilled expectations or lack of expectations. For example, participant 7 said:

"I am going through physio at the moment because, erm, my walking is not as good (...) I kind of expected my walking to have improved slightly, but it has not (...) before I was diagnosed with FND, I was diagnosed with psychogenic amnesia, so I was hoping for improvement with my memory too." While participant 6 explained:

"I did not really know what to expect from the group, so I did not have any expectations of what would happen, erm, sounds strange but because I did not know what it was for really."

Overall, there is no evidence that expectancy artefacts could explain changes in participants.

*Self-correction.* Several factors were considered to evaluate whether participants' self-help efforts, natural maturational process or spontaneous recovery caused changes. During the Change Interview, participants were asked what changes they noticed and how likely they would have occurred without treatment. Participants reported changes following the intervention and rated the changes as 'Very unlikely' or 'Somewhat unlikely' without the intervention, except for participant 5's change related to managing their anxiety, rated as 'Somewhat expected'. Unfortunately, with no baseline measure, it was impossible to identify pre-intervention trends that might suggest self-correction artefacts.

*Extra-therapy life events*. Factors outside of the intervention, including changes in relationships, social activities, or work that may have contributed to or negatively

affected outcomes, were considered. Participant 5's improvements in measures could, in part, be attributed to extra-therapy life events related to moving into a less stressful home environment. Participant 6's lack of improvement and a slight worsening in some measures may have been partially attributed to significant life stresses, including bereavement and ill-health.

*Psychobiological causes*. Improvement or worsening in study participants can be explained by biological changes, such as medication regime changes, hormonal processes, and health changes. Participant 6 missed two consecutive group sessions due to ill health. Participants 5 and 7 described experiencing significant difficulties with anxiety, while participant 7 also described re-occurring episodes of low mood. These factors may have impacted the improvements experienced by participant 5 or the lack of change for participant 6 and participant 7.

*Reactive effects of participating in research.* Another common artefact involves changes attributed to the sole fact that an individual participated in the research, which can create either negative or positive effects on outcomes (Elliott, 2002). Moreover, an adverse impact on outcomes can emerge if the procedure is perceived as too bothersome. In contrast, positive effects on outcomes can occur through the sense of altruism felt by research participants ('being able to help others') and the rapport with the researcher. Participants were attending the group as part of routine care but had agreed to complete an additional daily survey. There was a low adherence rate for daily surveys for two participants. Participant 7 described frustration with the daily survey:

"I found the questions rather plain (...) I really did expect it to be maybe ten questions or, erm, I do not know more in-depth questioning (...) it felt like there was not much thought put into the questions."

- 148 -

Participant 7's adverse experience of the daily survey may have been a factor behind the slight worsening over time on this measure. It may have also contributed to the low adherence to the daily survey for participant 5 and participant 6.

Summary and conclusions of HSCED critical analysis. The final step of the HSCED is a summary of positive and negative evidence to decide whether or not any changes were observed and whether this could be attributed to the intervention. HSCED standards require replication of positive evidence across two out of five direct evidence types (e.g. retrospective attribution, outcome-process mapping, process-outcome mapping, early changes in stable problems, and events-shift sequences). This evidence was only established for participant 5, who had an incomplete data set for the daily survey and reported important positive extra-therapy life events. However, the SCED analysis suggests that this alone could not have accounted for their observed changes and suggests that change for participant 5 resulted from the intervention. For participant 6 and participant 7, other non-therapy explanations may have contributed to the lack of change and worsening for some standardised measures. Unfortunately, the lack of data collection across baseline measures and incomplete data hampers any further conclusions being drawn.

Overall, therapeutic change was not captured by the pre and post-standardised outcome measures, which included some lack of change and worsening. This was unexpected and juxtaposed to participants' descriptions of change directly linked to the intervention, such as feeling better able to manage distress, thought processes, feeling less alone, slowing down and putting themselves first. Notably, the lack of change and some worsening on standardised measures for the ACT group also contrasts with the limited literature on third-wave CBT interventions, which, while characterised by small samples and low quality, have found changes across various standardised outcome measures similar to those used in this work. For example, in the only SCED that explored a six-week self-help ACT intervention for NEAD participants, Barrett-Naylor et al. (2018) found improvements in distress, symptom interference and psychological flexibility measures. The only other studies to explore an ACT intervention and FND are Graham et al. (2017, 2018). These studies used a single-case study and a concurrent single-case series to examine the impact of an ACT intervention on symptom interference, distress and psychological flexibility measures, and again improvements were found across measures for most patients.

These unexpected findings will be explored further in 'Limitations' – Section 3.4.5. Next, the limitations and strengths of the quantitative methods used are outlined. This will be followed by a deeper exploration of the qualitative findings and limitations and strengths of this approach before summarising the multiple sources and discussing the findings collectively.

Limitations and strengths of the quantitative approach. There are several significant limitations to the pre and post-design and SCED. It was planned that pre and post-standardised measures collected for Phase 1 would be collected for the same participants in Phase 2. However, no participants contributed to both data sets. Consequently, it was impossible to track change across the intervention phases to explore how changes evolved. This was due to a lack of clinician adherence with the collection of routine clinical measures rather than due to participants not consenting.

The lack of outcome data also meant that the anticipated baseline measures for the ACT group SCED were not available, reducing the level of control over confounding variables. It was expected that data from participants attending a second ACT group would have mitigated against this and would have provided data for participants who attended both phases.

There was low adherence by participants in the SCED daily survey. Two out of three participants completed this measure at approximately a 50% level. Only one

participant completed one-month follow-up measures. The lack of data completion across the SCED participants limited the interpretation of the results and the conclusions drawn.

The daily survey attempted to capture FND symptom severity, interference and distress as three distinct concepts, but one participant did not distinguish between these measurements, making it unclear what the daily survey was capturing. The daily survey was kept brief, and sessional measures were not used in order to reduce the burdensomeness. However, more frequent data would have been beneficial in providing more meaningful analysis.

In hindsight, within the design, there was a lack of data regarding patient characteristics that may have impacted change. Formal recording of participant factors such as medication, other concurrent therapeutic inputs (e.g. physiotherapy and occupational therapy), and explicit checking of comorbidity and a rating of FND severity and acceptance of diagnosis would have provided useful contextual information to interpret the results.

Despite these limitations, the study had some important strengths. For example, the use of SCED allowed detailed observation of individuals' FND experiences and their use of ACT processes that could then be linked to various outcomes. The use of SCED exploring ACT for FND has only been carried out in one other study, which used a guided self-help format and recruited NEAD volunteers from a social media site (Barrett-Naylor et al., 2018). However, an advantage of the current study was the use of clinical populations within a clinical context. Also, changes in assessment and formulation were explored at the individual level rather than using group statistics, which provided a more meaningful exploration of this unexpectedly small data set.

Change Interviews were carried out by an independent researcher, reducing bias and enabling group participants to voice their intervention and change experiences. Published studies of third-wave CBT interventions for FND have overlooked this important source of data. In this research, the Change Interviews provided a richer understanding of SCED data not captured by standardised outcome measures. Finally, measurement of the fidelity in the ACT group was attempted. Although carried out by the facilitators, there were two clinicians, potentially increasing reliability.

Summary of the pre and post-design and SCED findings. The quantitative results indicated some lack of change and worsening, which was hard to reconcile with the broader literature on third-wave CBT for FND. Several factors may have contributed to the limited findings, including the time and type of measurement used, a lack of diagnosis acceptance and a lack of intervention effectiveness. These findings' clinical and research implications will be explored in the 'implications' – Section 3.4.6. Next, the qualitative results are discussed. As has been touched upon, the Change Interview findings were at odds with the quantitative findings and provided a rich account of participants' experience of the intervention and change, which will now be discussed.

## 3.4.3 Change Interview findings

A thematic analysis of participants' Change Interviews based on either their experiences of assessment and formulation sessions or the ACT group was carried out. This analysis revealed shared themes across each phase. All participants spoke of experiencing a safe space through validation and affirmation and the ACT group's social belonging. Several described how these experiences contrasted with previous experiences of feeling misunderstood or not believed by Health Care Professionals (HCPs) and family members. Participants' descriptions of feeling misunderstood by HCPs mirrors qualitative research exploring the experiences of people with FND, where many patients felt most HCPs misunderstood their difficulties and lacked confidence in the HCP's ability to help (Nielsen et al., 2019). Some of the current participants described experiencing a corrective experience of validation and affirmation that enabled them to ask questions and express themselves, which helped them process their diagnosis. The importance of sharing and feeling understood in participants' understanding of their FND diagnosis echoes previous work (Gerskowitch et al., 2015; Nielsen et al., 2019).

Previous work has found patients with FND can experience marginalisation, which may contribute to the emotional burden of the diagnosis and be a source of significant distress (Nielsen et al., 2019) and a longing for social recognition (Lind et al., 2014). Participants who attended the ACT group spoke of specific benefits formed through the group's social belonging that led to feeling understood and less alone, alongside creating supportive connections and receiving encouragement. This experience mirrors that of patients diagnosed with a somatoform disorder who attended a mindfulness group and described experiencing positive feelings of social belonging and reduced loneliness (Lind et al., 2014).

All participants described increased understanding of FND, themselves, and learning skills related to their thoughts and feelings. Several participants described having a limited understanding of FND before the intervention and benefitting from information that made it easier to talk to others about their diagnosis. Some participants also gained increased self-awareness of emotions and the role of their life history, including stressors and past traumas. These themes correspond with Lind et al.'s (2014) findings that a mindfulness group for patients with somatoform disorder improved patients' ability to identify and express their needs and feelings of distress. This increased understanding aided a range of new ways of thinking.

New ways of thinking involved effective management of thoughts, increased coping, greater acceptance and increased self-compassion. Participants described

changes in managing their thoughts that led to 'different perspectives' through 'unhooking' and 'dismissing' difficult thoughts. These changes supported increased coping. Some participants described gaining new mindfulness skills, breathing techniques, defusion, choice point, and value identification skills. Participants spoke of finding different combinations of these skills helpful in creating changes. Some participants described managing their emotions and stressful situations more effectively and subsequently going out more easily. Several participants also reported increased acceptance of emotions and of their diagnosis. This finding is important given that rejection of psychological explanations by patients with functional symptoms is widely reported in the literature and backed by evidence from qualitative studies (Nettleton et al., 2005; Rawlings & Reuber, 2016), illness belief questionnaires (Binzer et al., 1998), and anecdotal evidence from neurologists (Kanaan et al., 2011). Another theme across participants was increased self-compassion, reflected through participants' descriptions of slowing down, having increased time to themselves and putting themselves first. This theme is interesting when considered in the context of recent work that has focused upon the role of self-compassion and adjustment in patients with NEAD, where selfcompassion was associated with adaptive coping strategies (Clegg et al., 2019).

Limitations and strengths of the Change Interview findings. These qualitative findings represent the views of a small sample. Participants were restricted to patients who attended assessment and formulation and either part of or the full ACT group. Patients who declined the group or taking part in the research, dropped out of the service, or were referred elsewhere were excluded, making the sample biased and limiting generalisability. Four participants who attended the second ACT group had this intervention cut short due to the lockdown caused by the pandemic. Subsequently, these participants were asked to discuss their initial assessment and formulation sessions and their experiences of change at an unsettling and uncertain time, without a clear sense of when treatment or 'everyday' life would resume. The researcher's identity as being independent of the department was highlighted. However, a psychologist involved in the intervention was part of the research team, which may have influenced how participants responded (i.e. demand characteristics).

The qualitative analysis enabled the investigation of phenomenon and elicited data grounded in human experiences in an area in which there is a paucity of research (Sandelowski, 1995). The thematic analysis provided a structured but flexible approach to handling the data sets that allowed identifying similarities and differences between participants' accounts of experience (Braun & Clarke, 2006; Nowell et al., 2017). The flexibility of thematic analysis can also be perceived as a weakness. It can lead to inconsistencies and lack of coherence in data analysis (Holloway & Todres, 2003). However, inconsistencies were checked using an independent researcher to explore and compare themes, which revealed a shared consensus on the key themes. Of final consideration, while thematic analysis can be flexible, it is also a structured approach and could have resulted in an increased focus on the change, which was the focus of the structured Change Interview. Results may have looked very different had an open interview been used, which was focused more broadly on the intervention experiences.

Next, the multiple data sources' findings are summarised before considering the implications of the thesis.

# 3.5 Summary of findings

A scoping review examined the extent and nature of third-wave CBT for FND. Preliminary factors related to the feasibility, acceptability and effectiveness of thirdwave CBT for FND were also explored. The review identified eight low-quality intervention studies using varying designs. These studies captured DBT, MBT and ACT interventions delivered to people experiencing various FND presentations, although mainly NEAD. There was a lack of reporting on data that indicated intervention feasibility and acceptability. No specific intervention factors were found to relate to effectiveness, indicating that there may be particular feasibility in adopting manualised third-wave CBT that can be replicated across clinical contexts by facilitators with varying skills mixes. Intervention effectiveness was linked to improvements in FND symptoms and symptom interference, with the most robust evidence for reducing NEAD frequency. Some improvements were also found for standardised QoL, distress, and psychological flexibility measures. It is impossible to know whether changes were due to the intervention or other confounding factors due to the low-quality evidence.

When exploring the experiences and impact of a two-phase psychological intervention for FND, an unexpected and complex change pattern was found within pre and post-standardised outcome measures, which included some lack of change and worsening. Following assessment and formulation, only one participant experienced improvements in distress measures. Two participants experienced a reliable and clinically significant worsening in distress and symptom interference measures. Following the ACT group, only one participant experienced an improvement in distress, emotion processing and psychological flexibility measures. Using Elliott's (2002) HSCED approach, changes attributable to the intervention were found for this participant.

Participants' qualitative accounts from the Change Interview revealed shared themes across each intervention phase, with both representing a safe space where participants experienced validation and affirmation that led to feeling understood, listened to, able to express their feelings and ask questions. Participants attending the ACT group also spoke highly of the value of meeting other people with FND and gaining a sense of social belonging that created supportive connections and

- 156 -

encouragement. Within this context of a safe space, participants were able to gain an increased understanding of their diagnosis, self-awareness and new skills. This helped create several new ways of thinking – such as managing thoughts, increased coping, greater acceptance and increased self-compassion. Despite talking about painful topics, sessions brought about positive change. In summary, the thematic analysis results revealed that the interventions created therapeutic changes, with both phases being described as acceptable by participants.

### 3.5.1 Implications

This work set out to explore the impact of third-wave CBT for FND using multiple methods, which will now be explored collectively to make sense of the overall findings. Several areas for reflection when reconciling these different data sources. Findings indicate that some people with FND experience positive therapeutic changes from third-wave CBT. However, it is unclear what patient and treatment characteristics contribute to this, which appears in part to be an artefact of the challenges in measuring change and providing psychological interventions for this complex and heterogeneous clinical group. These areas will now broadly be discussed before outlining clinical implications, overall limitations and strengths and research implications, including future research recommendations, before concluding.

A key finding in this work was the lack of change and some worsening in the ACT group's standardised outcome measures. At first glance, this is not easily reconciled with the scoping review findings on third-wave CBT intervention for FND. This review found previous studies using third-wave CBT for FND were of small samples and low methodological quality but generally found changes across the various standardised outcome measures used in this work. However, these were published studies and may represent a publication bias – where only positive findings are published. Importantly,

the review identified that that are no RCTs on third-wave CBT for FND. However, higher-quality research using ACT interventions and related clinical samples has found limited effectiveness. For example, Pedersen et al. (2019) carried out a large RCT for an ACT group-based intervention for 180 patients with functional somatic syndromes randomly assigned to enhanced care with a brief ACT workshop or a nine three-hour session ACT group. The authors found no differences in post-intervention measures for the ACT group other than overall self-rated health improvement.

The limited evidence for third-wave CBT approaches for FND makes it unclear whether a more protracted ACT intervention may have created change. Several studies using third-wave CBT for FND have found that the patients least likely to experience improvements, or in some cases worsening, had severe FND presentations and comorbid physical and mental health difficulties (Baslet et al., 2015; 2020; Bullock et al., 2015; Graham et al., 2018). The participants who experienced worsening in the current study also described comorbid mental health and physical health difficulties. Furthermore, the literature indicates that FND prognosis is poor – a systematic review found that 39% of patients with mFND had the same or worse symptoms at follow-up, and only 20% had complete remission (Gelauff et al., 2014). Given the relatively short seven-week ACT group evaluated in this work, it is perhaps unsurprising that it was not effective in creating change. This work indicates that for some people with FND, thirdwave CBT is not effective.

More robust and high-quality evidence of effectiveness exists for alternative psychological approaches for FND. For example, Goldstein et al. (2020) recruited 368 patients with NEAD into an RCT for either standard medical care or routine medical care plus CBT. They found improvements in QoL, symptom interference, distress and somatic symptom measures that remained at 12-month follow-up for the CBT group. The CBT intervention involved twelve one-hour sessions over four to five months, with a booster session nine months' post-randomisation. In another trial, Sattel et al.'s (2012) twelve weekly session PIT for patients with multisomatoform disorder found the intervention improved physical QoL and somatisation measures better than enhanced medical care (three sessions). The current evidence base for third-wave CBT for FND is a long way off this level of robust research design, perhaps unsurprisingly given its more recent emergence.

Another key finding of this work was that standardised measures following the two-phase intervention revealed a lack of change and worsening for some. These findings contrasted with participants' interview accounts. Here participants described experiencing a range of positive therapeutic changes resulting from the intervention, with rich accounts full of idiosyncratic detail on how changes linked to the intervention. The unexpected changes for both intervention phases may have perhaps been an artefact of when and how the change was measured. For example, standardised outcome measures were collected immediately following each phase. However, it may have taken time for change to have become apparent and meaningfully captured.

Although there is a broad consensus that therapy's goal is to create change (Miller, Duncan, & Hubble, 2005), what this looks like and how this is measured is often arbitrary (Wampold, 2001). While the standardised outcome measures selected were psychometrically sound, such measures are 'arbitrary metrics' (Blanton & Jaccard, 2006) and perhaps may not have translated into participants' real-world functioning (Kazdin, 2001). In contrast, the Change Interview was more flexible and rooted in the participants' experience and highlighted that each participant was unique and experienced their own distinctive set of changes. The concept of reliable and clinically significant change can also be problematic as a participant must fall within the 'clinical' population to achieve clinical significance. However, several current participants fell into a subclinical range for some of the standardised measures. Additionally, some individuals may never return to within the non-clinical population cut-off due to the chronicity of their difficulties, despite making meaningful change for themselves (Hansen et al., 2002), which may have also contributed to the lack of change found for some in this work.

Across the two-phase psychological intervention, participants' intervention descriptions suggest high acceptability. However, when exploring the Clinical Health Psychology Services overall FND referral numbers between June 19th 2019, to February 27th 2020, forty-eight patients were referred, but seventeen dropped out or did not respond – no other service referral numbers are available to draw comparisons. Additionally, three did not attend the first appointment for the ACT group out of the fifteen patients offered the ACT group within this data. While in the group used for the SCED, three participants attended the final group session out of the nine invited. These high drop-out rates indicate a lack of acceptability for the two-phase psychological intervention for some. Although it is important to remember that this data is collected in a clinical setting from a recently established treatment pathway that contrasts with large scale well-funded trials set up to perhaps be more efficient than clinical settings at engaging and retaining participants.

Patients in this work were predominantly referred from the hospital neurology department and are typically at an early stage of receiving an FND diagnosis and making sense of this, likely impacting the patient's readiness to engage in the psychological intervention. Literature indicates that rejection of psychological explanations of FND can be related to perceived incompatibility between physical problems and psychological mechanisms (Neilson et al., 2019). A mind-body dualistic way of thinking is embodied in society in general (Wade & Halligan, 2017). This mindbody dualism may be reinforced in patients with FND by being given overly simplistic psychological explanations (e.g. symptoms caused by stress) and explanations that fail

- 160 -

to take precipitating physical events into account when they are an essential part of a patient's narrative. Indeed, this underlined the experiences of feeling stigmatised and ultimately de-stigmatisation by one participant in the current study.

Moreover, the stigma associated with mental health can contribute to participants' dissatisfaction with psychological explanations of FND (Neilson et al., 2019). Several participants referred to the negative attitudes held by some HCPs towards FND and felt that they had to prove their experiences' legitimacy. Negative attitudes towards FND have been reported in clinician surveys (Ahern et al., 2009; Evans & Evans, 2010). One of the few qualitative studies on patients with somatoform disorder experiences of a mindfulness intervention highlighted the importance of patients feeling acknowledged as legitimately ill (Lind, Delmar & Nielsen, 2014).

Literature indicates that an important variable in predicting post-intervention improvement for patients with FND is their acceptance of a psychological formulation for their symptoms (O'Connell et al., 2019). A participant's lack of acceptance of a psychological understanding of their diagnosis may have contributed to some participants' lack of engagement in using ACT processes and subsequent lack of change and, for some, deciding to drop out or not engage in the service all. In O'Connell et al.'s (2019) sample of 98 patients with mFND, the authors found that only 49% of their sample accepted a psychological formulation before the commencement of therapy. The authors found that patients' acceptance of a psychological account of symptoms predicted post-measure improvements – those that did not accept a psychological framework were less likely to use therapeutic tools.

The high drop-out rates in this work reflect the challenges in providing psychological therapy for FND. Many patients do not perceive psychological interventions as an acceptable treatment for their physical symptoms and can feel that their symptoms are not being taken seriously (Carson et al., 2012; Nettleton, 2006; Reid et al., 2001; Stone et al., 2002). Indeed, referral to psychology can be perceived as tantamount to saying that the individual's very real physical symptoms are all in their head. Nevertheless, psychological intervention is often considered the most important treatment option for FND (Howlett et al., 2007; Reuber, Howlett, & Kemp, 2005).

The patients represented in this work accepted a psychological intervention enough to engage with the Clinical Health Psychology Service and then experienced some benefits that kept them engaged in the intervention. Thus, current findings only represent a small subsection of the FND population. Furthermore, those referred to the ACT group were pre-selected based on clinicians' perceptions of suitability, further reducing the findings' generalisability. This process highlights the need to be cautious in generalising FND intervention study's findings to broader FND populations and suggests that future psychological studies on FND will have limited feasibility and acceptability when considered in the context of the broader FND population.

Arguably, the commissioning and service structure of separate physical and mental health service reinforces unhelpful messages on the nature of FND that can make it hard for some to reconcile that their very physical symptoms may have a psychological explanation (Nettleton et al., 2005; Rawlings & Reuber, 2016). In the current service evaluated, patients with pre-existing mental health and trauma-specific issues as their primary concern are referred to mental health services. However, the literature indicates that it is not meaningful to separate mental health problems from FND symptoms, given that FND symptoms can be a physical manifestation of the same underlying difficulties as those found in mental health difficulties. These underlying difficulties include a range of cognitive-emotional processes (Brown, 2004; Edwards et al., 2018; Novakova et al., 2015) and difficulties recognising or acknowledging affect (Novakova et al., 2015). Subsequently, there is limited validity in having an FND treatment pathway separate from a mental health pathway.

- 162 -

The problematic separation between mental and physical health services has started to be tackled in recent years through the growing acknowledgement and support for a multidisciplinary approach to treating FND. A multidisciplinary approach shares knowledge from a physical, psychological and social perspective that supports a patient through providing physical therapy (physiotherapy and occupational therapy), pharmacotherapy, individual and family therapy and psychoeducation (Carson et al., 2012; Kozlowska, 2017; Kozlowska et al., 2012, 2013). Multiple studies assessing multidisciplinary inpatient and outpatient rehabilitation treatments that vary from three to fourteen weeks indicate that most patients experience significant improvements in physical function and quality of life (Demartini et al., 2014; Jordbru et al., 2014; McCormack et al., 2014; Petrochilos et al., 2020). However, this structured multidisciplinary team (MDT) approach is not consistently available in the UK and is not supported by national guidelines (NICE, 2017).

Clinical implications. The current findings indicate that whilst some patients value the sessions provided by Clinical Health Psychology Services; a third-wave CBT intervention is neither acceptable nor effective for all. Findings suggest that acceptable and effective interventions for some people with FND will need to provide a joined-up multidisciplinary approach that is personalised and formulation-driven. The present Clinical Health Psychology Service two-phase psychological intervention may be an acceptable and feasible first-line approach for some people with FND within current service commissioning limits. Offering assessment and formulation sessions can help tackle the unhelpful mind-body dualism by providing a psychologically informed understanding of symptoms, but only if patients are ready to consider this perspective. In this work, participants described having space for their stories to be listened to, which increased understanding and acceptance of their diagnosis. This process emphasises the importance of listening to patients' stories and the need for an integrated

biopsychosocial explanatory model to help patients make sense of their illness experience.

Following assessment and formulation, the ACT group could be seen as part of a stepped-care treatment pathway, followed by individualised, one-to-one input using a range of evidence-based therapeutic approaches when required. The ACT group is an initial intervention that could provide high feasibility, given the group format and brief nature. The current findings suggest that the group format provides additional value for some patients, although some will not find it acceptable. Moreover, ACT can offer a shared understanding and language-focused upon increasing value-based activity that can be translated across different disciplines. Providing a choice of the ACT group or other individualised therapeutic approaches can help patients feel empowered and that their concerns are heard, which are important factors contributing to improved patient outcomes (Mauksch, 2000; Williams, Frankel, Campbell, & Deci, 2000).

The study findings also highlight the power of group-based interventions for FND, which can offer a social affiliation that leads to patients building supportive connections, receiving encouragement, feeling more understood and less alone. Literature and the current findings highlight several group factors that can support change, such as hope, advice, kindness and socialising (Yalom & Leszcz, 2008). Bullock et al. (2010) suggest coping skills may be more readily accepted and learnt by patients with FND after interacting with and observing others experiencing symptoms similar to their own. Consequently, it may also be beneficial for clinicians to consider ways to provide a structured, supportive space for patients with FND to meet others with the diagnosis.

**Limitations and strengths.** Using several methods allowed for a rounded understanding of the feasibility, acceptability and effectiveness of third-wave CBT for FND. Although, this posed the challenge of interpreting findings that looked different from each other. A potential limitation of this work was that participants had a mix of different FND presentations. Research on different subcategories of FND indicates that patient's with NEAD and mFND may have varying treatment needs, which may have conflated results and made findings less pertinent.

This thesis included a thorough review of the literature that identified significant gaps and highlighted the need for further research and the importance of the questions explored in this work, which is the first to explore an ACT group for FND and participants' experiences of a psychological intervention. Unfortunately, the scoping review was carried out retrospectively following data collection disruptions, and although the review provided useful insights into conducting SCEDs in clinical practice, this did not shape the SCED presented. Despite this, the SCED was robustly designed, with the full potential unfortunately not realised due to the second ACT group's abrupt ending.

Data collection was also hampered by SCED participants' low adherence to the daily survey. Although the researcher attended the first group to discuss the research, it appears additional time spent on getting participants to understand and invest in this survey was necessary. However, a strength of this work was that participants' burden was prioritised in designing measures, which were finalised in consultation with past patients of the service. This decision reflected the clinical context that offered high ecological validity, albeit at the expense of more stringent controls and meaningful data collection. A final key strength of this work was the value placed on participants' experiences. Using a semi-structured Change Interview provided rich qualitative information on participants' experiences of the intervention and change.

**Research implications.** This work demonstrates that research within clinical settings can be feasibly carried out and contribute to the evidence base for FND. Findings highlight that some people with FND benefit from third-wave CBT. However, despite the focus on understanding the impact of third-wave CBT, it remains unclear which patients with FND may benefit from this approach and the best time to offer the intervention. Unlike other therapeutic approaches for FND, the literature on third-wave CBT is limited and low quality, highlighting the need for more robust research in the area. Subsequently, different recommendations for future research are next outlined.

The SCED for the ACT group explored change at the individual level and did not require a large sample size. According to Morley (2017, p. 159), there is a 'tremendous potential in replicating single-case series' in developing interventions that can create an understanding of third-wave CBT interventions. Indeed, SCEDs can explore the unique contributions of different intervention parts that may contribute to therapeutic change. Through repeated replication, SCEDs can build evidence for the effectiveness of thirdwave CBT for FND that may generate enough evidence to warrant larger scale RCTs. Currently, RCTs have only been carried out for third-wave therapies in broader clinical populations and other therapeutic modalities within an FND population.

Through tracking change across the full two-phase psychological intervention, it was hoped that it would be possible to compare the differences in change for each phase for a participant and between phases. Using a SCED or non-randomised trial to explore different third-wave CBT approaches, deliveries (e.g. group-based versus individual work) and other therapies can help in understanding the differences and similarities in patient change and experiences. It is recommended that intervention studies use frequent high-quality time points of measurement before, during and after the intervention, rather than pre and post-measures of change. Such timepoints provide higher quality data and understanding of the intervention but need to be weighed up with the measures' burdensomeness. Follow-up measures at multiple time points can also assess change longevity. Recording potential confounding variables, such as concurrent treatments (e.g. medication, physiotherapy), can increase the validity of findings. Importantly, future research needs to explore how change is defined and measured for FND. It is recommended that idiosyncratic measures of change are used, such as the Change Interview and process measures directly targeted by the intervention. Moreover, it is recommended that treatment fidelity measures monitor the accuracy and consistency of the intervention delivered, ideally through an independent rater.

Future research is needed to understand factors that contribute to third-wave CBT effectiveness. It is currently unclear what role various factors, such as the chronicity and severity of FND symptoms, comorbid difficulties and acceptance of the diagnosis, play in intervention feasibility, acceptability and effectiveness. Exploring these factors requires researchers to collect a range of patient demographics and characteristics. Similarly, research also needs to provide detailed reporting on the uptake, drop-out, non-response and deterioration rates at different intervention stages. Analysing such variables to see if patterns emerge in patient change or experience will help identify patients that are more or less likely to benefit from third-wave CBT interventions or other therapeutic approaches.

Further research is needed to understand the outcomes for patients who do not attend services or drop-out at different time points of the intervention (e.g. before the group, after the first session). The limited evidence suggests patients with greater chronicity of FND symptoms, comorbid mental and physical health difficulties, who are younger, identify as being from an ethnic background and have fewer years of education may be less likely to find third-wave CBT interventions acceptable and effective. Qualitative research and mixed-method designs are essential in capturing these participants' perspectives. Understanding these patients' experiences and perceptions can help better understand what could be an acceptable and effective intervention for the individual. While feasibility research implemented before conducting intervention studies can also help consider real-world barriers and facilitators to intervention implementation and address cultural or linguistic relevance (Bowen et al., 2009; Kazdin, 2018).

Future work needs to continue to develop an understanding of this diverse clinical population's needs that can shape therapeutic interventions. Literature indicates a range of psychological and psychiatric factors associated with FND. It also suggests subgroups of patients with varying treatment needs (Brown & Reuber, 2016a). Differences in patient subgroups need to be considered in shaping therapeutic interventions that are feasible, acceptable and effective for the individual. It may be that different subtypes of FND respond in different ways to various interventions. Future research can consider how therapeutic interventions drawing upon different therapeutic modalities in varying formats and duration can be effectively tailored for different subgroups of patients with FND in a feasible and acceptable manner. It will be important to explore how such psychological therapies can also be offered in conjunction with other health treatments, such as physiotherapy and occupational therapy, to start bridging the gap between mental and physical health in treating FND.

## 3.5.2 Conclusion

This work used multiple methods to explore the impact of third-wave CBT for FND. A scoping review revealed that literature in the area is limited, diverse, and low quality and lacks information on feasibility and acceptability. There was some promise for third-wave CBT effectiveness with improvements found for QoL, distress and psychological flexibility measures. However, higher-quality research is required to explore the acceptability and effectiveness of such approaches, alongside the need for greater exploration of participants' perceptions and experiences of interventions. This work also explored the experiences and impact of a two-phase psychological intervention for patients with FND within a Clinical Health Psychology Service and included a SCED of a seven-week ACT group. Participants reported overwhelmingly positive experiences of the intervention and identified a variety of therapeutic changes attributable to the intervention. However, this contrasted with the broader service's high drop-out rates, reflecting the challenges of providing psychological intervention for people with FND, particularly within existing service structures set up for either mental or physical health.

Furthermore, across both intervention phases, standardised measures revealed limited change, and in some cases worsening, despite participants indicating that important changes resulted from the intervention. Whilst there were idiosyncratic explanations of the unexpected changes, the findings raise questions about both how we expect change to occur over the course of psychological intervention and how we measure that. Participants' descriptions of change included new ways of thinking, improved coping, greater acceptance of the diagnosis and increased self-compassion. These changes appeared to be facilitated through offering a safe space, validation and affirmation that enabled participants to ask questions and express themselves. Some participants appeared to experience the intervention as a corrective experience from past difficult experiences, such as misdiagnoses, stigma and dysfunctional health care professional encounters, which contributed to feeling misunderstood. This process highlights the need for clinicians to be curious and listening to patients' narratives and understanding their experiences when communicating the diagnosis, which is the first step in the treatment of FND. This is important given a patient's understanding, and acceptance of the diagnosis can significantly impact future treatment (Espay, Aybek, et al., 2018).

- 169 -

Given the adverse experiences that patients with FND can have before entering a psychology service, future work will be necessary to consider ways to enhance a patient's journey through the health care system. Findings highlight the need for integrated biopsychosocial explanations to help patients make sense of their illness, which requires the ongoing move away from a mind-body dualism that embodies health care services structures. Future work is needed in supporting these structural and cultural shifts. Perhaps this may best be carried out by helping patients with FND have their voice heard and ideas used in shaping treatment pathways and interventions through both clinical and research settings.

#### References

- A-tjak, J. G., Davis, M. L., Morina, N., Powers, M. B., Smits, J. A., & Emmelkamp, P.
   M. (2015). A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychotherapy and psychosomatics*, 84(1), 30-36.
- Addis, M. E. & Krasnow, A. D. (2000). A national survey of practising psychologists' attitudes toward psychotherapy treatment manuals. *Journal of Consulting and Clinical Psychology*, 68(2), 331–339.
- Adjei, M., & Coebergh, J. (2014). An Audit Of The Diagnosis And Costs Associated With Inpatients With Functional Neurological Symptoms In A District General Hospital. J Neurol Neurosurg Psychiatry, 85(8), e3-e3.
- Ahern, L., Stone, J., & Sharpe, M. C. (2009). Attitudes of neuroscience nurses toward patients with conversion symptoms. *Psychosomatics*, 50(4), 336-339.
- Ahn, H.-n., & Wampold, B. E. (2001). Where oh where are the specific ingredients? A meta-analysis of component studies in counseling and psychotherapy. *Journal of counseling psychology*, 48(3), 251.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5*®). American Psychiatric Pub.
- Anderson, S., Allen, P., Peckham, S., & Goodwin, N. (2008). Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy & Systems*, 6(1), 1.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19 - 32.
- Asadi-Pooya, A. A., Bahrami, Z., Homayoun. M. (2019). Natural history of patients with psychogenic nonepileptic seizures. *Seizure*. 66, 22-25.
- Asadi-Pooya, A. A., Emami, M., & Emami, Y. (2013). Gender differences in manifestations of psychogenic non-epileptic seizures in Iran. *Journal of the neurological sciences*, 332(1-2), 66-68.
- Aybek, S., Nicholson, T. R., O'Daly, O., Zelaya, F., Kanaan, R. A., & David, A. S. (2015). Emotion-motion interactions in conversion disorder: an FMRI study. *PloS* one, 10(4).
- Baek, K., Doñamayor, N., Morris, L., Strelchuk, D., Mitchell, S., Mikheenko, Y., Yeoh,S., Phillips, W., Zandi, M., & Jenaway, A. (2017). Impaired awareness of motor

- Baker, R., Thomas, S., Thomas, P. W., Gower, P., Santonastaso, M., & Whittlesea, A.
  (2010). The Emotional Processing Scale: scale refinement and abridgement (EPS-25). *Journal of Psychosomatic Research*, 68(1), 83-88.
- Baker, R., Thomas, S., Thomas, P. W., & Owens, M. (2007). Development of an emotional processing scale. *Journal of Psychosomatic Research*, 62(2), 167-178.
- Barrett-Naylor, R., Gresswell, D. M., & Dawson, D. L. (2018). The effectiveness and acceptability of a guided self-help Acceptance and Commitment Therapy (ACT) intervention for psychogenic nonepileptic seizures. *Epilepsy and Behavior*, 88, 332-340.
- Barsky, A. J., & Wyshak, G. (1990). Hypochondriasis and somatosensory amplification. *The British Journal of Psychiatry*, 157(3), 404-409.
- Baslet, G., Dworetzky, B., Perez, D. L., & Oser, M. (2015). Treatment of psychogenic nonepileptic seizures: updated review and findings from a mindfulness-based intervention case series. *Clinical EEG and neuroscience*, 46(1), 54-64.
- Baslet, G., Ehlert, A., Oser, M., & Dworetzky, B. A. (2020). Mindfulness-based therapy for psychogenic nonepileptic seizures. *Epilepsy and Behavior*, *103*, 106534.
- Baslet, G., & Hill, J. (2011). Case report: brief mindfulness-based psychotherapeutic intervention during inpatient hospitalization in a patient with conversion and dissociation. *Clinical Case Studies*, 10(2), 95-109.
- Bayliss, K. (2018). Confirmatory Factor Analysis and further validation of the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT) University of Nottingham].
- Bègue, I., Adams, C., Stone, J., & Perez, D. L. (2019). Structural alterations in functional neurological disorder and related conditions: a software and hardware problem? *NeuroImage: Clinical*, 101798.
- Bègue, I., Blakemore, R., Klug, J., Cojan, Y., Galli, S., Berney, A., Aybek, S., & Vuilleumier, P. (2018). Metacognition of visuomotor decisions in conversion disorder. *Neuropsychologia*, 114, 251-265.
- Bermingham, S. L., Cohen, A., Hague, J., & Parsonage, M. (2010). The cost of somatisation among the working-age population in England for the year 2008– 2009. *Mental Health in Family Medicine*, 7(2), 71.

- Billones, R., Nada, L., & Saligan, L. (2020). What Works in Mindfulness Interventions for Medically Unexplained Symptoms? A Systematic Review. *Asian/ Pacific Island Nursing Journal*, 5(1), 21 – 34
- Binzer, M., Andersen, P. M., & Kullgren, G. (1997). Clinical characteristics of patients with motor disability due to conversion disorder: a prospective control group study. *Journal of Neurology, Neurosurgery & Psychiatry*, 63(1), 83-88.
- Binzer, M., Eisemann, M., & Kullgren, G. (1998). Illness behavior in the acute phase of motor disability in neurological disease and in conversion disorder: a comparative study. *Journal of Psychosomatic Research*, 44(6), 657-666.
- Black, D. W., & Andreasen, N. C. (2014). *Introductory Textbook of Psychiatry*. American Psychiatric Publishing.
- Blackledge, J. T., & Barnes-Holmes, D. (2009). Core processes in acceptance and commitment therapy. Acceptance and Commitment Therapy: Contemporary theory, research, and practice, 41-58.
- Bogousslavsky, J. (2011). Hysteria after Charcot: back to the future. In *Following charcot: A forgotten history of neurology and psychiatry* (Vol. 29, pp. 137-161).
  Karger Publishers.
- Bowman, E. S. (2006). Why conversion seizures should be classified as a dissociative disorder. *Psychiatric Clinics of North America*.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Sage.
- Bragge, P., Clavisi, O., Turner, T., Tavender, E., Collie, A., & Gruen, R. L. (2011). The global evidence mapping initiative: scoping research in broad topic areas. *BML Medical Research Methodology*, 11 (92).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.
- Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. Sage.
- Breuer, J., & Freud, S. (2009). Studies on hysteria. Hachette UK.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637.
- Brooks, R., Rabin, R., & De Charro, F. (2013). The measurement and valuation of health status using EQ-5D: a European perspective: evidence from the EuroQol BIOMED Research Programme. Springer Science & Business Media.

- Brown, R. (2016). Dissociation and functional neurologic disorders. In *Handbook of clinical neurology* (Vol. 139, pp. 85-94). Elsevier.
- Brown, R. J. (2006). Different types of "dissociation" have different psychological mechanisms. *Journal of Trauma & Dissociation*, 7(4), 7-28.
- Brown, R. J., & Reuber, M. (2016a). Psychological and psychiatric aspects of psychogenic non-epileptic seizures (PNES): a systematic review. *Clinical psychology review*, 45, 157-182.
- Brown, R. J., & Reuber, M. (2016b). Towards an integrative theory of psychogenic non-epileptic seizures (PNES). *Clinical psychology review*, 47, 55-70.
- Bullock, K. D., Mirza, N., Forte, C., & Trockel, M. (2015). Group Dialectical-Behavior Therapy Skills Training for Conversion Disorder With Seizures. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 27(3), 240-243.
- Canna, M., & Seligman, R. (2020). Dealing with the unknown. Functional neurological disorder (FND) and the conversion of cultural meaning. *Social Science & Medicine*, 246, 112725.
- Carlson, P., & Perry, K. N. (2017). Psychological interventions for psychogenic nonepileptic seizures: a meta-analysis. *Seizure*, 45, 142-150.
- Carson, A., Brown, R., David, A. S., Duncan, R., Edwards, M. J., Goldstein, L. H., Grunewald, R., Howlett, S., Kanaan, R., & Mellers, J. (2012). Functional (conversion) neurological symptoms: research since the millennium. *J Neurol Neurosurg Psychiatry*, 83(8), 842-850.
- Carson, A., Lehn, A., Ludwig, L., & Stone, J. (2016). Explaining functional disorders in the neurology clinic: a photo story. *Practical neurology*, *16*(1), 56-61.
- Carson, A., Stone, J., Hibberd, C., Murray, G., Duncan, R., Coleman, R., Warlow, C., Roberts, R., Pelosi, A., & Cavanagh, J. (2011). Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. *Journal of Neurology, Neurosurgery & Psychiatry*, 82(7), 810-813.
- Centre for Reviews and Dissemination. (2008). Systematic reviews: CRD's guidance for undertaking reviews in health care. CRD.
- Chalder, T., & Willis, C. (2019). Medically Unexplained Symptoms. In C. D.
  Llewellyn, C. McManus, J. Weinman, K. J. Petrie, S. Newman, S. Ayers, & T. A.
  Revenson (Eds.), *Cambridge Handbook of Psychology, Health and Medicine* (3 ed., pp. 78-83). Cambridge University Press.

- Clegg, S., Sirois, F., & Reuber, M. (2019). Self-compassion and adjustment in epilepsy and psychogenic nonepileptic seizures. *Epilepsy & Behavior*, 100, 106490.
- Cope, S. R., Poole, N., & Agrawal, N. (2017). Treating functional non-epileptic attacks–Should we consider acceptance and commitment therapy? *Epilepsy & Behavior*, 73, 197-203.
- Crits-Cristoph. P., Carroll, K., Perry, K., Luborsky, L., McLellan, A. T., Woody, G. E., Thompson, L., Gallagher, D., & Zitrin, C. (1991). Meta-analysis of therapist effects in psychotherapy outcome studies. *Psychotherapy Research*, 1, 81–91.
- Dahl, J. (2015). Valuing in ACT. Current Opinion in Psychology, 2, 43-46.
- Dallocchio, C., Tinazzi, M., Bombieri, F., Arnó, N., & Erro, R. (2016). Cognitive behavioural therapy and adjunctive physical activity for functional movement disorders (conversion disorder): a pilot, single-blinded, randomized study. *Psychother Psychosom*, 85(6), 381-383.
- Deary, V., Chalder, T., & Sharpe, M. (2007). The cognitive behavioural model of medically unexplained symptoms: a theoretical and empirical review. *Clinical psychology review*, 27(7), 781-797.
- Demartini, B., Batla, A., Petrochilos, P., Fisher, L., Edwards, M. J., & Joyce, E. (2014). Multidisciplinary treatment for functional neurological symptoms: a prospective study. *Journal of Neurology*, 26(12), 2370 – 2377.
- Dixit, R., Popescu, A., Bagić, A., Ghearing, G., & Hendrickson, R. (2013). Medical comorbidities in patients with psychogenic nonepileptic spells (PNES) referred for video-EEG monitoring. *Epilepsy & Behavior*, 28(2), 137-140.
- Driver-Dunckley, E., Stonnington, C. M., Locke, D. E., & Noe, K. (2011). Comparison of psychogenic movement disorders and psychogenic nonepileptic seizures: is phenotype clinically important? *Psychosomatics*, 52(4), 337-345.
- Edwards, M. J., Adams, R. A., Brown, H., Parees, I., & Friston, K. J. (2012). A Bayesian account of 'hysteria. *Brain*, *135*(11), 3495-3512.
- Elliott, R. (1999). Client change interview protocol. *Network for Research on Experiential Therapies*.
- Elliott, R. (2002). Hermeneutic single-case efficacy design. *Psychotherapy research*, *12*(1), 1-21.
- Elliott, R., Slatick, E., & Urman, M. (2001). Qualitative change process research on psychotherapy: Alternative strategies. *Psychological Test and Assessment Modeling*, 43(3), 69.

- Espay, A. J., Aybek, S., Carson, A., Edwards, M. J., Goldstein, L. H., Hallett, M., LaFaver, K., LaFrance, W. C., Lang, A. E., & Nicholson, T. (2018). Current concepts in diagnosis and treatment of functional neurological disorders. *JAMA neurology*, 75(9), 1132-1141.
- Espay, A. J., Maloney, T., Vannest, J., Norris, M. M., Eliassen, J. C., Neefus, E., Allendorfer, J. B., Lang, A. E., & Szaflarski, J. P. (2018). Impaired emotion processing in functional (psychogenic) tremor: a functional magnetic resonance imaging study. *NeuroImage: Clinical*, 17, 179-187.
- Evans, C., Margison, F., & Barkham, M. (1998). The contribution of reliable and clinically significant change methods to evidence-based mental health. *Evidence-Based Mental Health*, 1(3), 70-72.
- Evans, R. W., & Evans, R. E. (2010). A survey of neurologists on the likeability of headaches and other neurological disorders. *Headache: The Journal of Head and Face Pain*, 50(7), 1126-1129.
- Fleiss, J. L. (1971). Measuring nominal scale agreement among many raters. *Psychological Bulletin*, 16(5), 378-382.
- Francis, A. W., Dawson, D. L., & Golijani-Moghaddam, N. (2016). The development and validation of the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT). *Journal of Contextual Behavioral Science*, 5(3), 134-145.
- Gale, A. (2000). Review of People studying people: Artifacts and ethics in behavioral research. *Journal of Psychophysiology*, *14*(1), 47-48.
- Gardiner, P., MacGregor, L., Carson, A., & Stone, J. (2018). Occupational therapy for functional neurological disorders: a scoping review and agenda for research. *CNS Spectr*, 23(03), 205-212.
- Gelauff, J., Stone, J., Edwards, M. & Carson, E. (2014). The prognosis of functional (psychogenic) motor symptoms: a systematic review. *Journal of Neurology*, *Neurosurgery & Psychiatry*, 85, 220–226.
- Gerskowitch, C., Norman, I., & Rimes, K. A. (2015). Patients with medically unexplained physical symptoms experience of receiving treatment in a primarycare psychological therapies service: a qualitative study. *The Cognitive Behaviour Therapist*, 8.
- Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in psychiatric treatment*, *15*(3), 199.

- Godwin, M., Ruhland, L., Casson, I., MacDonald, S., Delva, D., Birtwhistle, M. L., & Seguin, R. (2003). Pragmatic controlled clinical trials in primary care: the struggle between external and internal validity. *BMC Medical Research Methodology*, 3(28)
- Goldstein, L., Chalder, T., Chigwedere, C., Khondoker, M., Moriarty, J., Toone, B., & Mellers, J. (2010). Cognitive-behavioral therapy for psychogenic nonepileptic seizures: a pilot RCT. *Neurology*, 74(24), 1986-1994.
- Goldstein, L., & Mellers, J. (2006). Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. *Journal of Neurology, Neurosurgery & Psychiatry*, 77(5), 616-621.
- Goldstein, L., & Mellers, J. (2016). Psychologic treatment of functional neurologic disorders. In *Handbook of clinical neurology* (Vol. 139, pp. 571-583). Elsevier.
- Goldstein, L. H., Robinson, E. J., Mellers, J. D., Stone, J., Carson, A., Chalder, T., Reuber, M., Eastwood, C., Landau, S., & McCrone, P. (2020). Psychological and demographic characteristics of 368 patients with dissociative seizures: data from the CODES cohort. *Psychological medicine*, 1-13.
- Graham, C. D., Gouick, J., Krahé, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical psychology review*, 46, 46-58.
- Graham, C. D., O'Hara, D. J., & Kemp, S. (2018). A case series of Acceptance and Commitment Therapy (ACT) for reducing symptom interference in functional neurological disorders. *Clinical psychology & psychotherapy*.
- Graham, C. D., Stuart, S. R., O'Hara, D. J., & Kemp, S. (2017). Using acceptance and commitment therapy to improve outcomes in functional movement disorders: a case study. *Clinical Case Studies*, 16(5), 401-416.
- Hall-Patch, L., Brown, R., House, A., Howlett, S., Kemp, S., Lawton, G., Mayor, R., Smith, P., Reuber, M., & collaborators, N. (2010). Acceptability and effectiveness of a strategy for the communication of the diagnosis of psychogenic nonepileptic seizures. *Epilepsia*, 51(1), 70-78.
- Hann, K. E., & McCracken, L. M. (2014). A systematic review of randomized controlled trials of Acceptance and Commitment Therapy for adults with chronic pain: Outcome domains, design quality, and efficacy. *Journal of Contextual Behavioral Science*, 3(4), 217-227.

- Hansen, N. B., Lambert, M. J., & Forman, E. M. (2002). The Psychotherapy Dose-Response Effect and Its Implications for Treatment Delivery Services. *Clinical Psychology: Science and Practice*, 9(3), 329–343.
- Hassa, T., Sebastian, A., Liepert, J., Weiller, C., Schmidt, R., & Tüscher, O. (2017). Symptom-specific amygdala hyperactivity modulates motor control network in conversion disorder. *NeuroImage: Clinical*, 15, 143-150.
- Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third-wave of behavioral and cognitive therapies. *Behavior therapy*, 35(4), 639-665.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2011). *Acceptance and commitment therapy: The process and practice of mindful change*. Guilford Press.
- Hayes, S. C., Villatte, M., Levin, M., & Hildebrandt, M. (2011). Open, aware, and active: Contextual approaches as an emerging trend in the behavioral and cognitive therapies. *Annual review of clinical psychology*, 7.
- Henin, A., Otto, M. W., Reilly-Harrington, N. A. (2001). Introducing flexibility in manualized treatments: application of recommended strategies to the cognitivebehavioural treatment of bipolar disorder. *Cognitive and Behavioral Practice*, 8, 317–328
- Higgins, J. P., & Green, S. (2011). Cochrane handbook for systematic reviews of interventions (Vol. 4). John Wiley & Sons.
- Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative research*, *3*(3), 345-357.
- Holmes, E. A., Brown, R. J., Mansell, W., Fearon, R. P., Hunter, E. C., Frasquilho, F., & Oakley, D. A. (2005). Are there two qualitatively distinct forms of dissociation? A review and some clinical implications. *Clinical psychology review*, 25(1), 1-23.
- Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P.,
  Gagnon, M.-P., Griffiths, F., Nicolau, B., & O'Cathain, A. (2018). The Mixed
  Methods Appraisal Tool (MMAT) version 2018 for information professionals and
  researchers. *Education for Information*, 34(4), 285-291.

- Hopp, J., Anderson, K., Krumholz, A., Gruber-Baldini, A., & Shulman, L. (2012).
  Psychogenic seizures and psychogenic movement disorders: are they the same patients? *Epilepsy & Behavior*, 25(4), 666-669.
- Howlett, S., Grünewald, R. A., Khan, A., & Reuber, M. (2007). Engagement in psychological treatment for Functional Neurological Symptoms - barriers and solutions. *Psychotherapy: Research, Practice and Training*, 44(3), 354–360.
- Howlett, S., & Reuber, M. (2009). An augmented model of brief psychodynamic interpersonal therapy for patients with nonepileptic seizures. *Psychotherapy: Theory, Research, Practice, Training*, 46(1), 125.
- Jacobson, N. S., & Truax, P. (1992). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research.
- Jalilianhasanpour, R., Ospina, J. P., Williams, B., Mello, J., MacLean, J., Ranford, J., Fricchione, G. L., LaFrance Jr, W. C., & Perez, D. L. (2019). Secure attachment and depression predict 6-month outcome in motor functional neurological disorders: a prospective pilot study. *Psychosomatics*, 60(4), 365-375.
- Jordbru, A. A., Smedstad, M., Klungsoyr, O., & Martinsen, E. W. (2014). Psychogenic gait disorder: a randomised controlled trial of physical rehabilitation with oneyear follow-up. *Journal of Rehabilitation Medicine*, 46(2), 181–187
- Kahl, K. G., Winter, L., & Schweiger, U. (2012). The third-wave of cognitive behavioural therapies: what is new and what is effective? *Current opinion in psychiatry*, 25(6), 522-528.
- Kanaan, R. A., Armstrong, D., & Wessely, S. C. (2011). Neurologists' understanding and management of conversion disorder. *Journal of Neurology, Neurosurgery & Psychiatry*, 82(9), 961-966.
- Kaplan, M. J. (2014). A psychodynamic perspective on treatment of patients with conversion and other somatoform disorders. *Psychodynamic Psychiatry*, 42(4), 593-615.
- Kazdin, A. E. (2001). Almost Clinically Significant (p<.10): Current Measures May Only Approach Clinical Significance. *Clinical Psychology: Science and Practice*, 8(4), 455–462.
- Keynejad, R. C., Frodl, T., Kanaan, R., Pariante, C., Reuber, M., & Nicholson, T. R. (2019). Stress and functional neurological disorders: mechanistic insights. *Journal* of Neurology, Neurosurgery & Psychiatry, 90(7), 813-821.

- Kompoliti, K., Wilson, B., Stebbins, G., Bernard, B., & Hinson, V. (2014). Immediate vs. delayed treatment of psychogenic movement disorders with short term psychodynamic psychotherapy: randomized clinical trial. *Parkinsonism & related disorders*, 20(1), 60-63.
- Kozlowska, K. (2013). Stress, distress, and bodytalk: co-constructing formulations with patients who present with somatic symptoms. *Harvard review of psychiatry*, *21*(6), 314-333.
- Kozlowska, K. (2017). A stress-system model for functional neurological symptoms. *Journal of the Neurological Sciences*, 383, 151–152.
- Kozlowska, K., English, M., Savage, B., & Chudleigh, C. (2012). Multimodal
  Rehabilitation: A Mind-Body, Family-Based Intervention for Children and
  Adolescents Impaired by Medically Unexplained Symptoms. Part 1: The Program. *The American Journal of Family Therapy*, 40(5), 399–419.
- Kozlowska, K., & Williams, L. M. (2009). Self-protective organisation in children with conversion and somatoform disorders. *Journal of Psychosomatic Research*, 67(3), 223–233.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, 16(9), 606-613.
- Kroenke, K., Spitzer, R. L., Williams, J. B. W., & Löwe, B. (2010). The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. *General hospital psychiatry*, 32(4), 345-359.
- Kuyken, W., Byford, S., Taylor, R. S., Watkins, E., Holden, E., White, K., Barrett, B., Byng, R., Evans, A., & Mullan, E. (2008). Mindfulness-based cognitive therapy to prevent relapse in recurrent depression. *Journal of consulting and clinical psychology*, 76(6), 966.
- LaFrance, W. C., Baird, G. L., Barry, J. J., Blum, A. S., Webb, A. F., Keitner, G. I., Machan, J. T., Miller, I., & Szaflarski, J. P. (2014). Multicenter pilot treatment trial for psychogenic nonepileptic seizures: a randomized clinical trial. *JAMA psychiatry*, 71(9), 997-1005.

- Lambert, M. J., & Ogles, B. M. (2004). The Efficacy and Effectiveness of Psychotherapy. In M. J. Lambert (Ed.), *Bergin and Garfield's Handbook of Psychotherapy and Behavior Change* (Fifth., pp. 139–193). New York: Wiley.
- Lambert, M. J., & Ogles, B. M. (2009). Using clinical significance in psychotherapy outcome research: The need for a common procedure and validity data. *Psychotherapy research*, 19(4-5), 493-501.
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. Biometrics, 159-174
- Lane, J. D., & Gast, D. L. (2014). Visual analysis in single-case experimental design studies: Brief review and guidelines. *Neuropsychological Rehabilitation*, 24(3-4), 445-463.
- Levita, L., Mayberry, E., Mehmood, A., & Reuber, M. (2020). Evaluation of LiNES: a new measure of trauma, negative affect, and relationship insecurity over the life span in persons with FND. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 32(1), 43-49.
- Lind, A. B., Delmar, C., & Nielsen, K. (2014). Searching for existential security: a prospective qualitative study on the influence of mindfulness therapy on experienced stress and coping strategies among patients with somatoform disorders. *Journal of Psychosomatic Research*, 77(6), 516-521.
- Linehan, M. M. (1993). Dialectical behavior therapy for treatment of borderline personality disorder: implications for the treatment of substance abuse. *NIDA research monograph*, 137, 201-201.
- Lipowski, Z. J. (1988). Somatization: the concept and its clinical application. *Am J Psychiatry*, *145*(11), 1358-1368.
- Logothetis, N. K., Pauls, J., Augath, M., Trinath, T., & Oeltermann, A. (2001). Neurophysiological investigation of the basis of the fMRI signal. *Nature*, 412(6843), 150-157.
- Lorentzen, S., Høglend, P., Martinsen, E. W., & Ringdal, E. (2011). Practice-Based Evidence: Patients Who Did Not Respond to Group Analysis. *International Journal of Group Psychotherapy*, 61(3), 366–95.
- Ludwig, L., Pasman, J. A., Nicholson, T., Aybek, S., David, A. S., Tuck, S., Kanaan, R.
  A., Roelofs, K., Carson, A., & Stone, J. (2018). Stressful life events and maltreatment in conversion (functional neurological) disorder: systematic review and meta-analysis of case-control studies. *The Lancet Psychiatry*, 5(4), 307-320.

- Mauksch, L. B. (2000). Commentary: An Evidence-Based Recipe for Primary Care, Psychotherapy and Patient Preferences: Response to "A Systematic Review of Brief Psychological Therapies in Primary Health Care." *Family, Systems and Health*, 18(3), 315–321.
- Maurer, C. W., LaFaver, K., Ameli, R., Epstein, S. A., Hallett, M., & Horovitz, S. G. (2016). Impaired self-agency in functional movement disorders: a resting-state fMRI study. *Neurology*, 87(6), 564-570.
- Mayor, R., Howlett, S., Grünewald, R., & Reuber, M. (2010). Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: seizure control and health care utilization. *Epilepsia*, 51(7), 1169-1176.
- McCormack, R., Moriarty, J., Mellers, J.D., Shotbolt, P., Pastena, R., Landes, N., Goldstein, L., Fleminger, S., & David, A. S. (2014). Specialist inpatient treatment for severe motor conversion disorder: a retrospective comparative study. *Journal* of Neurology, Neurosurgery and Psychiatry, 85(8), 895 – 900.
- McEwen, B. S. (2004). Protection and damage from acute and chronic stress: allostasis and allostatic overload and relevance to the pathophysiology of psychiatric disorders. *Annals of the New York academy of sciences*, *1032*(1), 1-7.
- Mckay, M., Wood, J., & Brantley, J. (2007). The Dialectical Behavior Therapy Skills. *Tehran: Arjmand*, *1*, 328.
- McKenzie, P., Oto, M., Russell, A., Pelosi, A., & Duncan, R. (2010). Early outcomes and predictors in 260 patients with psychogenic nonepileptic attacks. *Neurology*, 74, 64-69.
- McMain, S. F., Links, P. S., Gnam, W. H., Guimond, T., Cardish, R. J., Korman, L., & Streiner, D. L. (2009). A randomized trial of dialectical behavior therapy versus general psychiatric management for borderline personality disorder. *American Journal of Psychiatry*, *166*(12), 1365-1374.
- Miller, S. D., Duncan, B. L., & Hubble, M. A. (2005). Outcome-Informed Clinical Work. In J. C. Norcross & M. R. Goldfried (Eds.), Handbook of Psychotherapy Integration (2nd edition., p. 84–102). New York: Oxford University Press.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS med*, 6(7), e1000097.

- Morley, S. (1996). Single case research. *Behavioural and mental health research: A handbook of skills and methods*, 2, 277-314.
- Morley, S. (2017). Single case methods in clinical psychology: A practical guide. Routledge.
- Morris, L. S., To, B., Baek, K., Chang-Webb, Y.-C., Mitchell, S., Strelchuk, D., Mikheenko, Y., Phillips, W., Zandi, M., & Jenaway, A. (2017). Disrupted avoidance learning in functional neurological disorder: implications for harm avoidance theories. *NeuroImage: Clinical*, 16, 286-294.
- Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. M. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry*, 180(5), 461-464.
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., &Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18 (143).
- Myers, L., Trobliger, R., Bortnik, K., Zeng, R., Saal, E., & Lancman, M. (2019).
  Psychological trauma, somatization, dissociation, and psychiatric comorbidities in patients with psychogenic nonepileptic seizures compared with those in patients with intractable partial epilepsy. *Epilepsy & Behavior*, 92, 108-113.
- Nakao, M., & Barsky, A. J. (2007). Clinical application of somatosensory amplification in psychosomatic medicine. *BioPsychoSocial Medicine*, 1(1), 17.
- Neacsiu, A. D., Ward-Ciesielski, E. F., & Linehan, M. M. (2012). Emerging approaches to counseling intervention: Dialectical behavior therapy. *The Counseling Psychologist*, 40(7), 1003-1032.
- Nettleton, S. (2006). "I just want permission to be ill": Towards a sociology of medically unexplained symptoms. *Social Science and Medicine*, 62(5), 1167– 1178.
- Nettleton, S., Watt, I., O'Malley, L., & Duffey, P. (2005). Understanding the narratives of people who live with medically unexplained illness. *Patient education and counseling*, *56*(2), 205-210.
- Nezu, A. M. & Nezu, C. M. (2008). *Ensuring treatment integrity*. Oxford University Press; New York, NY.

- NICE guidelines. (2017). Suspected neurological conditions: recognition and referral. Retrieved from <u>https://www.nice.org.uk/guidance/ng127/documents/draft-guideline</u>
- Nicholson, T., Aybek, S., Craig, T., Harris, T., Wojcik, W., David, A., & Kanaan, R. A. (2016). Life events and escape in conversion disorder. *Psychological medicine*, 46(12), 2617-2626.
- Nielsen, G., Buszewicz, M., Edwards, M. J., & Stevenson, F. (2019). A qualitative study of the experiences and perceptions of patients with functional motor disorder. *Disability and Rehabilitation*, 1-6.
- Nielsen, G., Buszewicz, M., Stevenson, F., Hunter, R., Holt, K., Dudziec, M., Ricciardi, L., Marsden, J., Joyce, E., & Edwards, M. (2017). Randomised feasibility study of physiotherapy for patients with functional motor symptoms. *J Neurol Neurosurg Psychiatry*, 88(6), 484-490.
- Novakova, B., Howlett, S., Baker, R., & Reuber, M. (2015). Emotion processing and psychogenic non-epileptic seizures: A cross-sectional comparison of patients and healthy controls. *Seizure*, *29*, 4-10.
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International journal of qualitative methods*, 16(1), 1609406917733847.
- O'Connell, N., Nicholson, T., Wessely, S., & David, A. (2020). Characteristics of patients with motor functional neurological disorder in a large UK mental health service: a case-control study. *Psychological medicine*, *50*(3), 446-455.
- O'Neill, L. F. (2018). *Development of a fidelity measure for Acceptance and Commitment Therapy* University of Leeds].
- O'Connell, N., Watson, G., Grey, C., Pastena, R., McKeown, K., & David, A. S. (2020). Outpatient CBT for motor functional neurological disorder and other neuropsychiatric conditions: a retrospective case comparison. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 32(1), 58-66.
- Olfson, M., Mojtabai, R., Sampson, N. A., Hwang, I., Druss, B., Wang, P. S., Wells, K.
  B., Pincus, H. A., & Kessler, R. C. (2009). Dropout from outpatient mental health care in the United States. *Psychiatric Services*, 60(7), 898-907.
- Panayiota, P., Elmelem, M. S., Patel, H., Louissaint, K., Hayward, J., R., & Selai, C.(2020). Outcomes of a 5-week individualised MDT outpatient (day-patient)

treatment programme for functional neurological symptom disorder (FNSD). *Journal of Neurology*, 267(9), 2655-2666.

- Paola, L. D., Marchetti, R. L., & Teive, H. A. G. (2014). Psychogenic nonepileptic seizures and psychogenic movement disorders: two sides of the same coin? *Arquivos de neuro-psiquiatria*, 72(10), 793-802.
- Peters, M.D.J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A.C., Khalil, H. (2020) Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z (Editors). *Joanne Briggs Institute Manual for Evidence Synthesis*.
- Pick, S., Goldstein, L. H., Perez, D. L., & Nicholson, T. R. (2019). Emotional processing in functional neurological disorder: a review, biopsychosocial model and research agenda. *Journal of Neurology, Neurosurgery & Psychiatry*, 90(6), 704-711.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*, b92.
- Rachman, S. (1980). Emotional processing. *Behaviour Research and Therapy*, 18(1), 51-60.
- Radcliffe, K., Masterson, C., & Martin, C. (2018). Clients' experience of non-response to psychological therapy: a qualitative analysis. *Counselling and Psychotherapy Research*, 18 (2), 220-229
- Rancourt, D., & Darkes, J. (2018). Conversion disorder (functional neurological symptom disorder) in primary care mental health. *Clinical Case Studies*, 18(1), 54-68.
- Rawlings, G. H., & Reuber, M. (2016). What patients say about living with psychogenic nonepileptic seizures: a systematic synthesis of qualitative studies. *Seizure*, 41, 100-111.
- Redhead, S., Johnstone, L., & Nightingale, J. (2015). Clients experiences of formulation in cognitive behavioural therapy. *Psychology and Psychotherapy: Research Practice*, 88(4), 453 – 467.
- Reid, S., Wessely, S., Crayford, T., & Hotopf, M. (2001). Medically unexplained symptoms in frequent attenders of secondary health care: retrospective cohort study. *British Medical Journal*, 322(7289), 767–771

- Reuber, M. (2018). Trauma, traumatisation, and functional neurological symptom disorder-what are the links? *Lancet Psychiatry*.
- Reuber, M., Burness, C., Howlett, S., Brazier, J., & Grünewald, R. (2007). Tailored psychotherapy for patients with functional neurological symptoms: a pilot study. *Journal of Psychosomatic Research*, 63(6), 625-632.
- Reuber, M., Howlett, S., & Kemp, S. (2005). Psychologic treatment of patients with psychogenic nonepileptic seizures. *Expert Opinion Review in Neurotherapeutics*, 5(6), 737–752.
- Reuber, M., Pukrop, R., Bauer, J., Derfuss, R., & Elger, C. E. (2004). Multidimensional assessment of personality in patients with psychogenic non-epileptic seizures. *Journal of Neurology, Neurosurgery and Psychiatry*, 75, 743-748
- Revell, E. R. (2019). A cognitive behavioural approach to functional neurological disorder: a systematic review, meta-analysis and grounded theory study University of Edinburgh].
- Ricciardi, L., & Edwards, M. J. (2014). Treatment of functional (psychogenic) movement disorders. *Neurotherapeutics*, *11*(1), 201-207.
- Roberts, N. A., & Reuber, M. (2014). Alterations of consciousness in psychogenic nonepileptic seizures: emotion, emotion regulation and dissociation. *Epilepsy & Behavior*, 30, 43-49.
- Robinson, P. L., Russell, A., & Dysch, L. (2019). Third-Wave Therapies for Long-Term Neurological Conditions: A Systematic Review to Evaluate the Status and Quality of Evidence. *Brain Impairment*, 20(1).
- Roelofs, J. J., Teodoro, T., & Edwards, M. J. (2019). Neuroimaging in functional movement disorders. *Current neurology and neuroscience reports*, *19*(3), 12.
- Ryan, R. (2013). Cochrane Consumers and Communication Review Group. 'Cochrane Consumers and Communication Review Group: data synthesis and analysis. http://cccrg.cochrane.org accessed 16.12.2020.
- Safran, J. D., Greenberg, L. S., & Rice, L. N. (1988). Integrating psychotherapy research and practice: Modeling the change process. *Psychotherapy: Theory, Research, Practice, Training*, 25(1), 1.
- Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in nursing & health*, 18(4), 371-375.

- Şar, V., Akyüz, G., Kundakçı, T., Kızıltan, E., & Doğan, O. (2004). Childhood trauma, dissociation, and psychiatric comorbidity in patients with conversion disorder. *American Journal of Psychiatry*, 161(12), 2271-2276.
- Sattel, H., Lahmann, C., Gündel, H., Guthrie, E., Kruse, J., Noll-Hussong, M., Ohmann, C., Ronel, J., Sack, M., & Sauer, N. (2012). Brief psychodynamic interpersonal psychotherapy for patients with multisomatoform disorder: randomised controlled trial. *The British Journal of Psychiatry*, 200(1), 60-67.
- Schmid, D., Allum, J., Sleptsova, M., Gross, S., Gaab, J., Welge-Lüssen, A., Schaefert, R., & Langewitz, W. (2018). Effects of a program of cognitive-behavioural group therapy, vestibular rehabilitation, and psychoeducational explanations on patients with dizziness and no quantified balance deficit, compared to patients with dizziness and a quantified balance deficit. *Journal of Psychosomatic Research*, *105*, 21-30.
- Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research*, 17(88), 1 - 13.
- Selkirk, M., Duncan, R., Oto, M., & Pelosi, A. (2008). Clinical differences between patients with nonepileptic seizures who report antecedent sexual abuse and those who do not. *Epilepsia*, 49(8), 1446-1450.
- Sharpe, M., Walker, J., Williams, C., Stone, J., Cavanagh, J., Murray, G., Butcher, I., Duncan, R., Smith, S., & Carson, A. (2011). Guided self-help for functional (psychogenic) symptoms A randomized controlled efficacy trial. *Neurology*, WNL. 0b013e318228c318220c318227.
- Shaw, R. L., Larkin, M., & Flowers, P. (2014). Expanding the evidence within evidence-based healthcare: thinking about the context, acceptability and feasibility of interventions. *BMJ Evidence-Based Medicine*, 19(6), 201-203.
- Shields, C., Ownsworth, T., O'Donovan, A., & Fleming, J. (2016). A transdiagnostic investigation of emotional distress after traumatic brain injury. *Neuropsychological Rehabilitation*, 26(3), 410-445.
- Solem, S., Håland, Å. T., Vogel, P. A., Hansen, B., & Wells, A. (2009). Change in metacognitions predicts outcome in obsessive-compulsive disorder patients undergoing treatment with exposure and response prevention. *Behaviour Research* and Therapy, 47(4), 301-307.

- Soler, J., Pascual, J. C., Tiana, T., Cebrià, A., Barrachina, J., Campins, M. J., Gich, I., Alvarez, E., & Pérez, V. (2009). Dialectical behaviour therapy skills training compared to standard group therapy in borderline personality disorder: a 3-month randomised controlled clinical trial. *Behaviour Research and Therapy*, 47(5), 353-358.
- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. Archives of internal medicine, 166(10), 1092-1097.
- Steffen, A., Fiess, J., Schmidt, R., & Rockstroh, B. (2015). "That pulled the rug out from under my feet!" – adverse experiences and altered emotion processing in patients with functional neurological symptoms compared to healthy comparison subjects. *BMC psychiatry*, 15(1), 133.
- Stiles, W. B., Shapiro, D. A., & Elliott, R. (1986). Are all psychotherapies equivalent? *American psychologist*, 41(2), 165.
- Stone, J., Carson, A., Duncan, R., Coleman, R., Roberts, R., Warlow, C., Hibberd, C., Murray, G., Cull, R., & Pelosi, A. (2009). Symptoms 'unexplained by organic disease' in 1144 new neurology out-patients: how often does the diagnosis change at follow-up? *Brain*, 132(10), 2878-2888.
- Stone, J., Carson, A., Duncan, R., Roberts, R., Warlow, C., Hibberd, C., Coleman, R., Cull, R., Murray, G., & Pelosi, A. (2010). Who is referred to neurology clinics? the diagnoses made in 3781 new patients. *Clinical neurology and neurosurgery*, *112*(9), 747-751.
- Stone, J., LaFrance Jr, W. C., Brown, R., Spiegel, D., Levenson, J. L., & Sharpe, M. (2011). Conversion disorder: current problems and potential solutions for DSM-5. *Journal of Psychosomatic Research*, 71(6), 369-376.
- Stone, J., Sharpe, M., & Binzer, M. (2004). Motor conversion symptoms and pseudoseizures: a comparison of clinical characteristics. *Psychosomatics*, 45(6), 492-499.
- Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., Mackenzie, L., Warlow, C.P., & Sharpe, M. (2002). Reading, writing, and revalidation What should we say to patients with symptoms unexplained by disease? The "number needed to offend". *British Medical Journal*, 325, 1449–1450.

- Szaflarski, J. P., Allendorfer, J. B., Nenert, R., LaFrance Jr, W. C., Barkan, H. I., DeWolfe, J., Pati, S., Thomas, A. E., & Ver Hoef, L. (2018). Facial emotion processing in patients with seizure disorders. *Epilepsy & Behavior*, 79, 193-204.
- Tak, L. M., Cleare, A. J., Ormel, J., Manoharan, A., Kok, I. C., Wessely, S., & Rosmalen, J. G. (2011). Meta-analysis and meta-regression of hypothalamicpituitary-adrenal axis activity in functional somatic disorders. *Biological psychology*, 87(2), 183-194.
- The Centre for Economic Performance's Mental Health Policy Group. (2012). *How Mental Illness Loses Out in the NHS*. London.
- Toussaint, A., Hüsing, P., Gumz, A., Wingenfeld, K., Härter, M., Schramm, E., & Löwe, B. (2020). Sensitivity to change and minimal clinically important difference of the 7-item Generalized Anxiety Disorder Questionnaire (GAD-7). *Journal of affective disorders*, 265, 395-401.
- Tyndall, I., Waldeck, D., Pancani, L., Whelan, R., Roche, B., & Dawson, D. L. (2019). The Acceptance and Action Questionnaire-II (AAQ-II) as a measure of experiential avoidance: Concerns over discriminant validity. *Journal of Contextual Behavioral Science*, 12, 278-284.
- Urbanek, M., Harvey, M., McGowan, J., & Agrawal, N. (2014). Regulation of emotions in psychogenic nonepileptic seizures. *Epilepsy & Behavior*, 37, 110-115.
- Van den Bergh, O., Brown, R. J., Petersen, S., & Witthöft, M. (2017). Idiopathic environmental intolerance: a comprehensive model. *Clinical Psychological Science*, 5(3), 551-567.
- Van der Heiden, C., Muris, P., & van der Molen, H. T. (2012). Randomized controlled trial on the effectiveness of metacognitive therapy and intolerance-of-uncertainty therapy for generalized anxiety disorder. *Behaviour Research and Therapy*, 50(2), 100-109.
- Villatte, M., Villatte, J. L., & Hayes, S. C. (2015). Mastering the clinical conversation: Language as intervention. Guilford Publications.
- Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: a model whose time has come. SAGE Publications Sage UK: London, England.
- Wampold, B. E. (2001). The Great Psychotherapy Debate: Models, methods, and findings. Mahwah, NJ: Lawrence Erlbaum. Blanton, H., & Jaccard, J. (2006). Arbitrary Metrics in Psychology. *The American Psychologist*, 61(1), 27–41.

- Wells, A. (2011). Metacognitive therapy. *Acceptance and mindfulness in cognitive behavior therapy: Understanding and applying the new therapies*, 83-108.
- Wells, A., Fisher, P., Myers, S., Wheatley, J., Patel, T., & Brewin, C. R. (2012). Metacognitive therapy in treatment-resistant depression: A platform trial. *Behaviour Research and Therapy*, 50(6), 367-373.
- Wierzbicki, M., & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. *Professional psychology: research and practice*, 24(2), 190.
- Williams, G. C., Frankel, R. M., Campbell, T. L., & Deci, E. L. (2000). Research on Relationship-Centered Care and Healthcare Outcomes from the Rochester Biopsychosocial Program: A Self-Determination Theory Integration. *Family, Systems and Health*, 18(1), 79–89.
- Williams, I. A., Levita, L., & Reuber, M. (2018). Emotion dysregulation in patients with psychogenic nonepileptic seizures: A systematic review based on the extended process model. *Epilepsy & Behavior*, 86, 37-48.
- Wilson, G.T. (1998). Manual-based treatment and clinical practice. *Clinical Psychology: Science and Practice*, 5, 363–375.
- Witkiewitz, K., & Bowen, S. (2010). Depression, craving, and substance use following a randomized trial of mindfulness-based relapse prevention. *Journal of consulting and clinical psychology*, 78(3), 362.
- Yalom, I. D., & Leszcz, M. (2008). The Theory and Practice of Group Psychotherapy. Basic Books.
- Zahra, D., Qureshi, A., Henley, W., Taylor, R., Quinn, C., Pooler, J., Hardy, G., Newbold, A., & Byng, R. (2014). The work and social adjustment scale: Reliability, sensitivity and value. *International Journal of Psychiatry in Clinical Practice*, 18(2), 131-138.

### List of Abbreviations

AAQ-II	Acceptance and Action Questionnaire-II
ACT	Acceptance and Commitment Therapy
BAPIT	Brief Augmented Interpersonal Therapy (BAPIT)
B-IPQ	Brief Illness Perception Questionnaire
CBT	Cognitive Behavioural Therapy
CFT	Compassion Focused Therapy
compACT	Comprehensive Measure of Acceptance and Commitment
	Therapy
CSC	Clinically Significant Change
DBT	Dialectical Behaviour Therapy
DASS-21	Depression Anxiety and Stress Scale-21
EPS	Emotional Processing Scale
EQ-5D-3L	EuroQol-5D-3L
FND	Functional Neurological Disorder
FNEAD	Functional Non-Epileptic Attack Disorder
GAD-7	Generalised Anxiety Disorder-7
НСР	Health Care Professional
HPA	hypothalamic-pituitary-adrenal
HSCED	Elliot's Hermeneutic Single-Case Efficacy Design
ICM	Integrative Conceptual Model
MBI	Mindfulness-Based Intervention
MBT	Mindfulness-Based Therapy
MCT	Meta Cognitive Therapy
mFND	motor Functional Neurological Disorder
MUS	Medically Unexplained Symptoms
MMAT	Mixed Methods Appraisal Tool
NEAD	Non-Epileptic Attack Disorder
NES	Non-Epileptic Seizures
PHQ-9	Physical Health Questionnaire
PIT	Psychodynamic-Interpersonal Therapy
PNES	Psychogenic Non-Epileptic Seizures
RCI	Reliable Clinical Index

Randomised Control Trial
Single-Case Experimental Design
Somatoform Symptom Disorder
Quality of Life
Quality of Life in Epilepsy-10
Work and Social Adjustment Scale

#### - 193 -

### Appendix A

### Full details of the search strategy, including MESH terms

- 1. [(bodily stress adj2 (syndrome\* or disorder\*)).tw,kw.
- 2. [complex physical symptoms.tw,kw.]
- 3. Conversion Disorder/
- 4. [conversion disorder\*.tw,kw.]
- 5. Dissociative Disorders/
- 6. [(dissociative adj2 (disorder\* or convulsion\* or seizure\*)).tw,kw.]
- 7. [FND.tw,kw.]
- [(functional adj2 (tic\* or tremor\* or stroke\* or movement\* or motor\* or somatic\* syndrome\* or neurological\* or disorder\* or symptom\* or seizure\*)).tw,kw.]
- 9. [((functional or psychogenic) adj2 (paresis\* or weakness\* or twitching\* or sensory disturbance\*)).tw,kw.]
- 10. Gait Disorders, Neurologic/
- 11. [gait disorder\*.tw,kw.]
- 12. [hysteric\*.tw,kw.]
- 13. [(medically unexplained adj2 (physical\* or disorder\* or syndrome\* or symptom\*)).tw,kw.]
- 14. medically unexplained symptoms/
- 15. [medically unexplained symptoms.tw,kw.]
- 16. [((movement or motor) adj (disorder\* or symptoms\*)).tw,kw.]
- 17. [NEAD.tw,kw.]
- 18. [((nonepileptic or non-epileptic) adj (attack\* or seizure\* or event\*)).tw,kw.]
- 19. medically unexplained symptoms/
- 20. [medically unexplained symptoms.tw,kw.]
- 21. [((movement or motor) adj (disorder\* or symptoms\*)).tw,kw.]
- 22. [NEAD.tw,kw.]
- 23. [((nonepileptic or non-epileptic) adj (attack\* or seizure\* or event\*)).tw,kw.]
- 24. [nonorganic.tw,kw.]
- 25. Psychophysiologic Disorders/
- 26. [pseudoseizure\*.tw,kw.]
- 27. [psychosomatic\*.tw,kw.]
- 28. [persistent physical symptom\*.tw,kw.]
- 29. [pseudoepilep\*.tw,kw.]
- 30. [(psychogenic adj2 (seizure\* or disorder\*)).tw,kw.]

- 31. Somatoform Disorders/
- 32. [somatoform\*.tw,kw.]
- 33. [somati#ation\*.tw,kw.]
- 34. [(unexplained adj2 (tremor\* or weakness\* or twitching\*)).tw,kw.]
- 35. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34
- 36. "Acceptance and Commitment Therapy"/
- 37. ["acceptance and commitment therapy".kw,tw.]
- 38. ((behavioural or behavior) adj activation).tw,kw.
- 39. (cognitive behavio\* analysis system of psychotherapy or CBASP).tw,kw
- 40. (compassion focused therapy or compassion focussed therapy or compassionate mind or self-compassion).tw,kw.
- 41. [defusion.tw,kw.]
- 42. (dialectical behavioural therapy or DBT).tw,kw.
- 43. [emotion\* processing.tw,kw.]
- 44. metacognitive therapy.tw,kw
- 45. Mindfulness/
- 46. [mindfulness.tw,kw.]
- 47. (mindfulness-based cognitive therapy or MBCT).tw,kw.
- 48. [(thirdwave or third-wave).tw,kw.]
- 49. 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48
- 50. 35 and 49
- 51. limit 45 to english language

#### - 195 -

### Appendix B

### **Extraction tool**

### **Study Characteristics**

Title

Authors

Date

Country of origin and setting

Study Aims

Design

### **Participant Characteristics**

Recruitment

Number

Gender

Type of FND

#### **Intervention Characteristics**

Description

Number of sessions

#### **Measurement Characteristics**

Measures

Timepoints

Results

Statistical analysis

Key findings

Acceptability and feasibility

### Appendix C

### Quality ratings and Fleiss's kappa calculatioN

Mixed Methods Appraisal Tool (MMAT) Version								Study 1	umbe	r						
Quantitative descriptive methodological quality criteria	s	1	s	2	s	3	s	4	s	5	s	6	s	7	s	58
Raters	Rater 1	Rater 2														
1. Is the sampling strategy relevant to address the research question?	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
2. Is the sample representative of the target population?	Υ	Υ	Υ	Υ	Υ	Υ	N/A	N/A	Υ	Υ	Y	Υ	N/A	N/A	N/A	N/A
3. Are the measurements appropriate?	Υ	Υ	Υ	Υ	Υ	Υ	Ν	Ν	Ν	Υ	Ν	Υ	Υ	Υ	Υ	Υ
4. Is the risk of nonresponse bias low?	С	С	С	С	Ν	Ν	N/A	N/A	С	С	С	С	N/A	N/A	N/A	N/A
5. Is the statistical analysis appropriate to answer the research question?	Υ	Υ	Υ	Υ	Υ	Υ	Ν	Ν	Ν	Ν	Y	Υ	Υ	Υ	Υ	Υ
Morley (2017) Quality appraisal guidelines																
<ol> <li>Clear specification of the experimental design and the rationale for using it</li> </ol>	Y	Y	Ρ	Ρ	N/A	N/A	N	Ν	N/A	N/A	Ρ	Ρ	Ρ	Ρ	Ρ	Р
<ol> <li>Clear definition and specification of the dependent variable(s) and evidence that its validity and reliability has been accessed</li> </ol>	Y	Y	Ρ	Ρ	N/A	N/A	N	Ν	N/A	N/A	Y	Υ	Y	Υ	Ρ	Ρ
3. Clear definition and description of the intervention and who conducted it, the number and timing of the treatment sessions, and the attempts made to verify treatment integrity	Ρ	Ρ	Р	Ρ	N/A	N/A	Р	Р	N/A	N/A	Y	Y	Р	Р	Р	Р
<ol> <li>Sufficient data points in the baseline and intervention phases for the intended analysis</li> </ol>	Y	Y	Υ	Y	N/A	N/A	Ν	Ν	N/A	N/A	Y	Υ	Y	Υ	Υ	Y
<ol><li>Data analysis clear and a report in who conducted it and how</li></ol>	Ρ	Ρ	Ρ	Ρ	N/A	N/A	Ν	Ν	N/A	N/A	Ρ	Ρ	Ρ	Ρ	Ρ	Р
6. The full data set is produced in a high- quality graph or table	Υ	Υ	Υ	Υ	N/A	N/A	Ν	Ν	N/A	N/A	Y	Υ	Υ	Υ	Υ	Υ

Note. S1 – Barrett-Naylor et al. (2018), S2 – Baslet et al. (2015), S3 – Baslet et al. (2020), S4 – Baslet & Hill (2011), S5 – Bullock et al. (2015), S6 – Grahamet al. (2018), S7 – Graham et al. (2017), S8 – Rancourt & Darkes (2018). Colour coding key: N = no/ not present, Y = yes/ present, P = partially present, C = cannot tell, N/A = Not applicable

### **Rating table**

	Rater 1	Rater 2
no/ not present	11	9
yes/ present	39	41
partially present	16	16
cannot tell	4	4

### **Appendix D**

### Measures used in scoping review studies and their references

- Acceptance and Action Questionnaire-II (AAQ-11, Bond et al., 2011)
- Alcohol Use Disorders Identification Test-Consumption (AUDIT-C, Bush et al., 1998)
- Beck Depression Inventory-II (BDI-II, Beck, Steer & Brown, 1996)
- Comprehensive assessment of Acceptance and Commitment Therapy (CompACT, Francis et al. (2016))
- Clinical Outcomes in Routine Evaluation-10 (CORE-10, Barkham et al., 2013)
- Depression, Anxiety and Stress Scale (DASS, Lovibond & Lovibond, 1995)
- Dissociative Experience Scale (DES, Vanijzendoorn & Schuengel. 1996)
- Patient Health Questionnaire-15 (PHQ-15, Spitzer et al. 2002)
- PTSD Checklist-Civilian Version (PCL-C, Blanchard et al., 1996)
- Quality of Life in Epilepsy-10 (QOLIE-10, Cramer, Perrine, Devinsky, & Meador, 1996)
- Work and Social Adjustment Scale (WSAS, Mundt, Marks, Shear & Griest, 2002)

### Appendix E Ethics approval

East of Scotland Research Ethics Service (EoSRES)

<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Ms Jocelyn Arbuthnott Clinical Psychologist in Training Leeds Teaching Hospitals NHS Trust Apartment 24 20 Halifax road WF13 2NE TAyside medical Science Centre Residency Block Level 3 George Pirie Way Ninewells Hospital and Medical School Dundee DD1 9SY

Date: 30 Your Ref: D Enquiries to: M Direct Line: 0 Email: <u>e</u>

30 May 2019 DL/19/ES/0053 Mrs Diane Leonard 01382 383871 eosres.tayside@nhs.net

Dear Ms Arbuthnott

Study title:

REC reference: Protocol number: IRAS project ID: Exploring change processes for individuals with Functional Neurological Disorder participating in a Psychological Therapies Service treatment pathway 19/ES/0053 n/a 260286

Thank you for your letter of 20 May 2019, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact <u>hra.studyregistration@nhs.net</u> outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.





V2.20/05/2019





# Exploring change processes in Functional Neurological Disorder

## PARTICIPANT INFORMATION SHEET

The Clinical Health Psychology Service is recruiting individuals experiencing Functional Neurological Symptoms (FNS) to support a research project sponsored by the University of Leeds. We want to explore how the FNS treatment helps people experiencing FNS achieve positive changes. To do this we require access to individuals' routine clinical data. Routine clinical data is collected from the questionnaires you are asked to complete by psychologists. Everybody who accesses the service is asked to complete these questionnaires at different time points as part of their clinical care.

Please see information below, which will hopefully answer any questions you may have.

# WHY HAVE I BEEN CHOSEN TO TAKE PART IN THIS PROJECT?

You have been chosen to take part in this project because you have been referred to the Clinical Health Psychology Functional Neurological Disorder treatment pathway.

### WHAT WILL I HAVE TO DO?

If you want to take part in this research, we will ask for your consent to use the routine clinical questionnaires that the Clinical Health Psychology Service ask everyone to complete. We would use these anonymised routine clinical measures to explore what changes may be made for people who attend the service.

# WHAT WILL HAPPEN TO THE INFORMATION I PROVIDE?

The Clinical Health Psychology Service will keep your name, NHS number and contact details confidential and will not pass this information to the University of Leeds. We would pass over your clinical routine questionnaires fully anonymised to researchers and the information that the University of Leeds will receive will not have any identifying information. Certain individuals from the University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The University of Leeds will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

IRAS Project ID: 260286

V2. 20/05/2019

The researcher will write a report exploring changes on different measures and how this might relate to the Clinical Health Psychology Services END, treatment pathway. We hope through collecting this information we will be able to develop and refine treatment, to make it as effective as possible for individuals experiencing FNS.

### WHO IS THE RESEARCHER?

The person responsible for leading this research will not be working for Clinical Health Psychology Services. The researcher will be a psychologist in clinical training at the University of Leeds, working alongside an academic researcher from the institute. They will be carrying out this research with Dr Charlotte Baker, Consultant Clinical Psychologist, working at the Clinical Health Psychology Services at Pinderfields Hospital. The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep non-identifiable information about you 3 years after the study has finished. 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.

You can find out more about how we use your information from the University Data Protection Officer on <u>doo@leeds.ac.uk</u>

# WHAT WILL BE THE CONSEQUENCES IF I DON'T WANT TO PARTICIPATE?

There will be no consequences if you do not want to participate.

# CAN I WITHDRAW MY CONSENT TO TAKE PART?

Yes, you can withdraw at any time. You do not need to give a reason. This can be done through letting Dr Charlotte Baker know or through contacting the researchers below.

## WHO HAS REVIEWED THIS STUDY?

The East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from the University of Leeds and Mid Yorkshire Hospitals NHS Trust, whose role is

### Phase 1 participant information sheet

**Appendix F** 

					ŏ						
IRAS Project ID: 260286					Title of Project. Exploring change processes in Functional Neurological Disorder Name of Researcher. Jocelyn Arbuthnott Please initial box	<ol> <li>I confirm that I have read the information sheet dated 20<sup>th</sup> May 2019 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</li> </ol>	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	3. I agreed to my routine clinical measures being anonymised and passed to researchers	Signature	Signature	The Clinical Health Psychology Services will keep a copy of this consent form in your clinical records.
IRAS Projec				mber for this trial:	ange processes in Fun n Arbuthnott	ad the information shu the opportunity to c atisfactorily.	articipation is voluntar son, without my medic	clinical measures bei	Date	Date	gy Services will keep
V2. 20/05/2019			CONSENT FORM	IRAS ID: 260286 Participant Identification Number for this trial: CONSENT FORM	Title of Project: Exploring change process Name of Researcher. Jocelyn Arbuthnott	<ol> <li>I confirm that I have read the infor above study. I have had the oppor had these answered satisfactorily.</li> </ol>	<ol><li>I understand that my p without giving any reas</li></ol>	3. I agreed to my routine	Name of Participant	Name of Person taking consent	The Clinical Health Psycholo
IRAS Project ID: 260286	to check that research is properly conducted and the interests of those taking part are adequately protected.	WHO CAN I CONTACT TO GET MORE INFORMATION?	If you have any questions directly related to the study please get in touch using the contact dessite helow:	Dr Ciara Masterson <u>c.masterson@leeds.ac.uk</u>	Clinical Psychology Leeds Institute of Health Sciences Level 10 Worsley Building University of Leeds						
S Proje	Juduc	EII	ed to		alth						

- 201 -

V3. 20/05/2019

IRAS Project ID: 260286



UNIVERSITY OF LEEDS

# Exploring change processes in Functional Neurological Disorder

## PARTICIPANT INFORMATION SHEET

The Clinical Health Psychology Service is recruiting individuals experiencing Functional Neurological Symptoms (FNS) to support a research project sponsored by the University of Leeds. We want to explore how the FNS treatment pathway and newly established Acceptance and Commitment Therapy (ACT) group helps people experiencing FNS achieve positive changes. To do this we require access to individuals' routine clinical data, as well as addity information from people taking part in the ACT group in order to monitor different aspects of change. We also want people at the end of the group to share some of their experiences. Routline clinical data is collected from the questionnaires you are asked to complete by psychologists. Everybody who accesses the service is asked to complete these questionnaires at different time points as part of their clinical care.

Please see information below, which will hopefully answer any questions you may have.

# WHY HAVE I BEEN CHOSEN TO TAKE PART IN THIS PROJECT?

You have been chosen to take part in this project because you have been referred to the Clinical Health Psychology Functional Neurological Disorder treatment pathway.

### WHAT WILL I HAVE TO DO?

If you want to take part in this research, we will ask for your consent to use your routine clinical measures that the Clinical Health Psychology Service ask everyone to complete, you may have already done this. If you are referred to the ACT group, we will also ask you to take part in one or both of the following:

A daily and weekly measure whilst attending the seven-week group.

This involves completing a daily survey of your functional neurological symptoms and activities. The survey will ask how you are feeling and if you have been using any ideas from the group. It should not take longer than five minutes to complete and it can be completed via an online or paper survey.

An interview at the end of the group.

V3. 20/05/2019 IRAS Project ID: 260286

This involves meeting a researcher at the end of the group to discuss your experiences of the group using a semi-structured interview, whilds be recorded using an audiotape. This will be at the hospital site. It shouldn't last any more than 50 minutes. You will be reimbursed full travel costs if you want to take part. We might use non-identifiable quotes from this interview to add into the report.

# WHAT WILL HAPPEN TO THE INFORMATION I PROVIDE?

The Clinical Health Psychology Service will keep your name, NHS number and contact details confidential and will not pass this information to the University of Leeds. However, if you opt to be sent an online survey link via email or telephone message the researcher will have access to this information, along with your name. This information will be stored on a password protected file within a secure computer system at the University of Leeds, only accessible by the researcher. They will use this information to send you the survey online via an email or text message link, dependent on your preference. Individuals from the University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The Clinical Health Psychology Services will pass these details to the University of Leeds along with the information collected from you. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details. The Clinical Health Psychology Service will keep identifiable information about you from this study 3 years after the study has finished. All identifiable information held by the university of Leeds will be deleted on completion of this study. The researcher will write a report exploring changes on different measures and how this might relate to the Clinical Health Psychology Services FND treatment pathway. We hope through collecting this information we will be able to develop and refine treatment, to make it as effective as possible for individuals experiencing FNS.

### CONFIDENTIALITY OF DATA

Your data will be anonymised by the clinician randomly assigning your measures a unique identifying code and removing identifiable information before providing the researcher a copy of this information. The online survey used to collect data is secure and will only be accessible by the researcher. If you take part in semi-structured interview the audio recording of this will be encrypted and only accessed by the researcher who will transcribe the interview (deleting all identifiable patient information in the process). On completion of transcribing the audio recording will be deleted immediately.

### Appendix G Phase 2 participant information sheet

	NO. ZUJUDIZUTO
	WHO CAN I CONTACT TO GET MORE INFORMATION?
this research will not be working for Clinical Health	If you have any questions directly related to the study please get in touch:
vill be a psychologist in clinical training at the University mic researcher from the institute. They will be carrying Baker, Consultant Clinical Psychologist, working at the Pinderfields Hospital.	Ms Jocelyn Arbuthnott Dr Ciara Masterson umia@leeds.ac.uk Clinical Psychology Leeds Institute of Health Sciences Level 10 Worsley Building
for this study based in the United Kingdom. We will be undertake this study and will act as the data controller responsible for looking after your information and using ill keep non-identifiable information about you 3 years , identifiable information, such as your email address or completion of your final contact with the researcher.	University of Leeds LS2 9NL
e your information are limited, as we need to manage rder for the research to be reliable and accurate. If you eep the information about you that we have already s, we will use the minimum personally-identifiable	
use your information you using the following link to e on the university website: <u>p-content/uploads/sites/48/2019/02/Research-</u>	
CES IF I DON'T WANT TO PARTICIPATE?	
do not want to participate.	
TO TAKE PART? u do not need to give a reason. This can be done through rough contacting the researchers below.	
2	
Service REC 2, which has responsibility for scrutinising humans, has examined the proposal and has raised no research ethics. It is a requirement that your records in	

V3. 20/05/2019

IRAS Project ID: 260286

IRAS Project ID: 260286

V3.20/05/2019

## WHO IS THE RESEARCHER?

The person responsible for leading th Psychology Services. The researcher will out this research with Dr Charlotte Ba Clinical Health Psychology Services at Pi of Leeds, working alongside an academ

for this study. This means that we are re it properly. The University of Leeds will telephone number will be deleted on co The University of Leeds is the sponsor fi using information from you in order to u after the study has finished. However, it

your information in specific ways in ord withdraw from the study, we will kee Your rights to access, change or move obtained. To safeguard your rights, information possible.

You can find out more about how we us https://dataprotection.leeds.ac.uk/wpthe research participant privacy notice Privacy-Notice.pdf.

# WHAT WILL BE THE CONSEQUENCE

There will be no consequences if you do

## CAN I WITHDRAW MY CONSENT TO

letting Dr Charlotte Baker know or thro Yes, you can withdraw at any time. You

## WHO HAS REVIEWED THIS STUDY?

monitors from the University of Leeds and Mid Yorkshire Hospitals NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are this research, together with any relevant medical records, be made available for scrutiny by The East of Scotland Research Ethics Se all proposals for medical research on hu objections from the point of view of res adequately protected.

Change Interview Record

Date: Client ID number:

1. General Questions [about 5 min]

1a. How are you doing now in general?

1b. What has therapy been like for you so far? How has it felt to be in therapy?

### 2. Changes [about 10 min]

you got from therapy so far, including ideas about yourself or other people? Have any changes been 2a. What changes, if any, have you noticed in yourself since therapy started? For example, are you doing, feeling, or thinking differently from the way you did before? What specific ideas, if any, have 2b. Worsening Has anything changed for the worse for you since therapy started? brought to your attention by other people?

2c. Wants Is there anything that you wanted to change that hasn't since therapy started?

Note them here - then insert in the change list - then rate them.

### CHANGE LIST

Change	Change was:	Without therapy:	Importance:
		<ol> <li>unlikely</li> </ol>	1-not at all
	3 - neither	3 - neither	2-slightly
	5 - surprised by	5 - likely	3-moderately
			4-very
			5-extremely
1.	12345	12345	12345
2.	12345	12345	12345
3.	12345	12345	12345
4.	12345	12345	12345
5.	12345	12345	12345
6.	12345	12345	12345
7.	12345	12345	12345
8.	12345	12345	12345

CHANGE SCALES

For each change, please rate how much you expected it vs. were surprised by it? (Use this rating Expected vs Surprised: scale)

(3) Neither expected nor surprised by the change Very much expected it (2) Somewhat expected it

(4) Somewhat surprised by it (5) Very much surprised by it Likely without therapy for each change, please rate how likely you think it would have been if you (2) Somewhat unlikely without therapy (probably would not have happened) (1) Very unlikely without therapy (clearly would not have happened) hadn't been in therapy? (Use this rating scale)

(4) Somewhat likely without therapy (probably would have happened) (5) Very likely without therapy (clearly would have happened anyway) (3) Neither likely nor unlikely (no way of telling)

Importance or significance How important or significant to you personally do you consider this change to be? (Use this rating scale) (3) Moderately important Not at all important (2) Slightly important (4) Very important

### 3. Attributions [about 2 min]

(5) Extremely important

3a. In general, what do you think has caused these various changes? In other words, what do you think might have brought them about? (Including things both outside of therapy and in therapy)

### Helpful Aspects [about 5 min]

4a. Can you sum up what has been helpful about your therapy so far? Please give examples. (For example, general aspects or specific events)

### 5. Problem Aspects [about 5 min]

5b. Were there things in the therapy which were difficult or painful but still OK or perhaps helpful? 5c. Has anything been missing from your treatment? (What would make/have made your therapy 5a. What kinds of things about the therapy have been hindering, unhelpful, negative or disappointing for you? (For example, general aspects. specific events) What were they?

more effective or helpful?)

5d. Suggestions Do you have any suggestions for us, regarding the research or the therapy? Do you have anything else that you want to tell me?

## Feedback on Measures [about 2 min]

6b. Other measures. In general, do you think that your daily diary ratings mean the same thing now 6a. Daily diary. In general, do you think that your daily diary ratings mean the same thing now that they did before therapy? If not, how has their meaning changed? (Sometimes clients change how that they did before therapy? If not, how has their meaning changed? (Sometimes clients change they use the scales; did that happen for you?)

how they use the scales; did that happen for you?)

6c. Were any of these measures difficult for you to complete? Can you tell me why?

7. Any other comments you would like to make? [about 5 min]

Thank you for your time!

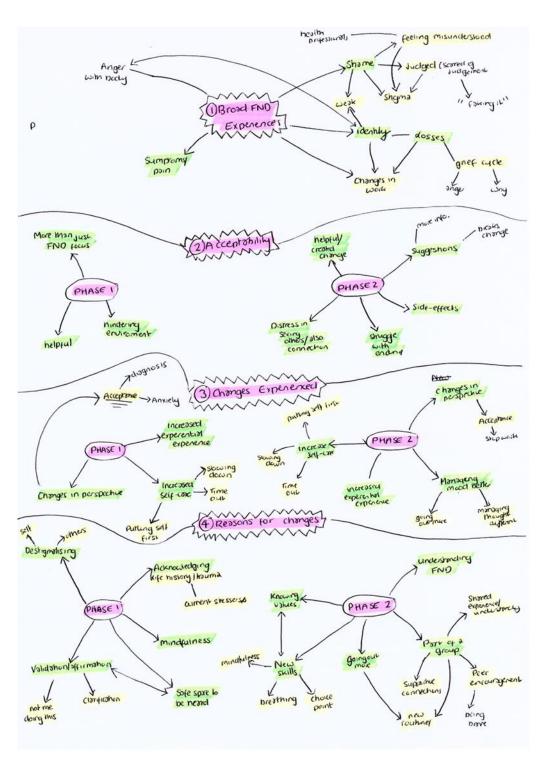
References:

Elliott, R., & Rogers, B. (2008). The Client Change Interview. Retrieved August 02, 2017, from http://www.drbrianrodgers.com/research/client-change-interview.

**Appendix H** 

**Change Interview** 

### Appendix I



### **Preliminary thematic map**